The Use of Complementary and Alternative Medicine for Breast Cancer Management in Indonesia: A Phenomenological Study

by

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Thesis

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THESIS SUMMARY

Complementary and alternative medicine (CAM) describes a group of non-conventional health practises and products that are commonly used in conjunction with, or in place of, medical treatment. Globally, the demand for CAM use in the cancer population is continuously increasing, particularly among women with breast cancer in Indonesia. Misuse of CAM may, however, cause adverse effects, health deterioration, delayed healing and incur high financial costs. Thus, this study aimed to explore women's lived experiences and CAM providers' views on the use of CAM for breast cancer management in Indonesia.

An integrative literature review was conducted to understand what is currently known about the experiences of women with breast cancer and CAM providers' perceptions regarding the use of CAM for breast cancer specifically in Asian countries. The majority of reviewed studies were quantitative research projects that mainly reported the prevalence of CAM use, sociodemographic factors, and types of CAM, efficacy and safety, and sources of information about CAM. Qualitative studies investigating the phenomena of CAM use for breast cancer were minimal. There were no studies that explored the lived experiences of women with breast cancer and CAM providers' views regarding the use of CAM for breast cancer management specifically in Indonesia.

van Manen's hermeneutic phenomenology was used as the methodology and method to understand the meaning of the lived experiences of women with breast in relation to their use of CAM, and to understand CAM providers' experiences and their views in providing CAM for breast cancer management. A total of 21 women with breast cancer and 10 CAM providers from two regions of Indonesia voluntarily participated to share their lived experiences. The examples of lived experiences were gathered by undertaking in-depth

interviews guided by semi-structured questions. The interviews were conducted in Bahasa (Indonesian language) and audio - digitally recorded. All the interviews were transcribed verbatim and then translated into the English language for data analysis.

The findings of the study emerged through thematic analysis and using van Manen's guided existential reflection. Four main themes were generated from the thematic analysis including:

- Access, affordability and support for medical treatment
- Beliefs in CAM treatment
- Feeling the potential benefits of CAM
- Acknowledging the negative aspects of CAM

These themes were used for phenomenological reflection guided by the existential concept of the lifeworld: relationality (lived self-other), corporeality (lived body), spatiality (lived space), temporality (lived time), and materiality (lived things). Additionally, the views of CAM providers about the use of CAM for breast cancer management provided greater depth of understanding of the findings of the lived experiences of women with breast cancer. The CAM providers' views produced four main themes: characteristics of women with breast cancer who used CAM therapy, providing non-evidence-based CAM, CAM providers' beliefs in potential benefits of CAM, and progressive and not so progressive attitudes toward CAM. All the study's findings were discussed using the CAM healthcare model. This model specifically structured the discussion of the lived experiences of women with breast cancer on the use of CAM, and CAM providers' views on CAM into determinant factors that influenced CAM utilisations such as:

- Predisposing factors (age, knowledge and cultural practice)

- Enabling factors (poverty and lack of access and availability of medical cancer treatment)
- Need for care factors (relieve breast cancer symptoms, reduce the side effects of chemotherapy, and prevent recurrent breast cancer)
- Health service use (the need of professional CAM providers, the need of standardised CAM products, promotion on self-care activity, as well as purpose and manner of CAM service use)
- Outcomes of care (improved quality of life, and delayed medical cancer treatment and aggravated health condition).

The lived experiences of women with breast cancer and CAM providers' views in this study revealed that the use of CAM for breast cancer management has both potential therapeutic effects and negatives effects. The outcomes from using CAM based on the lived experiences of women with breast cancer as presented in the findings chapter indicated that some CAM could improve quality of life. However, some fraudulent CAM obtained from unprofessional CAM providers could cause harmful effects, delay medical cancer treatment, and increase breast cancer treatment costs. Therefore, there is an urgent need to enhance the awareness of women with breast cancer related to the importance of appropriate breast cancer treatment, and to increase CAM providers' knowledge to provide evidence-based CAM. Insight and knowledge from this thesis may inform healthcare professionals, CAM providers, CAM educators and researchers as well as policy makers to improve cancer care services in Indonesia. Ultimately, improving quality cancer care services could contribute to increasing the quality of life and survival rates of women with breast cancer in Indonesia.

DECLARATION

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed……. Date: 26 September 2020

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DEDICATION

This PhD thesis is dedicated to women with breast cancer in Indonesia, and particularly to those who participated in sharing their lived experiences for this research project. Without your participation, this PhD would not have been possible. Your ideas and thoughts in this thesis may contribute to improving the quality of oncology care and CAM services in Indonesia.

To my husband**,** Berry, thank you for giving me a chance to achieve my dream. Your endless support, encouragement and understanding enable me to reach all the milestones.

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LIST OF ABBREVIATIONS

BPJS: Badan Penyelenggara Jaminan Sosial (Social Insurance Administration Organisation)

CAM: Complementary and Alternative Medicine

JBI: Joanna Brigg Institute

LMIC: Low-Middle Income Country

NCCIH: National Centre for Complementary and Integrative Health

UN: United Nations

WHO: World Health Organisation

LIST OF AUTHOR PUBLICATIONS AND CONFERENCE PRESENTATIONS

Publications:

1. Christina, J., Abigail, W., Cuthbertson, L.A., & Whitehead, D. (2019). Nurses' Knowledge and Attitudes toward Complementary and Alternative Medicine for Adult Patients with Cancer in Bandung, West Java, Indonesia: A Qualitative Study. *Journal of Holistic Nursing,* 37(2), 130-139.

2. Christina, J. (2018). Use of Complementary therapies in Australia: Past, Present and Future. In Lindquist, R., Snyder, M., & Tracy, M. F. (2018). *Complementary & alternative therapies in nursing* (Seventh edition. ed.): New York: Springer Publishing Company. USA.

3. Christina, J., Abigail, W., Cuthbertson, L.A. (2016). Nurses' Knowledge and Attitudes toward Complementary Therapies for Cancer: a review of the literature. *Asia - Pacific Journal of Oncology Nursing,* 3 (3), 241-251.

Conference Presentations:

1. Juliana Christina, 2019, 'Women experiences in the use of complementary and alternative medicine for breast cancer management in Indonesia', The 4th Nursing World Conference 2019, London, UK, August 19-21.

2. Juliana Christina, 2018, 'The use of complementary and alternative medicine for breast cancer management in Asian countries: An integrative review', Inaugural Higher Degree Research Student Conference, College of Nursing and Health Science, Flinders University, Adelaide, South Australia, November 5 – 7.

3. Juliana Christina, 2017, ‘The use of complementary and alternative medicine for breast cancer management in Indonesia’, SoNM Higher Degrees Research Week, School of Nursing & Midwifery, Faculty of Medicine, Nursing and Health Sciences, Adelaide, South Australia, June 26 – 29.

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CHAPTER ONE: INTRODUCTION

1.1. Introduction

The use of complementary and alternative medicine (CAM) has become a global phenomenon in the general population worldwide and particularly among the population of people with cancer (World Health Organization, 2019b). The National Centre for Complementary and Integrative Health defines CAM as a group of non-mainstream therapies and health approaches (NCCIH, 2019). According to the National Cancer Institute in the United States, CAM is considered a 'complementary therapy' when it is used alongside standard medical treatment, and it is considered as 'alternative medicine' when it is utilised to substitute or to replace standard medical treatment (National Cancer Institute, 2019). In Indonesia, the term of CAM is popular and commonly used in relation to 'integrated traditional medicine' where traditional treatment is integrated with conventional medicine (Ministry of Health of Republic Indonesia, 2017). Accordingly, the term CAM was used through this study due to the traditional treatment aspect of CAM, CAM is also well-known and there is global acceptability of this term and abbreviation.

The NCCIH classifies CAM into two categories: natural products and mind and body practices. Natural products are therapies that are produced by substances found in nature such as animal and plant-based remedies, herbs, vitamins, minerals, and dietary supplements probiotics (Lindquist, Snyder, & Tracy, 2018). Mind and body practices include a diverse group of procedures or techniques that are administered or taught by trained practitioners, for example, acupuncture, massage, yoga, relaxation techniques, meditation, imagery and tai chi (NCCIH, 2019). Other systems of care such as practices by traditional healers, traditional Chinese medicine, naturopathy and homeopathy are

categorised as other CAM health approaches. These systems of care are delivered based on the beliefs and experiences indigenous to different cultures, theories and practice apart from and earlier than Western medicine (Lindquist et al., 2018; World Health Organization, 2019b).

The use of CAM specifically for breast cancer management is the phenomenon explored in this research project for the purpose of developing an in-depth understanding of the lived experiences of women with breast cancer, specifically those related to the use of CAM for breast cancer management in Indonesia. Additionally, this study also sought to assess CAM providers' understanding and attitudes toward the use of CAM for breast cancer in Indonesia.

This chapter introduces the study and orientates the reader to the researched phenomenon. Beginning with a background of breast cancer and the use of CAM in Indonesia, this concept is then followed by the aim of the study, the research question and the objectives of the study. The significance of the study and a brief overview of the chapters of this thesis will also be presented.

1.2. Background: The use of CAM

Cancer incidence and mortality are rapidly increasing worldwide (Bray et al., 2018). The International Agency for Research on Cancer estimated in 2018, that there were18.1 million new cancer cases and 9.6 million cancer deaths worldwide (Bray et al., 2018). Cancer is commonly treated using a variety of medical standard treatments including surgery, chemotherapy, immunotherapy, targeted therapy, hormone therapy and radiation therapy (National Cancer Institute, 2018). However, despite the evidence that medical cancer treatments have been proven to be effective to treat cancers, they have also been found to have negative effects that could aggravate health conditions and decrease quality of life (Chui, 2019). Cancer and its treatments causes not only physical

symptoms but also negatively affects psychological and spiritual well-being (Alqahtani et al., 2018).

In many cases, CAM is utilised as an additional cancer treatment because the application of medical cancer treatment alone does not adequately overcome overall health and well-being conditions affected by cancer (Alqahtani et al., 2018). This condition has led to an increasing demand for CAM to be used as a part of cancer treatment (Hill, Mills, Li, & Smith, 2019; Rhee, Pawloski, & Parsons, 2019; Sanford, Sher, Ahn, Aizer, & Mahal, 2019).

A recent survey in the United States reported that approximately 35.1% of adult patients with cancer, including women with breast cancer, have used some form of CAM for their treatment (Rhee et al., 2019). In Canada, up to 75% of cancer survivors have used biological based CAM (Qureshi, Zelinski, & Carlson, 2018). Interest in using CAM was also high in patients with cancer in European countries such as Hungary and France (Filbet et al., 2020; Sárváry & Sárváry, 2019). In Australia, it was estimated that in 2018 approximately more than 80% of patients with cancer including women with breast cancer had used at least one form of CAM as a part of their cancer treatment, and the majority of CAM users were female (Cancer Council Australia, 2019; Harnett et al., 2019; Jones, Nissen, McCarthy, Steadman, & Windsor, 2019; Porter, Cochrane, & Zhu, 2017). CAM is often used after cancer diagnosis while undergoing, or after, completing mainstream cancer treatments (Filbet et al., 2020; Keene, Heslop, Sabesan, & Glass, 2019). In general, CAM therapy is used to reduce the side effects of medical cancer treatments, and to improve overall health well-being, and quality of life (Chui, Abdullah, Wong, & Taib, 2018; Keene et al., 2019; Knight, Hwa, & Hashim, 2015; Rhee et al., 2019; Sárváry & Sárváry, 2019).

The use of CAM is also prevalent among women with breast cancer in both high income countries and low-middle income countries (LMIC) (Akhtar, Akhtar, & Rahman, 2018; Albabtain, Alwhaibi, Alburaikan, & Asiri, 2018; Haque, Chowdhury, Shahjahan, & Harun, 2018; Knight et al., 2015; Lambe, 2013; Lopez et al., 2019; Neuhouser et al., 2016; Saghatchian et al., 2014; Sanuade et al., 2018; Toivonen, Tamagawa, Speca, Stephen, & Carlson, 2018; Wong, Tan, Chen, Teo, & Chan, 2014; World Health Organization, 2019b). Women with breast cancer use a variety of CAM based on their socioeconomic status, culture and beliefs.

In high income countries, women with breast cancer with higher income and higher education levels generally use CAM that are provided by professional practitioners such as natural products, vitamins, acupuncture, yoga, Qigong, massage therapy and Chinese medicine (Han, Jang, Suh, & Hwang, 2019; Porter et al., 2017; Sárváry & Sárváry, 2019). These CAM therapies are used by wealthy women with breast cancer as complementary therapies to reduce the side effects of medical cancer treatment, improve quality of life, and maintain health and well-being (Gül, Üstündağ, & Andsoy, 2014; Kang et al., 2012; Lee et al., 2014; Rossi et al., 2018).

A literature review by Hill et al. (2019) showed that CAM was highly used by patients with cancer in low-middle income countries particularly those that had a low level of medical cancer treatment sources. In many low-middle income countries, such as Bangladesh, Indonesia, Malaysia, Myanmar and Thailand, CAM therapies are often used as the main cancer treatment instead of being used as an adjunctive therapy; this is due to limited access, financial constraints, or lack of knowledge about appropriate breast cancer treatment (Akhtar et al., 2018; Akyuz, Oran, Yucel, Eksioglu, & Kocak, 2019; Almasdy, Eptiyeni, Khamri, & Kurniasih, 2018; Azhar, Achmad, Lukman, Hilmanto, & Aryandono, 2016; Haque et al., 2018; Muhamad, Merriam, & Suhami, 2012; Wanchai, Armer, &

Stewart, 2016). Unlike women with breast cancer in high income countries, women with breast cancer in low-middle income countries commonly obtain CAM from traditional healers or shamans; for example, herbal remedies, massage, eating particular indigenous plants (banana blossom, galangal flower, moringa leaf, and mushrooms), supernatural power healing rituals, and even extreme remedies such as cow's urine therapy (Almasdy et al., 2018; Alsharif & Mazanec, 2019; Azhar et al., 2016; Han, 2018; Haque et al., 2018; Muhamad et al., 2012; Wanchai, Armer, & Stewart, 2012).

In addition to socioeconomic status, women with breast cancer also use CAM based on their cultural and religious beliefs. For example, Muslim women with breast cancer in Iran and Saudi Arabia utilise Islamic-based CAM such as reciting the Holy Quran, praying, drinking holy water, consuming camel milk or camel urine, skin cauterization and cupping therapy (Alqahtani et al., 2018; Alsharif & Mazanec, 2019). In Indonesia and Malaysia, besides prayer therapy, Muslim women with breast cancer do *dhikr* therapy, an Islamic-based meditation practice to remember Allah[1] (Muhamad et al., 2012; Sulistyawati & Probosuseno, 2019). Buddhist women with breast cancer in Thailand listen to prayers based on Buddha teaching as CAM therapy for breast cancer management (Wanchai et al., 2012). These CAM therapies are used by women with breast cancer to reduce stress and anxiety, and to strengthen their immune system (Abrahão, Bomfim, Lopes-Júnior, & Pereira-da-Silva, 2019; Farahani et al., 2019; Saghatchian et al., 2014).

1.2.1. Breast cancer and the healthcare system in Indonesia

The Republic of Indonesia Health System Review in 2017 reported that cancer is the second leading cause of death in Indonesia (Mahendradhata et al., 2017). Breast cancer is the first leading cause of cancer mortality and the most common type of cancer among women in Indonesia (Word Health Organization, 2019). According to the GLOBOCAN

[1] Allah means God in Islamic belief.

2018 database of cancer incidence and mortality rates, the number of new breast cancer cases in Indonesia was 58,256 or (30.9%) of 188,231 new cancer cases in females (World Health Organization, 2019). This high number of breast cancer cases placed this cancer in the first position of all new cancer cases ranked in Indonesia (World Health Organization, 2019). Recent data from the Indonesia Health Profile 2018 reported the mortality rate of breast cancer was 22,692 or 17 per 100,000 women (Ministry of Health Republic of Indonesia, 2019). The breast cancer incidence rate in Indonesia has increased from 1.4 per 100,000 in 2013 to 1.79 per 100,000 in 2018 (Agustina et al., 2018). In 2018, a clinical breast examination program in Indonesia (Pemeriksaan Payudara Klinis/ SADANIS) found that approximately 16,962 of 2,747,662 women nationwide had a breast tumour, and 2,253 of them were suspected of having breast cancer (Ministry of Health Republic of Indonesia, 2019). The data indicates that the number of women with breast cancer in Indonesia is increasing.

However, Indonesia is a low-middle income country with more than 260 million inhabitants where public healthcare systems and services for cancer management are limited (Huraerah, 2019; Mahendradhata et al., 2017; Ministry of Health Republic of Indonesia, 2019). There are only three cancer specialist hospitals, 15 provincial public hospitals and less than 500 clinical oncologists that provide cancer care for more than 775,120 cancer patients in the entire country of Indonesia (Mahendradhata et al., 2017; Ministry of Health Republic of Indonesia, 2018, 2019).

Indonesia is the largest archipelago in the world, where the population resides on more than 17,504 islands between the Pacific and Indian Oceans (Mahendradhata et al., 2017). The majority of the population live on the island of Java (58%), although the area of Java is less than 7% of the total of Indonesian land area (Mahendradhata et al., 2017). Accordingly, healthcare facilities and services including cancer treatments on the island

of Java are more developed than healthcare services on other less populous islands. Unequal geographical distribution of healthcare facilities is an obstacle for people living in rural and remote regions, in accessing medical treatment including cancer care facilities which are mostly provided in provincial hospitals located in the capital cities (Aron, 2019; Mulyanto, Kringos, & Kunst, 2019). A recent survey in 2018 revealed that 36.8% of the rural and remote population described access to hospitals as being very difficult, while 46.1% of the urban population reported access to hospital as being very easy (Ministry of Health Republic of Indonesia, 2018).

The Indonesia Health Profile in 2018 reported that in the last five years, approximately 25 million people lived below the poverty line in Indonesia, and had very limited access to basic healthcare and education (Mahendradhata et al., 2017; Ministry of Health Republic of Indonesia, 2018, 2019). In order to increase access to medical treatment, the government of Indonesia introduced National Health Insurance for poor people including those with low income, those who were unemployed and people with a disability (BPJS, 2014; Mahendradhata et al., 2017). However, inadequate cancer care facilities and the shortage of health professional resources in Indonesia has resulted in medical treatments becoming expensive. Hence, they are inaccessible and unaffordable for poor people particularly those in rural and remote regions (Huraerah, 2019). Additional expenses related to treatment costs such as travel costs, accommodation and meal expenses create further financial burden for many poor patients who live in rural and remote regions (Huraerah, 2019). Therefore, financial constraints lead unemployed poor cancer patients in Indonesia, including women with breast cancer, to seek alternative treatment such as CAM therapy (Deliana, Suza, & Tarigan, 2019; Ministry of Health Republic of Indonesia, 2018).

1.2.2. Women and breast cancer in Indonesia

The highest prevalence of CAM use in Indonesia was found among patients with cancer including women with breast cancer (Pengpid & Peltzer, 2018). The National Health Survey 2018 reported that 24.1% of the cancer population selected CAM to treat their condition (Ministry of Health Republic of Indonesia, 2018). Despite women with breast cancer being introduced to breast cancer medical treatment by healthcare professionals, CAM is still chosen over the medical treatments (Setyowibowo et al., 2019). CAM therapy is often chosen as the first source of healthcare at the community level because this therapy is more widely available and affordable than medical treatment (Deliana et al., 2019; Nurhayati & Widowati, 2017; Pahria, 2017). The use of CAM is woven into everyday life and belief systems, and its utilisation is associated with socioeconomic status, religion, religiosity, residence geography, and health status (Nurhayati & Widowati, 2017; Pengpid & Peltzer, 2018).

In Indonesia, most women with breast cancer use at least one form of CAM when breast cancer symptoms occur, while undergoing treatment and after completion of medical cancer treatment (Almasdy et al., 2018; Azhar et al., 2016; Pahria, 2017). Limited access to conventional treatment, financial constraints, fear of surgery and chemotherapy, and lack of trust for medical treatment were the common reasons cited for CAM use (Almasdy et al., 2018; Azhar et al., 2016; Deliana et al., 2019; Tobing & Erpinna, 2019). CAM use is also influenced by family members, relatives and friends (Almasdy et al., 2018; Pahria, 2017).

The use of CAM treatments such as herbal therapy, supernatural therapy and traditional medicine in Indonesia are more popular than medical cancer treatment. Most women with breast cancer had used herbal medicines as they perceived herbal therapy to be an inexpensive and safe natural remedy (Achyar & Dewi, 2018; Almasdy et al., 2018;

Situmorang, 2017). Herbal medicine is more affordable than medical treatment as it is made from Indonesian local medicinal plants and produced by traditional methods (Deliana et al., 2019; Rahayu & Andini, 2019). The popularity of herbal therapy for breast cancer in Indonesia is often published in public media and on social media (Desideria, 2017; Solahuddin, 2020). One of the most popular herbal therapies for breast cancer was produced by Jeng (Madam) Ana. Jeng Ana become known as a queen of herbal therapies since her ability to cure cancer by using herbal therapies were trusted and endorsed by cancer patients from various community levels including celebrities (Desideria, 2017). Similarly, Ningsih Tinampi, a woman who is famous in Indonesia for having supernatural healing abilities, also introduced herbal therapy for breast cancer on social media (Solahuddin, 2020). Ningsih Tinampi provided a combination of supernatural ritual and herbal medicine that consisted of bitter melon extract to cure breast cancer (Solahuddin, 2020). Ningsih Tinampi published a breast cancer healing ritual video on YouTube and social medial with more than 1.7 million subscribers (Fauziah, 2020; Prabayanti, Sari, & Emmanuel, 2020; Solahuddin, 2020). The video has successfully brought a huge number of sick people nationally and internationally to her practice including women with breast cancer (Fadhila, 2020)

Traditional medicine from traditional healers is also popular among women with breast cancer in Indonesia, particularly in the North Sumatra Province. A descriptive qualitative study conducted by Tobing and Erpinna (2019) found that many Bataknese[2] women with breast cancer sought traditional medicine for breast cancer from a shaman (also known as '*Namalo*') (Ismail, Manurung, & Daulay). Based on Namalo's cultural belief and healing ability, which was derived from their ancestors, Namalo removes a breast tumour by using an ordinary blade, then spits chewed herbs onto the breast wound (Tobing &

[2] Bataknesse is an Indonesian ethic group in North Sumatra.

Erpinna, 2019). A similar treatment method is applied to breast cancer at any stage of the diseases' progression (Tobing & Erpinna, 2019). Namalo's treatment can be paid for according to the patients' ability and willingness to pay (Tobing & Erpinna, 2019).

Another most popular non-medical breast cancer treatment is Electro Capacitive Cancer Therapy (ECCT) , which was developed by a physics scientist (Nursya'bani, 2015). In the form of a jacket or bra, this device spreads electrostatic waves to destroy cancer cells (*The Jakarta Post*, 2015). In 2010, approximately 1,800 women with breast cancer used this therapy; 20 of them reported cured breast cancer and 80% of the women reported significant improvement from using the therapy (Fidrus, 2012). The scientist claimed that his therapy had effectively treated more than 600 cancer patients including women with breast cancer who had totally recovered from their cancer (Quamila, 2013). Therefore, this therapy has successfully attracted many women with breast cancer in Indonesia.

However, there was limited and insufficient information about the efficacy and safety of such non-medical treatments in the use for breast cancer management. The majority of women with breast cancer in Indonesia had a low level of awareness about breast cancer screenings and treatments, particularly those with low social economic status and low education levels (Anwar et al., 2019; Mardela, Maneewat, & Sangchan, 2017). Many women with breast cancer believed that CAM was more effective, cheaper and safer compared to medical treatment (Azhar et al., 2016). Accordingly, many women with breast cancer were tempted to seek and use only CAM for breast cancer management. According to Muhamad et al. (2012), however, using CAM as a single cancer therapy could not cure breast cancer; instead, it could delay women with breast cancer seeking approved medical cancer treatments (Akhtar et al., 2018). Furthermore, some CAM therapies, particularly herbal products, may be unsafe as they might contain toxic

compounds that could interfere with medical cancer treatments (White, 2020). The use of CAM could also cause unpleasant adverse effects that could negatively impact on quality of life (Yalcin, Hurmuz, McQuinn, & Naing, 2018). As such, the use of CAM without medical cancer treatment may result in negative outcomes for breast cancer treatment.

1.2.3. CAM practice in Indonesia

In Indonesia the concept of CAM is quite different to the global CAM concept as defined by the National Centre for Complementary and Integrative Health. In Indonesia, the term CAM was less recognised. Most CAM approaches were generally considered as part of traditional healthcare services. In Indonesia, traditional healthcare services are categorised into three different schemes: empirical traditional health services, complementary traditional health services and integrated traditional health services (Ministry of Health Republic of Indonesia, 2014). According to the Indonesian government's Regulation and Act Number 103 (in 2014), empirical traditional treatment services refers to the application of traditional treatment approaches in which the efficacy and safety have been empirically proven (Ministry of Health Republic of Indonesia, 2014). Empirical traditional healthcare services are provided by registered traditional healers, who obtained their healing knowledge and skills through non-formal education or derived from past generations (Ministry of Health Republic of Indonesia, 2014). According to the Ministry of Health Republic of Indonesia (2014), traditional treatment approaches should be used to promote health and to prevent diseases.

Complementary traditional healthcare services refers to bio-cultural and biomedical based traditional healthcare approaches, where the efficacy and safety have also been scientifically proven (Ministry of Health Republic Indonesia, 2017). These approaches include energy therapy, mind control therapy, and concoctions that contain plant extracts particularly those of indigenous plants, animal extracts and minerals (Ministry of Health

Republic of Indonesia, 2014). The complementary therapies must be provided by healthcare workers who have a minimum diploma degree in health education, are certified and are registered as a competent practitioner in specific complementary traditional approaches knowledge and skills (Mahendradhata et al., 2017; Ministry of Health Republic of Indonesia, 2014, p. 7). The Ministry of Health stated that complementary traditional approaches potentially can be used as a cure, used for health promotion, prevention of disease and used in rehabilitation process to increase quality of life (Ministry of Health Republic of Indonesia, 2014).

Integrated traditional healthcare services are a combination of both conventional treatment and complementary therapy that can be used as adjunctive or substitutive therapy for specific health conditions (Ministry of Health Republic Indonesia, 2017). The integrated traditional healthcare services should be provided by both certified and licenced medical CAM providers and traditional healthcare practitioners in clinical settings such as community health centres (*Puskesmas*) and hospitals (Ministry of Health Republic Indonesia, 2017). The application of the Ministry of Health approved integrated traditional treatment approaches in hospital settings must be provided under supervision by the hospital medical committee (Ministry of Health Republic Indonesia, 2017). Acupuncture, acupressure, hypnotherapy and herbal remedies are potential integrated complementary traditional therapies that are suggested to be provided in medical healthcare facilities (Erry, Susyanty, Raharni, & Sasanti, 2014; Ministry of Health Republic of Indonesia, 2019). According to the report in the Indonesia Health Profile 2018, integrated complementary traditional approaches have been implemented in about 4,252 community health centres throughout Indonesia (Ministry of Health Republic of Indonesia, 2019). However, integrated complementary traditional approaches have not been implemented in hospital settings (Ministry of Health Republic of Indonesia, 2019).

This may be due to the shortage of certified traditional health workers to provide the services (Ministry of Health Republic of Indonesia, 2019).

The Indonesian basic health research report (The Riskesdas 2018) listed the types of traditional healthcare services used by the Indonesian population to be mind and body-based therapies (65.3%), CAM providers'- processed concoction (48%), self-processed concoction (31.8%), energy therapy (2.1%) and mindfulness-based interventions (1.9%) (Ministry of Health Republic of Indonesia, 2019). However, most traditional healthcare services in Indonesia are provided by unregistered and unlicensed CAM providers who had no, or a lower level, of education (Amperawati, Pancasiwi, & Nugroho, 2018; Erry et al., 2014; Peltzer & Pengpid, 2019; Pengpid & Peltzer, 2018). There were approximately 989 professional traditional healthcare workers in all of Indonesia (Ministry of Health Republic of Indonesia, 2019). This indicates that women with breast cancer in Indonesia potentially have used traditional healthcare services as CAM therapy that are provided by unqualified, unlicensed and unregistered CAM providers.

There are a number of controversial non-medical cancer treatments in Indonesia that have become of public and government concern. Electro Capacitive Cancer Therapy (ECCT), as explained previously, for instance, was debated by the Indonesian Society of Surgical Oncology (*The Jakarta Post*, 2015). This controversial cancer therapy was banned by the Indonesian government because the anticancer device did not meet safety standards as regulated by the Health Ministry regulations on marketing licences for medical devices (Ramadhani, 2016). In addition, the therapy had not been clinically trialled in an Indonesian hospital, and was being provided by non-healthcare personnel who had no authority to apply the anticancer device for medical purposes on patients (*The Jakarta Post*, 2015). This therapy was also illegally trialled on breast cancer patients in Indonesia, based on a mathematical and physics principle (Nursya'bani, 2015).

Eventually, the clinic was closed by the Ministry of Health Republic of Indonesia due to unmet standards of practice and lack of an operational permit (Nursya'bani, 2015). This illegal CAM practice left about 3,200 cancer patients, who needed to make treatment decisions, whether they would discontinue or remain using this controversial cancer therapy (Ramadhani, 2016). Similarly, the other two most popular traditional healers previously mentioned, Jeng Ana and Ninghsih Tinampi, were warned by the Ministry of Health regarding breaches of the restrictions related to traditional treatment service advertisements in print and electronic media, and on social media (Desideria, 2017; Fauziah, 2020; Solahuddin, 2020). These controversial therapies have been potentially used by women with breast cancer as a part of their breast cancer management.

The commercialisation of herbal medicine products is also of great concern for the public and government. In Indonesia, herbal medicines are grouped into three different categories: registered *Jamu* (Indonesia traditional herbal medicines), standardised herbal products and *fitofarmaka* (herbal medicines that have been clinically tested). The National Agency for Food and Drug Control of the Republic of Indonesia (BPOM) is responsible for monitoring the quality, efficacy and safety of herbal medicines in Indonesia (Mahendradhata et al., 2017; World Health Organization, 2019a). Standardised and registered herbal medicine products in Indonesia are limited (Kartini, Jayani, Octaviyanti, Krisnawan, & Avanti, 2019; World Health Organization, 2019a). Locally produced and imported herbal medicine products are generally purchased over – the - counter from drugstores and/or herbal medicine stores (Kristian, Sumaryono, Widyastuti, & Lesmana, 2019). However, the Republic of Indonesia Health Review 2018 indicated that there is a high rate of illegal prescription drug sales by unlicensed drugstores, where they are also potentially commercialising illegal herbal medicines as well (Mahendradhata et al., 2017).

Data from the National Agency for Food and Drug Control of the Republic of Indonesia showed that the number of counterfeit herbal medicines is increasing (Nuryunarsih, 2017). From 2011 to 2014 there were 155 falsified herbal medicines that were combined with chemical drugs such as paracetamol, piroxicam and phenylbitazone, in order to deceive consumers by providing effect of those conventional medicines (Nuryunarsih, 2017). The counterfeit herbal medicine manufacturers often claimed their products were Indonesian traditional medicine and were marketed with a fake registered number (Mahendradhata et al., 2017; Nuryunarsih, 2017). In addition, inappropriate combinations of herbal medicine and substituted chemical medicine could cause toxic effects that lead to serious complications including death (Nuryunarsih, 2017; Yeung, Gubili, & Mao, 2018). Certainly, this behaviour may worsen heath conditions, as consumers might perceive that their symptoms are under treated by traditional medicine but actually it delayed appropriate treatment. Thus, women with breast cancer in Indonesia potentially have experienced the consumption of fraudulent herbal medicines for their breast cancer management.

Therefore, it is important that women with breast cancer need to be aware of, and have a good understanding about, the use of CAM for breast cancer management. However, women with breast cancer knowledge, and attitudes towards CAM for breast cancer management in Indonesia have not been explored. Therefore, this phenomenological study aimed to explore the lived experiences of women with breast cancer and CAM providers' views in the use CAM for breast cancer management in Indonesia.

1.3. Significance of the study

Complementary and alternative medicine is often considered as a main therapy for breast cancer among women with breast cancer in Indonesia (Azhar et al., 2016; Pahria, 2017). However, there is uncertainty in the implementation of CAM in Indonesia (Erry et al., 2014). Most CAM therapies are provided by unprofessional CAM providers, and many

fraudulent herbal medicines are offered to the community (Erry et al., 2014; Nuryunarsih, 2017; Peltzer & Pengpid, 2019; Pengpid & Peltzer, 2018). In some research, women with breast cancer were shown to have a lower quality of life compared to the general population, specifically in physical and psychosocial domains (Hari et al., 2018). Consequently, the use of inappropriate CAM could delay breast cancer healing processes and worsen the health condition of women with breast cancer (Azhar et al., 2016). Lack of awareness about breast cancer treatment and late detection may also contribute to higher breast cancer mortality in Indonesia (Solikhah, Promthet, & Hurst, 2019). In contrast, higher awareness levels of breast cancer and its treatment could lower the mortality rate related to breast cancer (Almutairi, Tamrin, Wirza, & Ahmad, 2019). Therefore, women with breast cancer need to be aware that they should obtain CAM therapies from professional licenced CAM providers in order to ensure safety and quality of CAM.

However, there was relatively little research concerning women with breast cancer's lived experiences in the use of CAM for breast cancer management in Indonesia. A number of quantitative studies from Asian countries described the demographic factors, the types of CAM and reasons to use CAM (Can, Demir, & Aydiner, 2012; Chen et al., 2008; Kang et al., 2012; Knight et al., 2015; Muhamad et al., 2012; Saibul, Shariff, Rahmat, Sulaiman, & Yaw, 2012; Wang & Chung, 2012; Yildirim, 2010). Several qualitative studies in Asian countries also focused on factors that influenced women with breast cancer to use CAM (Wanchai et al., 2016), the meaning of CAM from the perspective of women with breast cancer (Sirisupluxana, Sripichyakan, Wonghongkul, Sethabouppha, & Pierce, 2009) and women with breast cancer's performance care practice in CAM (Wanchai et al., 2012). There was only one study in Indonesia that had examined predictive factors in the use of CAM among women with breast cancer (Azhar et al., 2016). To date, there was no

known literature that informs what women with breast cancer experience in the use of CAM for breast cancer management.

The findings of this study have the potential to develop in-depth understanding of women with breast cancer's lived experiences in the use of CAM for breast cancer management. The exploration of the lived experiences of women with breast cancer and CAM providers' views will provide new insights and understanding regarding perspectives, expectations, values and knowledge of women with breast cancer in Indonesia concerning the use of CAM for breast cancer management. The findings may be useful for nurses, oncologists and CAM providers to improve their quality of care relating to the use of CAM for breast cancer management. The results of the study may inform policy makers in the development of guidelines and regulations regarding CAM practices for breast cancer management in the Indonesian setting. Indonesian nurses and CAM education, providers and researchers may benefit from the study as the findings may provide insight into evidence-based practice, research, course content development and curriculum evaluation in nursing and CAM education and research settings. Potentially, this study may have a positive impact on the quality of life for women with breast cancer in Indonesia as a result of better understanding and awareness about the use of CAM.

1.4. Aim, research question and objectives

This study aimed to explore the lived experiences of women with breast cancer, and CAM providers' views about the use of CAM for breast cancer management in Indonesia.

The researcher's curiosity about the phenomenon raised the phenomenological research question of '*What are the experiences of women with breast cancer, and their use of CAM, and CAM providers' views of breast cancer management in Indonesia?'* This major question had specific sub-research questions which were used to assist in answering the research question, and guide the interview process:

1. What does CAM mean to women with breast cancer?
2. What types of CAM do women with breast cancer use and how do they use it?
3. What do women with breast cancer feel from the use of CAM for breast cancer management, including benefits and disadvantages?
4. What do women expect from the use of CAM for breast cancer management?
5. What do women perceive and their response toward the use of CAM for breast cancer management?

In addition, supplementary information from CAM providers was sought to support answering the research question. This study also assessed the CAM providers' knowledge, perceptions and attitudes toward CAM by asking questions that included:

1. What do CAM providers understand about the use of CAM for breast cancer management?
2. How do CAM providers respond toward the use of CAM for breast cancer management in Indonesia?

The aim of this study and the answers to the research questions will be achieved through the following three objectives:

1. To explore women with breast cancer lived experiences and perspectives about CAM, as well factors that influence CAM use for breast cancer management.
2. To investigate women with breast cancer's knowledge, attitudes and expectations of using CAM for breast cancer management.
3. To identify the CAM providers' levels of understanding and perspectives regarding the use of CAM for breast cancer management.

1.5. Overview of the thesis

This thesis is divided into eight chapters. The overview of each chapter is presented as follows:

1.5.1. Chapter One: Introduction and Background of the Study

Chapter One (p.1 - 22) briefly introduces the study by providing background information of CAM use for breast cancer management specifically in Indonesia. This Chapter One also explains the aim of the study, the significance, the research question, and the objectives of this study.

1.5.2. Chapter Two: Literature Review

Chapter Two provides an integrative review of recently published literature relevant to the use of CAM for breast cancer particularly in Asian countries. This integrative review was conducted to understand and gain insight about women's experiences in the use of CAM for breast cancer management. Chapter Two presents the systematic search process of articles, the critical appraisal process and the results from the reviewed articles. The reviewed articles mainly presented the prevalence and factors associated with CAM use, the types of CAM used, as well as the information sources of CAM. Chapter Two concludes with a discussion of knowledge gaps that were identified through conducting this integrative review.

1.5.3. Chapter Three: Philosophy of Phenomenology

Chapter Three focuses on the theoretical approach and framework used in this study. This chapter examines and justifies the methodological approach underpinning this research. The chapter begins with an overview of phenomenology followed by the hermeneutic phenomenological approach based on that of van Manen. The chapter then explains the five life existential concepts that are used to reflect on the lived experiences

of women with breast cancer and CAM providers' views regarding the use of CAM for breast cancer management explored in this study.

1.5.4. Chapter Four: Phenomenological Methods

Chapter Four demonstrates the application of the research framework and the research activities. The research activities include ethics approval, data collection, the data analysis process and the establishment of the rigour of the study. Ethics approval describes the ethical clearance application process and permissions to conduct the data collection. The data collection process includes description of recruitment and selection of the participants. The participants were selected based on inclusion criteria. Twenty-one women with breast cancer and 10 CAM providers voluntarily participated in the digitally recorded in-depth interviews. The data analysis process includes the interviews transcription and translation from Bahasa into English. The translated transcripts were analysed using a manual thematic analysis approach.

1.5.5. Chapter Five: Findings (Part 1) - lived experiences of women with breast cancer

The findings of the study are presented into two chapters. Chapter Five provides the first part of the findings chapters. This findings chapter describes the women with breast cancer lived experiences in the use of CAM for breast cancer in Indonesia. The descriptions of the lived experiences of women with breast cancer are presented in four main themes that emerged through the thematic analysis process. The main themes include 'access, affordability and support to medical cancer treatment', 'beliefs in CAM treatment', 'feeling the potential benefits of CAM', and 'acknowledging the negative aspects of CAM'.

1.5.6. Chapter Six: Findings (Part 2) - Views of CAM Providers

Chapter Six presents the findings chapter (part 2). This chapter elucidates the CAM providers' understanding and views on the use of CAM for breast cancer management

in Indonesia. It begins with the CAM providers demographic data descriptions. The CAM providers' understanding and views on CAM are presented in four main themes: 'Characteristics of women with breast cancer who used CAM therapies', 'providing non-evidence based CAM', 'CAM providers' beliefs in potential benefits of CAM' and 'progressive and not so progressive attitudes toward CAM therapies'. These findings supplement the main findings (part 1), which focuses on the lived experiences of women with breast cancer, specifically those experiences related to the use of CAM for breast cancer management.

1.5.7. Chapter Seven: Discussion of the Findings

Chapter Seven provides a discussion of the findings on women with breast cancer's experiences and CAM providers' views on the use of CAM. The discussion is guided by an integrated framework of van Manen's five life existential concepts and the CAM Healthcare Model which was developed by Fouladbakhsh and Stommel (2007). The five life concepts of lived - self others (*relationality*), lived body (*corporeality*), lived space (*spatiality*), lived time (*temporality*) and lived things (*materiality*) were applied to establish phenomenological interpretation of women with breast cancer's experiences in the use of CAM, and CAM providers' lived experience in providing CAM for breast cancer management. The reflections of women with breast cancer's experiences and CAM providers' views underpin the discussion based on the CAM Healthcare Model, which describes predisposing factors, enabling factors, and the need for care factors, health service use, as well as outcomes of care from using CAM.

1.5.8. Chapter Eight: Implications and Conclusion

Chapter Eight is the final chapter of the thesis. This chapter presents implications of the study for the Indonesian healthcare system, nursing practice, CAM education and research, policy makers, CAM providers and women with breast cancer. The limitations and strengths of this study, new knowledge from this study, and a concise summary of

this thesis complete this chapter. The reference list and relevant appendices are included at the end of the thesis.

1.6. Chapter summary

This chapter has described the use of CAM for breast cancer management globally and particularly in Indonesia. The existing relevant literature suggested that little is known about women with breast cancer's lived experiences and CAM providers' views in the use of CAM for breast cancer management in Indonesia. The discussion of CAM use in Indonesia generated research questions that are addressed in this study. The aim and objectives of this study have also been presented, as well as the significant of the study. This chapter is finalised by presenting an overview of the thesis. The next chapter provides a deeper exploration of the existing literature regarding what is known about the use of CAM for breast cancer, particularly in Asian countries.

CHAPTER TWO: LITERATURE REVIEW

2.1. Introduction

This chapter presents a review of relevant literature related to the use of complementary and alternative medicine (CAM) for breast cancer management across Asian countries. The literature review was undertaken to investigate what is currently known about the use of CAM for breast cancer management. In addition, this literature review was conducted in order to gain an in-depth understanding of the current phenomena, to generate new ideas and scientific knowledge, as well as to identify gaps related to the topic of interest (Torraco, 2005).

This chapter begins by explaining the framework used to conduct this literature review and the process of preparing the review including preparing the guiding question, searching, screening, extracting and selecting the most relevant articles based on inclusion and exclusion criteria. The studies in the selected articles were appraised with specifically recognised tools to determine their strengths and weaknesses. The findings of the selected studies were identified, critiqued, analysed and synthesised (de Souza, da Silva, & de Carvalho, 2010). This chapter concludes with a discussion of major themes in the literature and the identified gaps in knowledge related to the lived experiences of women with breast cancer and CAM providers' views about the use of CAM for breast cancer management.

2.2. Integrative literature review framework

An integrative literature review is a sophisticated non-experimental design that allows the researcher to critique, summarise and draw overall conclusions from past qualitative and quantitative studies through systematic research, categorisation and thematic analysis (Schneider, Whitehead, & LoBiondo-Wood, 2016; Torraco, 2005; Whittemore & Knafl, 2005). Through this review method, the researcher can examine and analyse previous literature

that is relevant to the study of interest to generate new perspectives (Torraco, 2005). Conducting an integrative review also helped the researcher appraised the quality of scientific research, discover gaps in what is already known, identify central themes and develop connections between related areas of specialisation (Christmals & Gross, 2017). According to Schneider and Whitehead (2013), an integrative literature review is one of the most common types of review methods that is widely used in the disciplines of nursing and midwifery, as it has the potential to play a significant role in evidence-based nursing practice. This review method provides a way of analysing studies and synthesising significant results for practice (de Souza et al., 2010).

For this study's context, the integrative review method was applied to present the results from past empirical or theoretical studies with various research methods, regarding the use of CAM for breast cancer management. This integrative review was undertaken following the six critical activities required for conducting an integrative review as suggested by de Souza et al. (2010) which were: 1) formulating the guiding question, 2) searching literature, 3) extracting data from studies, 4) critically analysing the included studies, 5) synthesising and discussing the results and 6) presenting the integrative review. Each of the integrative review preparation activities are explained in detail below.

2.3. Formulating the guiding question and searching for literature

The first and most important activity in conducting an integrative review is defining the guiding question (de Souza et al., 2010). The guiding question determines which studies will be included to be reviewed and what specific information will be gathered from each study (de Souza et al., 2010). In this study, the guiding question and key terms were determined before searching for articles began. This integrative review aimed to explore what is currently known about the experiences of women with breast cancer and CAM providers' views about the use of CAM for breast cancer management specifically in Asian countries

of which Indonesia is included. Accordingly, the guiding question on this literature review was: 'What are Asian women and CAM providers' experiences about the use CAM for breast cancer management?'

The key terms included "complementary therapy", "alternative medicine", "breast cancer", "treatment", "women", "CAM therapist", "CAM provider", "experience and perception". Using electronic searches, these terms were used to search CAM publications in the major health science databases such as CINAHL, ProQuest Central, Scopus and Web of Science. To obtain potential relevant articles, the search strategy applied synonyms and Boolean operators. The key terms above were combined with 'and' and 'or'. Initially, 5,759 potentially related articles were retrieved. Two limitation phases using inclusion and exclusion criteria were employed to identify the most relevant research articles for this integrative review. A manual search was also conducted to obtain additional relevant primary research articles from the retrieved articles, citation by authors and hand-searched articles. Table 1 below (p. 25) shows the inclusion and exclusion criteria applied for the article screening process in each phase.

Table 1: Inclusion and Exclusion Criteria

Limitation Phases	Inclusion criteria	Exclusion criteria
Phase 1	• Primary research articles • Published between January 2007 to June 2020 • Published in English or Bahasa • Published peer-reviewed research articles	• Secondary studies • Studies published before 2007 • Studies published in languages other than English and Indonesian • Grey literature, proceedings, guidelines
Phase 2	• Focussing on the use of CAM for breast cancer • Participants were women with breast cancer and CAM providers • Studies conducted in Asian region countries	• Participants were women with multiple cancers or other complications • Participants were men or children with cancer • Studies conducted outside Asian region countries

2.3.1. The article screening process

The article screening process assisted in the selection of the most relevant articles related to the topic of this study. The screening process was conducted in two phases using inclusion and exclusion criteria (Table 1, p. 25). In the first phase, the researcher screened all the initial 5,759 articles according to the inclusion criteria such as primary research articles, published between January 2007 and June 2020, written in Bahasa or English, and peer-reviewed research articles. The articles published in both Bahasa and English were searched as the researcher is literate in Bahasa (Indonesian language) and English. However, there were no relevant articles published in Bahasa.

A total of 5,628 articles were removed due to duplication and unmet inclusion criteria of the first phase. Subsequently, the second phase screening aimed to identify the most relevant articles focusing on the use of CAM for breast cancer management in Asian countries. In this phase, only studies conducted in Asian countries where the participants of the studies were women with breast cancer and CAM providers were included. Articles that involved men and children with cancer as participants in the study were excluded as this review focused on the lived experiences of women with breast cancer and CAM providers' perceptions about the use of CAM. There were 131 potentially eligible articles retrieved from the second phase screening. The titles and abstracts of the 131 selected articles were re-read to identify studies against the inclusion criteria. Finally, 48 articles met the final inclusion criteria and were selected for this integrative review. The following Figure 1 (p. 27) demonstrates the literature searching process.

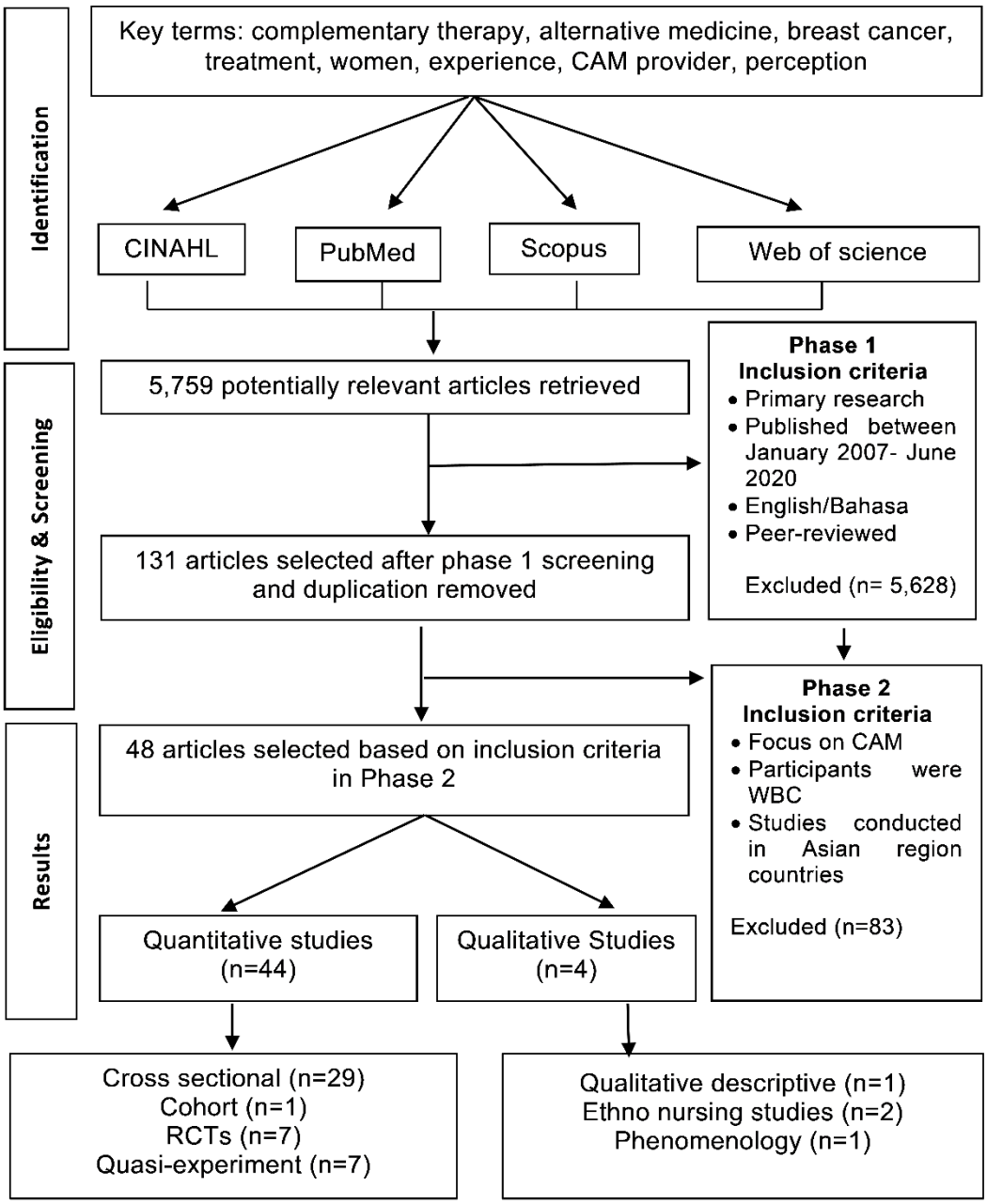


Figure 1: Flow diagram of the literature searching process

2.4. Extracting data from selected studies

The relevant data from the selected studies was collected and summarised. The data that was extracted included the articles' publication details, the country settings, the aim of the study, the methods and the sample size, the major findings, as well as the strengths and the weakness of the selected studies. This data provides essential

information for this integrative review. The details of extracted data are presented in Appendix 1 (p. 276 - 302) of this thesis and discussed in the following sections.

2.4.1. Publications and country settings of the reviewed studies

The studies included in this literature review were conducted and published by multidisciplinary healthcare experts and professionals with specific interests in breast cancer and CAM. The selected studies were conducted in low - middle and high - income countries across the Asian region. The United Nations (2014b) categorised low - and middle - income countries as having a low per capita income and human development index (HDI), poor living conditions, lack of education, and lack of health care facilities. Other characteristics include high mortality rates, illiteracy rates, malnutrition rates and a high level of poverty (United Nations, 2014b). In contrast, high - income countries generally have high levels of gross domestic products (GDP) and standards of living, and excellent education and health care facilities (United Nations, 2014a). The majority of the selected studies were conducted in low-middle income countries in the Asian region (*n=35*) including Bangladesh, China, Indonesia, Iran, Lebanon, Malaysia, Palestine, Thailand and Turkey. There were 13 studies from high income countries in the Asian region such as Hong Kong, Israel, Saudi Arabia, Singapore, South Korea and Taiwan. The table 2 (p. 28) presents the country settings of the included articles.

Table 2: The Selected Studies from Asian Region Countries

Asian Region Countries (n=48)	
Low & middle income countries (n =35)	**High income countries (n=13)**
Bangladesh (n=1)	Hong Kong (n=1)
China (n=5)	Israel (n=1)
Indonesia (n=2)	Saudi Arabia (n=2)
Iran (n=3)	Singapore (n=1)
Lebanon (n=1)	South Korea (n=4)
Malaysia (n=10)	Taiwan (n=5)
Palestine(n=1)	
Thailand (n=3)	
Turkey (n=9)	

There were only two published research articles related to CAM and breast cancer from Indonesia highlighting a gap in knowledge of this phenomenon. Those studies focused on factors associated with the use of CAM for breast cancer. The studies did not provide adequate information to understand women with breast cancer's experiences and CAM providers' perceptions about the use of CAM for breast cancer management in Indonesia. This omission showed a gap in the available literature.

2.4.2. Research methods and samples of the selected studies

The selected studies were conducted using a variety of research designs and methods. The majority of selected quantitative studies aimed to assess the prevalence, pattern and factors of CAM use, to investigate correlation between CAM use and quality of life, and to examine the effectiveness of particular CAM therapies on breast cancer. Twenty-nine of the 44 quantitative studies were cross-sectional surveys. These studies basically described the demographics of CAM users, the types of CAM, information sources and reasons to use CAM. Fourteen quantitative studies used experimental designs consisting of both randomised controlled trials (n=7) and quasi-experimental studies (n=7). The experimental studies investigated the efficacy of particular CAM in Asian countries for breast cancer management. The randomised controlled trial studies examined the effects of aromatherapy, Chinese medicine, classic massage, massage therapy, meditation, yoga, Qigong and spiritual therapy on breast cancer (Eyigor, Uslu, Apaydın, Caramat, & Yesil, 2018; Jafari et al., 2013; Kashani & Kashani, 2014; Kim, Kim, Ahn, Seo, & Kim, 2013; Ovayolu, Seviğ, Ovayolu, & Sevinç, 2014; Zhuang et al., 2011). The quasi-experimental studies investigated the effectiveness of bloodletting puncture and cupping, herbs (*Withania sommnifera*), Qigong exercise, reflexology, traditional Chinese medicine (TCM), Yang deficiency pattern, and yoga exercise on the quality of life of women with breast cancer (Biswal, Sulaiman, Ismail, Zakaria, & Musa, 2013; Fong et al., 2014; Hwang et al., 2015; Tarrasch et al., 2018; Tian et al., 2015; Wang et al., 2018; Yagli & Ulger, 2015). In addition, there was only one

population-based study that assessed the association between the use of TCM and women with breast cancer survival rates in Taiwan (Lee et al., 2014).

There were only four relevant qualitative studies included in this literature. Two of the studies used the ethno-nursing research method. These studies aimed to identify the cultural and social structure factors that influenced Thai women with breast cancer in selecting CAM, and to explore how women with breast cancer made the decision to use CAM (Wanchai et al., 2012, 2016). There was a Heideggerian phenomenological study conducted over 10 years ago in Thailand describing the perspective of women with breast cancer related to CAM and its meaning to their life (Sirisupluxana et al., 2009). Another qualitative study which was conducted over eight years ago employed an in-depth interview method to explore why women with breast cancer sought CAM therapy from traditional healers (Muhamad et al., 2012). The most common data collection method used in the qualitative studies were semi-structured interviews.

This literature review demonstrates the lack of qualitative studies and limited focus on women with breast cancer's lived experiences, and CAM providers' views related to the use of CAM in Asian countries, especially in Indonesia. To date, studies exploring women with breast cancer's experiences and CAM providers' views about the use of CAM for breast cancer, knowledge and attitudes toward CAM are lacking. An understanding of what is it like to use CAM for breast cancer was absent. Therefore, it is important that more qualitative studies be performed in Asian countries particularly in Indonesia, as the results of qualitative studies in this review might differ in an Indonesian context. The details of the research designs used in the selected studies are presented in Table 3 below (p. 31).

Table 3: Research Designs and Methods Used in the Selected Studies

Methodology	Research Designs	Number of Studies
Quantitative Study (n= 44)	Cross-sectional studies	29
	Cohort study	1
	Randomised control trials	7
	Quasi- experimental studies	7
Qualitative Study (n=4)	In-depth interviews	1
	Ethno nursing studies	2
	Phenomenology	1

The samples and participants of the reviewed studies were women with a history of breast cancer at all stages. These included women with breast cancer who were undergoing, or had completed, medical breast cancer treatment, breast cancer survivors and those who used only alternative medicine. The sample size of the reviewed studies varied. The sample size in the quantitative studies ranged from 68 to 70,102 samples, and participants involved in the qualitative studies ranged from 11 to 17 women with breast cancer. The selected studies were analysed and appraised to examine the rigour and the characteristics of each study, the validity of the methods and results as well as the level of evidence of each study (see Appendix 1, p. 276-302).

2.5. Critical analysis of the selected studies

Critical analysis, or appraisal, identifies the trustworthiness, rigour, value and relevance of the selected reviewed studies and to ensure the quality of the studies reported in academic journals (National Health Medical Research Council (NHMRC), 2019). Critical appraisal includes identification of the research methodologies and methods, sample size, ethics and results, the strengths and weaknesses of the reviewed studies. Examining the strengths and weaknesses of the studies uncovered robust justification for the need for further studies to be conducted.

de Souza et al. (2010) suggested that critical analysis, or critical appraisal, requires an organised framework. Therefore, the Joanna Briggs Institute (JBI) approach to evidence-based healthcare was used to appraise the selected studies. The JBI model was developed in South Australia by Pearson, Wiechula, Court, and Lockwood (2005) and was recently updated (Jordan, Lockwood, Aromataris, & Munn, 2016). This model is unique as it conceptualises evidence-based healthcare as clinical decision making that considers feasibility, appropriateness, meaningfulness and effectiveness of healthcare practices (Jordan et al., 2016; Pearson et al., 2005). Feasibility is the extent to which a research activity is practical and practicable (Jordan et al., 2016). Appropriateness is the extent to which an intervention or activity is suitable or relates to the context in which care is give (Pearson et al., 2005). Meaningfulness demonstrates an intervention or activity that is positively experienced by the patients (Pearson et al., 2005). Furthermore, meaningfulness relates to patients' personal experiences, opinions, values, thoughts, beliefs and interpretations (Jordan et al., 2016; Pearson et al., 2005). Effectiveness describes the expected effect or outcomes that are achieved through an appropriate intervention (Pearson et al., 2005). Accordingly, the JBI model has been widely used to develop evidence-based practice in healthcare including nursing and midwifery (Jordan et al., 2016). In addition, the JBI model uses internationally appropriate language so that it can be utilised by health professionals, researchers, and policy makers on the international stage (Jordan, Lockwood, Munn, & Aromataris, 2019).

The JBI model of evidence-based healthcare provides critical appraisal tools that are suitable to each methodology of the reviewed studies. Each tool consists of several criteria to assist in assessing the trustworthiness, relevance and results of published studies. For instance, a critical appraisal tool to examine a randomised control trial study has 13 criteria that focus on randomisation samples of the study, treatment and intervention, the outcome, as well as the statistical analysis process (Joanna Briggs Institute, 2017e). The appraisal

tool for a quasi-experimental study considers nine criteria to explore whether the study clearly stated the ‘cause’ and the ‘effect’ of the experiment (Joanna Briggs Institute, 2017d). Also, multiple measurements of pre-and post-intervention outcomes can be exposure (Joanna Briggs Institute, 2017d). Furthermore, 11 criteria of the cohort study critical appraisal tool examines whether the groups of participants were recruited from a similar population and whether the exposure was measured in a valid and reliable way (Joanna Briggs Institute, 2017b).

The critical appraisal tool to evaluate cross-sectional studies consists of eight questions that concern the inclusion criteria samples of the study, the subject and settings, confounding controls, and the measurement of outcomes (Joanna Briggs Institute, 2017a). The JBI critical appraisal tool for qualitative studies includes 10 criteria that verify the congruity between the research methodology and the research question, the research methods to collect data, the data analysis, as well as the interpretation process of results (Joanna Briggs Institute, 2017c). All the qualitative studies in this review met the JBI critical appraisal criteria while some of the quantitative studies did not meet all the criteria due to unclear methods used in data collection.

2.5.1. The strengths of the selected studies

The critical appraisal identified strengths and weaknesses of the reviewed studies. The strengths included that the studies utilised appropriate research designs and methods, as well as obtained ethical approval before conducting the studies. Approved ethics indicated the ‘rights, dignity, safety and well-being of participants’ in the studies were well protected and respected (Polit, 2014). The selected studies considered any potential or actual risks that might have occurred while conducting the research. Particularly in the trial studies, there were no participants reported to have been negatively affected by the intervention of

treatment (Eyigor et al., 2018; Jafari et al., 2013; Kashani & Kashani, 2014; Kim et al., 2013; Ovayolu et al., 2014; Tarrasch et al., 2018; Wang et al., 2018; Zhuang et al., 2011)

The selected studies recruited their sample or participants using appropriate non-probability and probability sampling techniques such as convenience sampling, quota sampling, purposive and random sampling. The samples and participants were also selected according to inclusion criteria which specified characteristics of the participants. The majority of the studies had high response rates and sufficient sample sizes (Chen et al., 2008; Chui, Abdullah, Wong, & Taib, 2015; Jaradat et al., 2016; Kang et al., 2012; Muhamad et al., 2012; Naja et al., 2015; Shaharudin, Sulaiman, Emran, & Shahril, 2011; Tian et al., 2015). Adequate sample size can enhance the possibility of generalising the results in quantitative studies (Schneider et al., 2016).

The credibility and integrity of the data in the reviewed studies were well maintained. The data in the selected studies were collected using reliable and valid instruments with appropriate methods. For instance, translated questionnaires from English into other languages were piloted before being used for data collection (Akyuz et al., 2019; Eyigor et al., 2018; Naja et al., 2015; Tarrasch et al., 2018). In addition, some of the reviewed studies were the first surveys or trials that had been conducted in the country settings. The results from the initial studies provided precise information that led to the development of evidence-based practice, further scientific research, and recommendations to policy makers and professional healthcare settings for caring for women with breast cancer (Azhar et al., 2016; Biswal et al., 2013; Eyigor et al., 2018; Fong et al., 2014; Lee et al., 2014; Lin & Chiu, 2011; Tarrasch et al., 2018; Zhuang et al., 2011).

2.5.2. Weaknesses of the selected studies

Weaknesses of the reviewed studies were also uncovered. For instance, some of the quantitative studies had low response rates and small sample sizes when the results of the

studies could not be generalised. Four randomised controlled studies did not clearly identify whether the treatment in the trials were blindly delivered to participants in both intervention and control groups (Jafari et al., 2013; Kashani & Kashani, 2014; Ovayolu et al., 2014; Zhuang et al., 2011). One of the studies had an ambiguous randomisation technique described in its study (Ovayolu et al., 2014). In addition, some of the cross-sectional studies did not clearly define the inclusion criteria of their selected samples (Hwang et al., 2015; Jaradat et al., 2016; Kalender et al., 2014; Lin & Chiu, 2011; Wong et al., 2014).

Another significant weakness identified in the selected studies was the lack of clarity regarding confounding controls in the studies. Two of the quasi-experimental studies did not explain the composition of the control group (Fong et al., 2014; Yagli & Ulger, 2015), and the cohort study (Lee et al., 2014) did not clearly mention any specific strategy to deal with confounding factors. The subjects and the setting of the studies, as well as confounding controls, were not specifically identified in some quantitative studies (Kalender et al., 2014; Lin & Chiu, 2011; Wong et al., 2014). Overall, none of the quantitative studies met the JBI critical appraisal criteria. These weaknesses may have produced risks of bias into the results of the reviewed studies.

2.5.3. The levels of evidence of the selected studies

It is important to recognise the levels of evidence of the reviewed studies as this evidence indicates how strong recommendations of studies can influence practice or treatment (Melnyk, 2015). For instance, healthcare professionals in clinical practice refer to recommendations from guidelines generated from the highest levels of evidence in the studies (Joanna Briggs Institute, 2014). The levels of evidence are arranged in a hierarchy based on the rigour of the research methods (Joanna Briggs Institute, 2014; Melnyk, 2015). The levels of evidence of the reviewed studies were assigned using the JBI levels of evidence. According to the JBI's levels of evidence for effectiveness, experimental studies

are positioned at the highest level of evidence (level 1) as these have a lower probability of bias or risk of systematic error (Joanna Briggs Institute, 2014). Experts' opinions and benchmark research are at the lowest level (level 5) due to potentially being biased by the researcher's opinion, as well as having no confounding control factors (Joanna Briggs Institute, 2014).

The JBI's levels of evidence not only consider the effectiveness of treatment but also the feasibility, appropriateness and meaningfulness of qualitative studies (Joanna Briggs Institute, 2014; Jordan et al., 2016; Jordan, Lockwood, Munn, & Aromataris, 2018; Pearson et al., 2005). The levels of evidence for meaningfulness were applied to the selected qualitative studies.

In terms of the levels of evidence for meaningfulness, qualitative or mixed – methods systematic reviews were placed at the highest level (level 1), and the expert's opinion is at the lowest level (level 5). Based on the JBI levels of evidence, the highest level of evidence for effectives of the reviewed studies is at level 1 (Randomised Controlled Trials) and the lowest level of evidence is at level 4 (cross-sectional studies). The levels of evidence for meaningfulness of the reviewed studies were at level 4, as all the selected qualitative studies were single qualitative studies. None of the reviewed studies were assigned at the highest level of evidence for effectiveness and meaningfulness because the highest level of evidence level is situated for evidence on systematic reviews. Systematic reviews were excluded from this review as this literature review considered only primary research studies. A summary of the levels of evidence of the reviewed studies were presented in the Table 4 (p. 37).

2.6. Data synthesis and analysis

At the stage of data synthesis and analysis, the results of the selected studies were examined to identify gaps in knowledge and new ideas, as well as to identify priorities for future studies. A taxonomy, or conceptual classification of constructs framework, was used

to synthesise new ideas from the reviewed studies. This framework allowed for the classification and categorisation of ideas, the results or information of the selected studies (Doty & Glick, 1994). The results of the selected studies were categorised using Braun and Clarke's (2006) thematic analysis methods. The methods applied included becoming familiarised with the results of the selected studies, extracting significant information and generating initial codes, searching for themes or categorising significant information, reviewing themes or the categorised information, defining and naming themes, and presenting the report (Braun & Clarke, 2006). In this literature review, identified significant results that related to the use of CAM for breast cancer management in Asian region countries emerged in four main categories and six sub-categories. The four main categories were: 1). the use of CAM for breast cancer, 2). sociodemographic factors, 3). types, efficacy, and safety of CAM used for breast cancer, and 4). sources of information and disclosure of CAM use. The synthesis of results from the selected studies are explained in the following sections.

Table 4: The Levels of Evidence of the Reviewed Studies Based on the JBI Model 2014

The Levels of Evidence	The Effectiveness (n=32)	The Meaningfulness (n=4)
Level 1	Experimental designs a. Systematic review of RCTs b. Systematic review of RCTs and other study designs c. RCT (n=6) d. Pseudo-RCTs	Qualitative or mixed-methods systematic review
Level 2	Quasi-experimental designs a. Systematic review of quasi-experimental studies b. Systematic review of quasi-experimental studies and other lower study designs c. Quasi-experimental prospectively controlled study d. Pre-test, post-test or historic/retrospective control group study (n=5)	Qualitative or mixed-methods systematic synthesis
Level 3	Observational-analytic designs a. Systematic review of comparable cohort studies b. Systematic review of comparable cohort studies and other lower study designs c. Cohort study with control group d. Case – controlled study e. Observational study without a control group (n=1)	Single qualitative studies (n=4)
Level 4	Observational-descriptive studies a. Systematic review of descriptive studies b. Cross-sectional studies (n=20) c. Case series	Systematic review of expert opinion

	d. Case studies	
Level 5	Expert opinion a. Systematic review of expert opinion b. Expert consensus c. Bench research/single expert opinion	Expert opinion

2.6.1. The use of CAM for breast cancer

The use of CAM among women with breast cancer in Asian countries was common. There were many studies using surveys that reported more than 50% of women with breast cancer had used at least one type of CAM as a part of their breast cancer treatment (Albabtain et al., 2018; Almasdy et al., 2018; Alsharif & Mazanec, 2019; Chen et al., 2008; Chui et al., 2015, 2018; Gül et al., 2014; Hwang et al., 2015; Kang et al., 2012; Lin & Chiu, 2011; Saibul et al., 2012). A national cohort study, which was conducted by Chen et al. (2008) revealed that the prevalence of CAM use among women with breast cancer in China was higher than in the United States.

According to the reviewed studies, Asian women with breast cancer used CAM as an adjunctive therapy to support conventional medicine or as an alternative therapy to substitute standard cancer treatment. The majority of women with breast cancer in the reviewed studies used CAM while undergoing or after completing cancer medical treatment such as chemotherapy or radiotherapy (Can et al., 2012; Chui, Abdullah, Wong, & Taib, 2014; Chui et al., 2015; Kang et al., 2012; Knight et al., 2015; Lin & Chiu, 2011; Muhamad et al., 2012; Saibul et al., 2012; Sirisupluxana et al., 2009; Wanchai et al., 2016; Wong et al., 2014; Yildirim, 2010). Some women with breast cancer preferred using CAM as a main therapy instead of seeking medical cancer treatment after breast cancer diagnosis (Akhtar et al., 2018; Azhar et al., 2016; Gulluoglu, Cingi, Cakir, & Barlas, 2008; Muhamad et al., 2012; Sirisupluxana et al., 2009). For example, a cross-sectional study in Bangladesh which was conducted by Akhtar et al. (2018), found that 93 of the 200 respondents in their study first sought homeopathy as an alternative medicine for breast cancer treatment. Almost all the Bangladeshi women with breast cancer who used alternative medicine in that study

perceived that homeopathy could shrink their breast lump (Akhtar et al., 2018). According to a qualitative study in Thailand, which was conducted by Sirisupluxana et al. (2009), women with breast cancer in their study sought CAM first because they perceived CAM to be more important and reliable than medical cancer treatment. In addition, the use of CAM in Asian countries was also popular among breast cancer survivors (Saibul et al., 2012; Shaharudin et al., 2011; Wanchai et al., 2012; Wang & Chung, 2012).

This literature review identified reasons why women with breast cancer were interested in using CAM. The foremost reason to use CAM were to alleviate the side effects of chemotherapy, increase their immune system and improve their quality of life, as well as to maintain their physical and emotional well-being during breast cancer treatment (Albabtain et al., 2018; Almasdy et al., 2018; Alsharif & Mazanec, 2019; Chen et al., 2008; Chui et al., 2018; Gül et al., 2014; Gulluoglu et al., 2008; Hwang et al., 2015; Jaradat et al., 2016; Naja et al., 2015; Saibul et al., 2012; Shaharudin et al., 2011; Sirisupluxana et al., 2009; Yildirim, 2010; Zulkipli et al., 2018). Additionally, CAM was reported to be utilised to reduce fatigue, pain and insomnia that occurred while undergoing chemotherapy or radiotherapy (Albabtain et al., 2018; Chui et al., 2014, 2015; Huang et al., 2015; Jaradat et al., 2016).

Other women with breast cancer used CAM to manage their emotional issues such as anxiety, depression, fearfulness, hopelessness, and powerlessness as these conditions were reported to lower their immune system and allowed cancer cells to grow (Akyuz et al., 2019; Alsharif & Mazanec, 2019; Kalender et al., 2014; Saibul et al., 2012; Sirisupluxana et al., 2009). In addition, some women with breast cancer used CAM as their main therapy to treat their breast cancer due to their disbelief in, and fear of breast tumour removal surgery, chemotherapy and radiotherapy. Hence, they used CAM to treat their breast cancer without medical treatment (Azhar et al., 2016; Chui et al., 2014; Jaradat et al., 2016; Muhamad et al., 2012; Naja et al., 2015; Sirisupluxana et al., 2009).

In summary, the reviewed studies explained the interests and common reasons for using CAM among women with breast cancer in Asian countries. However, the results were mainly based on survey studies where the women with breast cancer responded to information provided in questionnaires. Qualitative studies that allowed women with breast cancer to express in-depth details about their lived experiences in using CAM for breast cancer were lacking. The lived experiences of women with breast cancer could contribute to understanding values, new ideas and important information, which could contribute to improving cancer care in nursing practice. Therefore, more qualitative studies exploring women with breast cancer's understanding regarding CAM needs to be conducted.

2.6.2. Sociodemographic factors

Most of the reviewed studies identified age, education levels, personal income, and stages of breast cancer as the main sociodemographic factors associated with CAM usage among women with breast cancer in Asian countries. However, in some studies, these factors were not found to be associated with the use of CAM for breast cancer management.

2.6.2.1. Age

All of the reviewed studies identified the age of women with breast cancer who used CAM for breast cancer. The average age of women with breast cancer who used CAM was 50 years of age. The youngest participant was 19 years and the oldest was 75 years (Knight et al., 2015; Muhamad et al., 2012). Studies in China, Singapore and Taiwan found that the use of CAM was higher among Chinese women with breast cancer aged younger than 60 years (Chen et al., 2008; Lin & Chiu, 2011; Wong et al., 2014). Wong et al. (2014) stated that younger Chinese women with breast cancer were more likely to use CAM than older women with breast cancer because they expected to live longer with the use of CAM. Wong et al. (2014) claimed that younger women with breast cancer might be more attracted to use CAM because they were more apprehensive dealing with their breast cancer. Younger women with breast cancer in their study also perceived CAM to have no adverse effects, as

it is a natural treatment. These concerns lead the younger women with breast cancer to seek every available treatment option to manage their breast cancer including CAM (Wong et al., 2014).

The use of CAM among women with breast cancer aged older than 60 years was found in studies from Malaysia and Thailand (Muhamad et al., 2012; Shaharudin et al., 2011; Sirisupluxana et al., 2009). Particular types of CAM, such as yoga exercise, were perceived to be unsuitable for women at an older age with breast cancer. A quasi-experimental study, which was conducted by Yagli and Ulger (2015), considered that elderly women with breast cancer may be at risk of injury and discomfort from practicing yoga. The study investigated the effects of yoga on the quality of life among elderly women with breast cancer where the participants were aged 65 to 70 years old. However, the yoga exercises consisted of movements such as bending positions that could have been difficult to be practised by the elderly and could cause muscle injuries or fractures if such positions were not correctly performed. Yagli and Ulger (2015) stated that it was important to ensure the ability of the elderly related to their muscular strength and articular limitations before the elderly practiced yoga as a CAM.

In summary, age is one of the factors that needs to be considered in the use of CAM; thus, further research investigating appropriate types of CAM for elderly women with breast cancer is warranted. Qualitative studies exploring women with breast cancer's lived experiences in the use of CAM is also required as women with breast cancer at certain ages may have different experiences of CAM use.

2.6.2.2. Education levels

The majority of the reviewed articles documented the levels of education of Asian women with breast cancer who used CAM. The average level of education achieved of those women with breast cancer was 'high school graduate' (Alsharif & Mazanec, 2019; Azhar et al., 2016;

Chen et al., 2008; Chen et al., 2013; Chui et al., 2015, 2018; Gül et al., 2014; Gulluoglu et al., 2008; Hwang et al., 2015; Kim et al., 2013; Naja et al., 2015; Wanchai et al., 2016; Wong et al., 2014; Yildirim, 2010; Zulkipli et al., 2018). Seven studies in low-and middle-income countries, including Bangladesh, Indonesia and Turkey, demonstrated that CAM use was higher among women with breast cancer who had lower education levels or were 'primary school graduated' (Akhtar et al., 2018; Azhar et al., 2016; Can et al., 2012; Gül et al., 2014; Gulluoglu et al., 2008; Kalender et al., 2014; Yildirim, 2010). In contrast, studies in Korea, Malaysia, Saudi Arabia, Thailand and Turkey found the use of CAM was more prevalent among women with breast cancer with higher education levels such as secondary school and university graduated (Alsharif & Mazanec, 2019; Chui et al., 2014; Jaradat et al., 2016; Kang et al., 2012; Sirisupluxana et al., 2009).

Two cross-sectional studies from low-and middle-income countries revealed there were significant correlations between CAM usage and education levels (Azhar et al., 2016; Jaradat et al., 2016). Azhar et al. (2016) reported that Indonesian women with breast cancer with lower education levels were more likely to use CAM because they were afraid to undergo surgery and/or chemotherapy, and afraid of adverse effects that may occur from those treatments. However, Jaradat et al. (2016) found that the majority of well-educated Palestinian women with breast cancer had a strong belief in the effectiveness of herbal therapy; thus, they preferred to include herbal remedies into their breast cancer treatment.

Four of the reviewed studies reported that there were insignificant associations between CAM use and education levels (Kang et al., 2012; Knight et al., 2015; Wong et al., 2014; Yildirim, 2010). A descriptive study conducted eight years ago by Kang et al. (2012) showed that most well-educated women in Korea were more aware of the availability of different types of treatment options for breast cancer including CAM. Other women with breast cancer believed in and relied only on medical cancer treatment due to not trusting and being

unfamiliar with CAM (Kang et al., 2012). Similarly, studies in Malaysia and Singapore indicated that Asian women with breast cancer with better education levels used CAM wisely as a part of their breast cancer management (Chui et al., 2015; Wong et al., 2014) Another study in Malaysia also found that CAM usage was not significantly associated with educational levels due to the participants in that study having different socio-economic levels (Knight et al., 2015). There were no studies exploring women with breast cancer's knowledge and understanding about CAM use for breast cancer management.

It appears from the reviewed studies that women with breast cancer with less education in low-middle income countries were more enthusiastic to try CAM than those at higher education levels in higher income countries. For example, a cross-sectional study in Bangladesh, conducted by Akhtar et al. (2018), found that the use of CAM as alternative medicine for breast cancer was more prevalent in illiterate women with breast cancer than well-educated women with breast cancer. The higher levels of interest in the use of CAM among less-educated women with breast cancer can also be seen with the women with breast cancer involvement in randomised controlled trial studies, which were conducted to investigate the effectiveness and safety of CAM (Ovayolu et al., 2014; Vanaki et al., 2016). For example, the percentage of illiterate women with breast cancer who participated in a randomised controlled trial study investigating the effectiveness of therapeutic touch in Iran was higher than the percentage of women with breast cancer who held a university degree (Vanaki et al., 2016). Similarly, another controlled trial study which was conducted six years ago in Turkey by Ovayolu et al. (2014), also reported that the majority of women with breast cancer involved in their study were non-literate women with breast cancer. Illiterate women with breast cancer were considered more approachable than well-educated women with breast cancer who might have been more aware of the safety of being involved in trial studies. Overall, given the above, it is important to explore what women with breast cancer

understand about CAM use taking into consideration the differing education levels of participants.

2.6.2.4. Personal income

Personal income describes the total of individual earnings including wages, salaries, government benefits, pensions, allowances and other support that an individual receives at certain periods of time (Australian Bureau of Statistics, 2017). In this literature review, personal income refers to women with breast cancer's monthly or yearly earnings. Personal household income is one of the considerations for women with breast cancer when choosing to use CAM due to this treatment not always being supported by the government or covered by private insurance (Chui et al., 2015).

The use of CAM for breast cancer was identified among women with breast cancer who had lower and higher incomes (Akhtar et al., 2018; Azhar et al., 2016; Chen et al., 2008; Chui et al., 2014; Han et al., 2019; Kalender et al., 2014; Kang et al., 2012; Knight et al., 2015; Lin & Chiu, 2011; Wanchai et al., 2012, 2016). Six studies reported that the majority of CAM users with higher economic status were more likely to use additional therapies to cope with medical cancer treatment effects (Chen et al., 2008; Chui et al., 2014; Han et al., 2019; Kang et al., 2012; Knight et al., 2015; Lin & Chiu, 2011). For instance, studies in higher income countries such as South Korea and Taiwan found most women with breast cancer with higher income generally had CAM insurance cover and the ability to pay for out-of-pocket costs of CAM (Han et al., 2019; Huang et al., 2015; Lin & Chiu, 2011). In contrast, in Bangladesh, Indonesia, Thailand and Turkey, the use of CAM was more favourable among women with breast cancer with lower incomes (Akhtar et al., 2018; Azhar et al., 2016; Kalender et al., 2014; Wanchai et al., 2012, 2016). According to surveys, conducted by Akhtar et al. (2018) and Azhar et al. (2016), the majority of lower income women with breast cancer preferred to use CAM due to limited access to cancer care facilities and their inability to pay for medical cancer treatment. Women with breast cancer sought CAM for their initial

breast cancer treatment option before they could access medical cancer treatment (Akhtar et al., 2018; Azhar et al., 2016). Similarly, a study in Turkey also found that lower income women with breast cancer consumed a low-cost Turkish herb (stinging nettle) to treat their breast cancer (Kalender et al., 2014). Based on their belief, consuming such a herb could cure cancer hence it would reduce breast cancer treatment costs (Kalender et al., 2014). In contrast, a cross-sectional study in Korea revealed that more than 60% of 288 women with breast cancer did not believe that CAM use could decrease breast cancer treatment costs (Hwang et al., 2015). However, there was limited evidence that CAM could contribute to decreased breast cancer treatment expenses. Therefore, investigation into CAM use and breast cancer treatment costs is warranted particularly by exploring women with breast cancer's lived experiences in the use of CAM for breast cancer management.

Five of the reviewed studies identified significant correlations between CAM use and socioeconomic status (Azhar et al., 2016; Chen et al., 2008; Knight et al., 2015; Lin & Chiu, 2011; Naja et al., 2015). The cost of CAM in each different country varied and the use of CAM was influenced by personal income. Those women with breast cancer with higher income used CAM as a complement for medical cancer treatment because they could afford the additional expenses of CAM (Lin & Chiu, 2011). However, the cost of CAM was a barrier to use CAM among women with breast cancer on lower incomes. A cross-sectional study in Malaysia, conducted by Knight et al. (2015), revealed that the use of CAM was associated with the personal income of women with breast cancer. The use of CAM among women with breast cancer in that study was not prevalent due to the majority of participating women having no personal income or having personal income lower than average. Inadequate income prevented women with breast cancer from using CAM as they could not afford to outlay the extra expenses of CAM therapies (Knight et al., 2015).

Personal income was also described as one of the important considerations in making decisions on the use of CAM. A qualitative study in Thailand described how economic status was a factor that influenced women with breast cancer to continue or discontinue CAM use (Wanchai et al., 2016). According to the qualitative study, women with breast cancer in financial hardship discontinued CAM use as they could not afford the expensive costs of CAM (Wanchai et al., 2016). Other women with breast cancer sought an affordable CAM instead of using an expensive CAM, or even continued using CAM although the costs were too expensive (Wanchai et al., 2016). Overall, the cost of CAM was a barrier to the majority of low-income women with breast cancer who intended to use it.

In summary, the studies included in this section of the review illustrated that personal income plays an important role in CAM use for breast cancer management. The women with breast cancer with higher incomes could afford the cost of CAM and used CAM as an adjunct therapy to increase their quality of life. In contrast, women with breast cancer who had lower incomes utilised CAM as a main therapy for breast cancer as they perceived CAM to be cheaper than medical treatment. However, the use of CAM as a main therapy for breast cancer has not been proven to be safe or effective; it may decrease medical cancer treatment costs but the use of CAM does delay medical treatment (Akhtar et al., 2018; Chui et al., 2015; Huang et al., 2015; Mujar et al., 2017; Sirisupluxana et al., 2009). Therefore, it is important for women with breast cancer to enhance their awareness and understanding regarding the need of CAM for breast cancer management. Further studies may explore the cost effectiveness of CAM for breast cancer treatment among women with breast cancer in Asian countries, particularly in lower-middle income countries such as Indonesia. The availability of financial aid for CAM treatment is not clearly known. Another factor related to CAM use among women with breast cancer in Asian countries was cancer stages. The relationship between CAM usage and cancer stages is discussed in-depth below.

2.6.2.5. Stages of breast cancer

Stages of breast cancer describes how far the cancer has spread and has affected other parts of the body (Cancer Australia, 2017). The stages of breast cancer are numbered from zero to four, where zero refers to 'pre-invasive' breast cancer. Stage I and II describe the breast tumour size to be less than 5 cm in diameter, and as such this stage is considered as early breast cancer. At these stages, breast cancer has not invaded other parts of the body (Cancer Australia, 2017). Breast cancer stages III and IV represent advanced breast cancer where the size of the breast tumour is more than 5 cm and has spread into other body organs (Cancer Australia, 2017).

In the reviewed literature, there was a significant correlation between CAM use and breast cancer stages (Alsharif & Mazanec, 2019; Kang et al., 2012; Naja et al., 2015). Studies showed that the use of CAM for breast cancer in Asian countries was more prevalent among women with breast cancer at early stage breast cancer than at the advanced stage (Akhtar et al., 2018; Biswal et al., 2013; Chen et al., 2008; Chui et al., 2015; Huang et al., 2015; Jaradat et al., 2016; Kang et al., 2012; Naja et al., 2015; Sirisupluxana et al., 2009; Vanaki et al., 2016; Wang & Chung, 2012; Zulkipli et al., 2018). The women with breast cancer at an early stage of breast cancer immediately used CAM, as soon as they were diagnosed as they perceived that CAM could slow the cancer progression and cure the disease (Akhtar et al., 2018; Azhar et al., 2016; Kang et al., 2012; Zulkipli et al., 2018). Unlike the women with breast cancer at an early stage breast cancer, women with breast cancer at an advanced stage of breast cancer utilised CAM to relieve breast cancer symptoms (Jaradat et al., 2016; Naja et al., 2015).

It is important that CAM is used according to women with breast cancer's specific needs because the use of inappropriate CAM may cause physical, emotional and financial harm (Akhtar et al., 2018; Chui et al., 2018; Han et al., 2019; Mujar et al., 2017; Zulkipli et al., 2018). However, none of the studies included in this review identified what women with

breast cancer's expectations were in the use of CAM based on their breast cancer stage. Exploring their intentions and expectations on CAM use is necessary as these could provide greater understanding as to whether women with breast cancer select appropriate CAM that is suitable to their breast cancer stage and health conditions.

To sum up, the results of the reviewed studies found that CAM use for breast cancer among women with breast cancer in Asian countries was influenced by sociodemographic factors such as age, level of education, personal income and the stage of breast cancer. The studies highlighted that some women with breast cancer used CAM that may not be safe and effective for use at an older age. In terms of education levels, women with breast cancer with higher education levels used medical cancer treatments to treat their breast cancer, and complemented the treatment with scientifically proven CAM. In contrary, those with lower education levels were less familiar with medical cancer treatments and opted for CAM to treat their breast cancer. Similarly, wealthier women with breast cancer used CAM as an adjunct therapy to increase their quality of life while undergoing medical cancer treatment. However, the cost of CAM was a barrier to CAM use for most poor women with breast cancer in lower-middle income Asian countries. In addition, women with early-stage breast cancer were more likely to use CAM than those at the end stage cancer as they expected their breast cancer to heal from using any treatment including CAM. These associated factors of CAM use were mostly based on quantitative study reports, where the women with breast cancer's lived experiences in the use of CAM were not identified. Thus, an in-depth exploration of women with breast cancer's lived experience with the use of CAM could provide greater understanding on sociodemographic factors that may be associated with CAM use.

2.6.3. Types, efficacy and safety of CAM used for breast cancer

The National Centre for Complementary and Integrative Health (NCCIH, 2019) classified three categories of CAM approaches: natural products, mind and body practices and other complementary health approaches. Natural products are biologically-based products that are taken into the body such as herbs, dietary supplements, prebiotics, vitamins and minerals (NCCIH, 2019). Mind and body practices such as acupuncture, yoga, massage therapy and healing touch therapy are procedures that promote relaxation effects to alleviate cancer symptoms including pain, nausea, and insomnia (NCCIH, 2019). The practice of traditional healers, traditional Chinese medicine (TCM), Ayurveda therapy, naturopathy and homeopathy are parts of the other CAM health approaches (NCCIH, 2019). This literature review described the types of CAM that were commonly used by Asian women with breast cancer for breast cancer management (see Table 5, p. 49). The efficacy and safety of the CAM are also discussed in the following section.

Table 5: Types of CAM used for Breast Cancer management in Asian Countries

Country	Authors	Natural Products	Mind and Body Practices	Other Complementary Health Approaches
Bangladesh	Akhtar et al. (2018)	Not identified	Not identified	Homeopathy
China	Chen et al. (2008); Tian et al.(2015)	Herb (*Gonoderma Lucidum*)	Not identified	Traditional Chinese medicine
Hong Kong	Fong et al. (2014)	Not identified	Qigong	Not identified
Indonesia	Almasdy et al. (2018)	Herbal medicine, Jamu, supplements	Praying, meditation, massage	Acupressure, , Chinese medicine, cupping therapy, Warsito's jacket,
Iran	Jafari et al. (2012); Kashani & Kashani (2014); Vanaki et al. (2016)	Not identified	Spiritual therapy, massage, therapeutic touch	Not identified
South Korea	Han et al. (2019); Hwang et al. (2015); Kang et al. (2012); Kim et al. (2012).	Herbal medicine, ginseng, mushrooms vitamins and mineral, indirect moxibustion	Yoga, praying, meditation, bee venom, acupuncture, electro-acupuncture, herbal acupuncture, acupuncture	Warm or fire needling, dry cupping, exercise, wet cupping, physical therapy
Lebanon	Naja et al. (2015)	Special food (honey, black seed, camel milk, soy, pomegranate, and ginger), herbal teas	Spiritual healing (Zam-Zam water, prayers	Folk medicine

		(green tea), dietary supplements (prebiotic, graviola pills)		
Malaysia	Biswal et al. (2012); Chui, Abdullah, Wong & Taib (2014; 2018); Knight, Hwa & Hashim (2012); Mujar et al. (2017); Muhammad, Miriam & Suhami (2012); Shaharudin et al. (2011); Saibul et al. (2012)	Herbs (*Whitania somnifera*), vitamins, mineral, cactus juice spirulina, egg, white turmeric, evening primrose oil, herbal product, other dietary supplements	Prayer, massage meditation, tai chi, yoga, healing touch, Quranic healing, spiritual activities, breathing exercises, reiki, aromatherapy, acupuncture, therapeutic/ healing touch	Traditional healers, Homeopathy, Malay traditional medicine, cupping therapy, Ayurveda, ozone therapy
Palestine	Jaradat et al. (2016)	Herbs (Ephedra alata, nigella arvensis, arum palaestinum, phoenix dactylifera, oleaeuropaea, annona muricata, linumbienne, trigonella arabica	Not identified	Not identified
Saudi Arabia	Albabtain et al. (2017); Alsarif & Mazanec (2019)	Herbal therapy, black seed, honey, olive oil, fennel flower seed, ginger	Spiritual therapy, recitation of Holy Quran, prayers, positive thinking, relaxation techniques	Hojama, Islamic exorcism
Singapore	Wong et al. (2014)	Standardised herbal formulas	Not identified	Traditional Chinese medicine
Taiwan	Huang et al. (2015); Lee et al. (2014); Lin & Chiu (2011); Zhuang, Chiu, Chen, & Tsai (2012)	Vitamins, herbs (Ganoderma lucidum)	Prayer, spinal manipulation Qi gong, acupuncture/ traumatology manipulative therapies	Traditional Chinese medicine, Chinese herbal medicine
Thailand	Sirisupluxana et al. (2009); Wanchai, Armer & Stewart (2012)	Mushroom, coffee, vitamins, selenium, shark cartilage, flower pollen, herbs	Meditation prayer (listening to Buddha's teachings), massage	Changed diet, exercise
Turkey	Akyuz et al. (2019); Can, Demir& Aydiner (2012); Gul, Ustandag & Ansoy (2014); Gulluaglo, Cingi, Cakir & Barlas (2008); Kalender et al. (2014); Ovayolu et al. (2014); Yagli & Ulger (2015); Yildirim (2010)	Herbs (green tea, stinging nettle and ginger), nutritional supplements, multivitamins, honey pectin, herbal medicine	Prayer, spiritual healing, massage, yoga, guided imagery, meditation, acupuncture, reiki	Exercise, aquatic therapy, bioenergy

2.6.3.1. Natural products

Natural and biologically-based products including herbs, vitamins, minerals and nutritional supplements are often considered to be safe because they have been produced naturally without additional chemical substances (National Cancer Institute, 2017, 2019). This literature review identified natural products including herbs and herbal products, dietary supplements vitamins and minerals as the most popular CAM used by women with breast cancer in Asian countries. The selected studies showed that each Asian country had specific natural products that were commonly used by women with breast cancer as complementary therapy. For instance, the use of ginger and mushrooms as CAM was popular among women with breast cancer in Lebanon, South Korea, Thailand and Turkey (Gül et al., 2014; Hwang et al., 2015; Naja et al., 2015; Sirisupluxana et al., 2009). *Gonoderma lucidum (lingzhi)* capsules were commonly consumed as a supplement for boosting the immune system by Chinese women with breast cancer in China and Taiwan (Chen et al., 2008; Huang et al., 2015; Zhuang et al., 2011). For centuries, this Chinese folk medicine has been used to treat various human diseases including cancer in Asian countries, particularly in Taiwan (Zhuang et al., 2011). Furthermore, green tea was found as the most popular form of CAM for breast cancer treatment in Lebanon and Turkey (Gül et al., 2014; Naja et al., 2015). Shark cartilage products were the most favoured natural product used as CAM for breast cancer in Thailand (Sirisupluxana et al., 2009; Wanchai et al., 2012). In Malaysia, natural products that were commonly consumed by women with breast cancer were vitamins and minerals, herbs and herbal products, as well as dietary supplements such as cactus juice, spirulina, egg, white turmeric, evening primrose oil, and other dietary supplements (Chui et al., 2014, 2015; Knight et al., 2015; Muhamad et al., 2012; Saibul et al., 2012; Shaharudin et al., 2011).

Hwang et al. (2015) and Kang et al. (2012) claimed that the use of herbs as CAM for breast cancer mostly related to socio-cultural background. For example, women with breast cancer in Korea consumed ginseng for breast cancer management because ginseng is the most

popular nutritional therapy among the Korean population (Hwang et al., 2015; Kang et al., 2012). Similarly, most women with breast cancer in Turkey consumed stinging nettle based on their local folk traditions and beliefs (Kalender et al., 2014). In the Turkish culture, stinging nettle is believed to be a medicinal plant that can cure cancer; hence, women with breast cancer selected this plant first as their CAM option for breast cancer management (Kalender et al., 2014).

Furthermore, of the 48 selected studies in this review, there was only one study that described a standard formula to consume natural products including herbs and dietary supplements for breast cancer (Wong et al., 2014). A cross-sectional descriptive study in Palestine, which was conducted by Jaradat et al. (2016), stated that the consumption of natural products for breast cancer management was generally self-prescribed. As reported in their study, Palestinian women with breast cancer consumed wildlife plants such as *Ephedra alata*, *Nigella arvensis* and *Arum Palaestinum* by eating them raw or drinking the leaves infused in water for breast cancer management (Jaradat et al., 2016). This indicated that the herbs were taken without measured dosages and were home-processed procedures. However, Jaradat et al. (2016) and Kang et al. (2012) argued that some types of CAM, including herbs, may have potential toxicities effects if they are taken or integrated with medical treatment without a safe recommended standard dosage (Jaradat et al., 2016; Kang et al., 2012). Studies investigating the safety on the use of self-prescribed CAM were limited. Thus, further studies are recommended to explore what women with breast cancer experience in taking self-prescribed and home-processed CAM such as herbs and other natural products.

This literature review found only two trial studies that investigated the efficacy and safety of herbs used for breast cancer management that published in more the decade from 2007 to 2020. One of the studies was an open-label non-randomised comparative clinical trial, which

was conducted over seven years ago by Biswal et al. (2013) in Malaysia. This trial study investigated the efficacy of *Withania somnifera,* a popular herb used for breast cancer in Malaysia, to reduce fatigue and improve quality-of-life among women with breast cancer (Biswal et al., 2013). One hundred women with breast cancer who were undergoing chemotherapy participated in the trial, where 50 participants were included in the study group and 50 women with breast cancer were in the control group. The women with breast cancer in the study group were asked to take four *Withania somnifera* extract packed in a vegetable capsule (2 grams) per day, and a standard antiemetic during the six-cycles of chemotherapy. The women with breast cancer's fatigue score was assessed using a validated fatigue assessment instrument. This study found that the fatigue score in the study group was lower than in the control group (Biswal et al., 2013). None of the study's participants reported any complaints or disappointment from consuming the *Withania somnifera* capsules. The participants' liver and renal function observations during the study showed that no negative effects occurred from consuming *Withania somnifera* capsules. It was evident from the experimental study that *Withania somnifera* might potentially be safe and effective to be used to reduce fatigue related to breast cancer treatment (Biswal et al., 2013). Nevertheless, the results from that study cannot be generalised to the population of other women with breast cancer due to the sample size being small, and the administration of the treatment not being randomised. Thus, further randomised controlled trial studies with larger sample sizes should be conducted to develop stronger evidence of *Withania somnifera* efficacy and safety.

Another experimental study conducted was a randomised, double-blind, placebo-controlled trial investigating the efficacy and safety of a Chinese medicinal herb complex called GR-CMH, which is a mixture of rose geranium, *Gonoderma tsugae*, *Codonopsis pilosula* and *Angelica sinensis,* on cellular immunity and toxicity related to participants' breast cancer condition (Zhuang et al., 2011). It was believed by Taiwanese women with breast cancer that

the RG-CMH contained substances that were associated with immunomodulatory and anti-inflammatory functions. This belief prompted women with breast cancer in Taiwan to commonly use the GR-CMH to manage immunity impairment and leucopoenia which occurred from toxicity side effects of the cancer treatment (Zhuang et al., 2011).

The experimental study examined the potential effects of the GR-CMH in improving the immune cell count for women with breast cancer who were receiving chemotherapy or radiotherapy. Sixty-six Taiwanese women with breast cancer who were undergoing chemotherapy participated in this study, who were randomly assigned to receive either nine capsules of the RG-CMH (study group), or a placebo (control group), every day during the six weeks of treatment (including two chemotherapy cycles). Prior to the first or the next chemotherapy cycle, blood samples of the two groups of participants were collected for biochemical analysis (Zhuang et al., 2011). The women with breast cancer were also requested to visit their physician every week to monitor their leucocyte level. The study results indicated the administration of RG-CMH had the potential to reduce leucopoenia, and provide a strategy to improve leucopoenia and neutropenia conditions experienced by women with breast cancer undergoing chemotherapy (Zhuang et al., 2011). The RG-CMH might also be considered to be safe if integrated with medical treatment, as there were no symptoms of intolerance from the RG-CMH intervention during the treatment reported by the participants (Zhuang et al., 2011). However, further studies with larger sample sizes are required to provide stronger evidence of the effect of these herbs that have been shown in one study to delay the reduction of leucocytes and neutrophils during breast cancer treatment (Zhuang et al., 2011).

Overall, herbal medicine and dietary supplements were the most popular natural products used as CAM by women with breast cancer in Asian countries. The use of natural products varied based on the women with breast cancer's socio-cultural backgrounds and the

availability of the products in their countries. The high interest on the use of natural products for breast cancer management suggests further studies are required to investigate their efficacy and safety. In addition to natural products, women with breast cancer in Asian countries also utilised mind and body practices for breast cancer management.

2.6.3.2. Mind and body practices

The NCCIH (2019) grouped relaxation techniques, such as spiritual therapy, massage therapy, meditation, yoga, tai chi and qigong, into mind and body practices. These relaxation techniques may have provided therapeutic effects to reduce stress and anxiety associated with health conditions (NCCIH, 2019). Mind and body practices were used by women with breast cancer to manage stressful situations while facing their medical conditions (Chui et al., 2014). The Figure 2 (p. 55) below presents the types of mind and body practices that were frequently used by women with breast cancer in Asian countries.

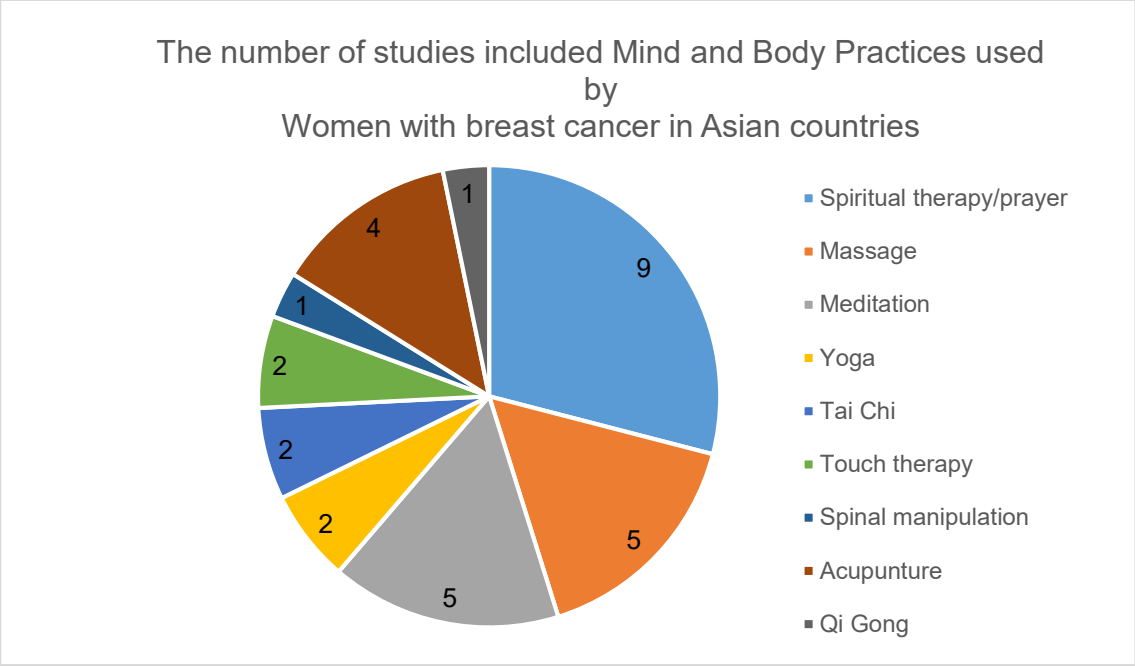


Figure 2: The number of studies included mind and body practices used by women with breast cancer in Asian countries

Spiritual therapy, particularly prayer therapy was identified as the most frequent mind and body practice used as a CAM by women with breast cancer in Asian countries. Spiritual therapy is a part of mind and body practices because the mind and emotions can affect both the physiological and physical condition (Chui et al., 2014; Sulistyawati & Probosuseno, 2019). For instance, a stressful situation can negatively affect the metabolic system resulting from physical illness and lead to physiological conditions including cognitive deficit, immunosuppression, and sexual dysfunction (Biswal et al., 2013; Cassileth, 2012).

The reviewed studies indicated that the majority of women with breast cancer, specifically those in Asian Islamic countries such as Iran, Lebanon, Malaysia, Saudi Arabia and Turkey, had used spiritual therapy including prayer therapy as a CAM for breast cancer management (Albabtain et al., 2018; Alsharif & Mazanec, 2019; Can et al., 2012; Chui et al., 2014; Gül et al., 2014; Gulluoglu et al., 2008; Jafari et al., 2013; Kalender et al., 2014; Knight et al., 2015; Muhamad et al., 2012; Naja et al., 2015; Saibul et al., 2012; Shaharudin et al., 2011; Yildirim, 2010). Most Muslim women with breast cancer were more likely to practice prayer therapy as a CAM because prayer is included in a daily repetitive (five times) worship as obligated in Islam religious practice (Chui et al., 2014; Gül et al., 2014). Prayer therapy was used as an alternative medicine to substitute breast cancer medical treatment (Can et al., 2012). A survey in Turkey reported that the use of prayer as a therapy for breast cancer was prevalent among Muslim women with breast cancer who did not have surgical intervention (Can et al., 2012). This decision was based on the fact the Muslim women with breast cancer believed that whatever happen to them came from God, and God would help them through prayer (Can et al., 2012). Therefore, for Muslim women with breast cancer, to pray, to ask for healing from Allah (God in Islam), to obtain psychological relief, and to improve their physical and psychological wellbeing is an important aspect of their holistic cancer care treatment (Can et al., 2012; Chui et al., 2014; Yildirim, 2010).

In addition to prayer therapy, Muslim women with breast cancer also applied other forms of spiritual therapy. A qualitative study conducted by Muhamad et al. (2012) revealed that Muslim women with breast cancer in Malaysia used prayer therapy and Quran (Islamic holy book) readings as CAM, as advised by their traditional healer. Feelings of calm, peacefulness and relaxation were experienced after implementing prayer therapy and Quran readings as reported by the women with breast cancer in that study (Muhamad et al., 2012). Beside prayer therapy, Muslim women with breast cancer in Lebanon used other forms of spiritual therapy such as lighting candles, pledging specific vows, consuming deemed holy water such as “Zam-Zam” water (holy water from Mecca), and fasting from dawn to sunset (Naja et al., 2015). Buddhist women with breast cancer in Taiwan and Thailand also used spiritual therapy such as chanting mantras, reciting sutras, meditating and listening to Buddha’s teaching as a CAM for breast cancer management (Huang et al., 2015; Sirisupluxana et al., 2009; Wanchai et al., 2012, 2016). However, there was little scientific evidence supporting the effectiveness of spiritual therapy to be used specifically for breast cancer management.

This literature review found only one study that investigated the effect of spiritual therapy in improving quality-of-life for women with breast cancer. Jafari et al. (2013) conducted a randomised controlled trial to examine the effects of spiritual therapy on women with breast cancer who were undergoing radiation therapy. Sixty-five Iranian women with breast cancer participated in the study who were randomly included in the intervention study group (n=34) and control group (n=31). The study group participated in an educational program and spiritual intervention for six weeks in spiritual therapy sessions. The six spiritual therapy intervention sessions were defining the course, practicing relaxation and meditation, putting things under God’s control, gaining self-positive energies to fight cancer, focusing on relationships with oneself, others and God, and praying and talking to God based on their beliefs (Jafari et al., 2013). The quality-of-life score of the women with breast cancer in both

groups was assessed before and after the intervention by using the European Organisation for Research and Treatment of Cancer Quality Group (EORTC QLQ). The results of the study showed evidence that spiritual therapy could improve quality of life of women with breast cancer who were undergoing radiotherapy. Therefore, spiritual therapy might be effective in improving health status including psychological and emotional aspects (Jafari et al., 2013). However, the sample size of the study was small and homogenous from a single city in Iran so that the results cannot be generalised to other women with breast cancer populations in other countries. Additionally, there was no follow-up program conducted to assess the effects of spiritual therapy after the six-weeks intervention (Jafari et al., 2013). A follow-up program could be conducted to assess whether spiritual therapy has long- or short-term therapeutic effects.

Other forms of mind and body practices such as massage, foot massage or reflexology meditation, yoga, and touch therapy were also used by women with breast cancer for breast cancer management in Asian countries. Several studies included in this literature review investigated the effects of those mind and body practices on breast cancer (Eyigor et al., 2018; Kashani & Kashani, 2014; Kim et al., 2013; Ovayolu et al., 2014; Vanaki et al., 2016; Yagli & Ulger, 2015). One of the studies was a single-blind clinical trial that invested the effects of massage therapy on the quality of sleep among women with breast cancer in Iran (Kashani & Kashani, 2014). Fifty-seven women with breast cancer who had no experience of stressful events for six months (divorce, relatives, being unemployed, major changes in life) and had not taken psychiatric drugs during the week before the study were randomly included in the intervention study and control group. The women with breast cancer in the study group received three sessions of the 20-minute Effleurage massage technique for four weeks. A validated questionnaire (Pittsburgh Sleep Quality Index [PSQI]) was used to assess the quality of sleep before the intervention and a month after the intervention was conducted (Kashani & Kashani, 2014). The results of the study showed that there was a

significant difference ($p<0.0001$) in the mean scores of the quality of sleep index before and after the four weeks of massage therapy in the study group (Kashani & Kashani, 2014). This study showed that massage therapy could increase the quality of sleep and that massage could be a solution for women with breast cancer with sleep disorders.

Another study, a randomised controlled trial that was conducted by Ovayolu et al. (2014), found that both aromatherapy massage and fragrance massage positively impacted on the quality-of-life for women with breast cancer in Turkey. A month of aromatherapy and fragrance massage intervention resulted in a significant improvement in the quality-of-life scale scores in terms of women with breast cancer's general well-being, appetite, sexual function, physical symptoms activity and medical interaction (Ovayolu et al., 2014). In addition, a non-randomised controlled study in Israel, which was recently conducted by Tarrasch et al. (2018), found that foot massage or reflexology had a positive effect on fatigue, quality of sleep, pain, and quality-of-life in women with breast cancer during radiation therapy. Forty-seven Israeli women with breast cancer who were undergoing radiotherapy in the intervention study group, received reflexology treatment (20 minutes) once a week for up to 10 weeks (Tarrasch et al., 2018). After completing the 10 weeks of reflexology intervention, the self-reported questionnaires of women with breast cancer indicated statistically significant lower levels of fatigue, and a significant improvement in the quality of sleep and in the quality-of-life (Tarrasch et al., 2018). Based on the positive results, Kashani and Kashani (2014), Ovayolu et al. (2014) and Tarrasch et al.(2018) suggested that massage therapy might be a safe CAM for women with breast cancer, as this non-invasive procedure may not cause injury or interact with medical cancer treatment. Massage therapy might also be implemented in nursing interventions as a CAM to improve women with breast cancer's quality of life (Kashani & Kashani, 2014; Ovayolu et al., 2014). However, further studies with more participants and over a longer duration of intervention needs to be

conducted to strengthen the evidence of the efficacy and safety of massage therapy on women with breast cancer.

Women with breast cancer in Asian countries also practiced meditation as a CAM for breast cancer management. According to Kim et al. (2013), women with breast cancer in Korea commonly practised meditation to reduce emotional symptoms including anxiety and depression while undergoing chemotherapy or radiotherapy. Based on this practice, they conducted a randomised clinical trial investigating the effects of brain wave vibration (BWV) meditation on anxiety, depression and fatigue among women with breast cancer undergoing radiotherapy (Kim et al., 2013). The BWV meditation is a “Body and Brain Holistic Fitness Training (Dahn yoga)” which was developed based on Korean traditional meditation methods (Kim et al., 2013). One hundred and two Korean women with breast cancer who were undergoing radiotherapy participated in the study. Fifty-one women with breast cancer were included in the intervention group, and the other 51 women with breast cancer were in the control group that did not receive any intervention. The women with breast cancer in the intervention study group received a 60-minutes BWV meditation session twice a week for six weeks during radiotherapy. Before and after receiving the intervention, anxiety, depression and fatigue levels were measured using two validated questionnaires, the Hospital Anxiety and Depression Scale and the Revised Piper Fatigue Scale (Kim et al., 2013). This experimental study found a significant reduction in the women with breast cancer’s anxiety and fatigue scores after receiving the BWV meditation; however, this intervention did not make any changes to depression scores (Kim et al., 2013). The results of this investigation have presented evidence that BWV mediation has positive effects on anxiety and fatigue of radiotherapy for breast cancer. Therefore, Kim et al. (2013) suggested that BWV mediation could be used to improve the quality of life in respect to emotional function for women undergoing radiotherapy for breast cancer. Meditation is a non-invasive

procedure that can be safely implemented as a CAM for women with breast cancer in cancer care facilities.

Similar to massage and mediation, yoga was also used by women with breast cancer to increase their quality-of- life during breast cancer treatment. Eyigor et al. (2018) claimed that yoga was an effective and safe exercise that could alleviate shoulder and arm pain in women with breast cancer due to complication after breast cancer treatment. Eyigor et al. (2018) recently conducted a randomised controlled single-blinded trial study, to investigate the effect of yoga on shoulder and arm pain, and quality-of-life among women with breast cancer in Turkey. Forty-two Turkish women with breast cancer participated in this prospective randomised study. Twenty-two of the women with breast cancer were included in the intervention study received a 10-week Hatha yoga exercise program, and 20 of them were included in the control group (Eyigor et al., 2018). The results of that study showed that women with breast cancer who received the yoga intervention had a significant improvement in shoulder and arm pain severity from baseline to post-treatment (Eyigor et al., 2018). In addition, Yagli and Ulger (2015) also conducted a quasi-experimental study to investigate the effects of yoga on the quality-of-life of elderly women with breast cancer in Iran. Twenty women with breast cancer age over 65 years participated in the study who were divided into two groups of a yoga intervention and exercise program. The women with breast cancer in each group completed eight sessions of the program in eight weeks. The study found a statistical difference in the quality of sleep and fatigue score of women with breast cancer in both groups. The women with breast cancer's quality of life significantly improved after completing eight weeks (one hour per week) of yoga intervention (Yagli & Ulger, 2015). The study highlighted that yoga could alleviate the severity of cancer pain and fatigue, as well as increase the quality of sleep in elderly women with breast cancer. In addition, none of the participants reported any injury from this intervention. The two experimental studies presented that yoga could be effective and safe for women with breast cancer. Nevertheless,

the results of the study cannot be generalised due to the small number of participants and the short duration of treatment.

Another potential mind and body practice that could benefit women with breast cancer is touch therapy (Vanaki et al., 2016). This therapy might be an affordable CAM as it uses only energy transferred using the laying on of hands from the therapist to women with breast cancer. Evidence of the effectiveness of touch therapy was presented from a randomised controlled trial that investigated the effectiveness of touch therapy in reducing nausea among Iranian women with breast cancer women receiving chemotherapy (Vanaki et al., 2016). The study found a significant decrease in the frequency and intensity of nausea on women with breast cancer participating in 25-minute sessions of touch therapy intervention. Based on the study results, Vanaki et al. (2016) suggested that touch therapy could be considered as a safe and affordable CAM. Touch therapy is non-prescription and non-contraindicated which means it could be included in nursing interventions for women with breast cancer. Therefore, touch therapy training programs should be introduced for nurses so that they could implement this technique as a CAM for women with breast cancer in their nursing care practice.

Acupuncture, spinal manipulation, tai chi and qigong exercise were mind and body practices that were less frequently used by women with breast cancer in Asian countries. The use of these mind and body practices were identified among women with breast cancer in Hong Kong, Malaysia , South Korea, and Taiwan, and Turkey (Akyuz et al., 2019; Chui et al., 2014; Fong et al., 2014; Han et al., 2019; Hwang et al., 2015). There was only one single-blinded non-randomised controlled study that investigated the effects of qigong exercise on upper limb lymphedema and blood flow in breast cancer survivors (Fong et al., 2014). Twelve breast cancer survivors participated in the qigong intervention and another 12 were assigned to the control group. The study revealed that qigong exercise could decrease upper limb

lymphedema and poor circulatory status (Fong et al., 2014). However, such effects may be temporary and further studies are required to explore longer-term effects of this CAM (Fong et al., 2014).

Overall, most women with breast cancer in Asia countries included mind and body practices as CAM into their breast cancer management. Some studies presented encouraging results that particular mind and body practices have potential therapeutic effects, and could be safe to be used for breast cancer management. Nonetheless, the use of mind and body practices among women with breast cancer was not found in the reviewed studies from China, Indonesia, Palestine and Singapore (Azhar et al., 2016; Chen et al., 2008; Jaradat et al., 2016; Wong et al., 2014).

2.6.3.3. Other CAM

Other CAM refer to whole systems of care that are built on theory and practice and have often evolved apart from, and earlier than, Western medicine or medical treatment (Lindquist et al., 2018; NCCIH, 2019). According to the reviewed studies, other CAM that are used by women with breast cancer in Asian countries were traditional Chinese medicine (TCM), cupping therapy, exercise, folk medicine, Malay traditional medicine and traditional healing (Almasdy et al., 2018; Alsharif & Mazanec, 2019; Can et al., 2012; Chen et al., 2008; Hwang et al., 2015; Kang et al., 2012; Knight et al., 2015; Muhamad et al., 2012; Naja et al., 2015; Saibul et al., 2012; Sirisupluxana et al., 2009; Wanchai et al., 2016; Wong et al., 2014). Traditional Chinese medicine was found to be the most popular CAM that was used by women with breast cancer in many Asian countries. A quantitative retrospective cohort study in China found that women with breast cancer who consumed TCM had a lower risk of severe chemotherapy-induced leucopoenia, neutropenia and febrile neutropenia than those who did not use TCM (Tian et al., 2015). In this study, the use of TCM was presented as being safe, as no serious renal or liver dysfunction was experienced by the women with breast cancer (Tian et al., 2015). Thus,

the study suggested this cheap TCM could be used alone or in combination with pharmacological agents (Tian et al., 2015). However, further randomised controlled studies should be conducted to confirm the effectiveness of TCM on breast cancer management. Studies investigating the efficacy and safety of other types of CAM were absent.

Another study in China also found that bloodletting puncture and cupping therapy could reduce arm circumference, and relieve upper limb pain related to lymphedema in women with breast cancer (Wang et al., 2018). Seventy-five Chinese women with breast cancer who were undergoing treatment for breast cancer-related lymphedema, participated in this non-randomised controlled study. Fifty of the women with breast cancer participated in the bloodletting and cupping therapy intervention, and another 25 women with breast cancer were assigned to the control group (Wang et al., 2018). The women with breast cancer in the intervention group underwent bloodletting puncture and cupping every five days for 15 minutes per session (one session per day, combined with exercise training once a day for 30 minutes during 50 days of the treatment period (Wang et al., 2018). At the end of the treatment period, the women with breast cancer in the intervention had a significantly greater reduction in their arm circumference, and a significantly lower visual analogue scale (VA) score for pain compared to women with breast cancer in the control group. None of the women with breast cancer in the study reported adverse events from the bloodletting and cupping therapy interventions (Wang et al., 2018). Based on the study's results, Wang et al. (2018) suggested that bloodletting puncture and cupping may be considered as a safe and clinical intervention for women with breast cancer-related lymphedema. However, the results of the study cannot be generalised due to the short follow-up duration, small sample size and non-randomisation.

Overall, this literature review indicated that women with breast cancer in Asian countries used a variety of CAM for breast cancer management. Commonly used CAM included herbs and dietary supplements, massage, yoga, meditation and traditional Chinese medicine. However, women with breast cancers lived experiences and CAM providers' perceptions regarding the use of CAM for breast cancer management in Indonesia have not been identified prior to this literature review being conducted. Therefore, qualitative study exploring women with breast cancer's lived experiences and CAM providers' perceptions about the use of a variety of CAM for breast cancer management is worthy. The following section describes how women with breast cancer in Asian countries obtained CAM-related information and its disclosure about the use of CAM.

2.6.4. Sources of information and disclosure of CAM use

Several studies in this review identified sources of information about CAM for women with breast cancer in Asian countries. According to the results of the study, family and friends were mostly reported as important information sources about CAM, followed by healthcare CAM providers, mass media and CAM practitioners (Akhtar et al., 2018; Akyuz et al., 2019; Albabtain et al., 2018; Almasdy et al., 2018; Gulluoglu et al., 2008; Jaradat et al., 2016; Kalender et al., 2014; Knight et al., 2015; Muhamad et al., 2012; Saibul et al., 2012; Shaharudin et al., 2011; Wanchai et al., 2012, 2016; Wong et al., 2014; Yildirim, 2010). The bar chart below presents the number of studies that reported CAM information sources in Asian countries.

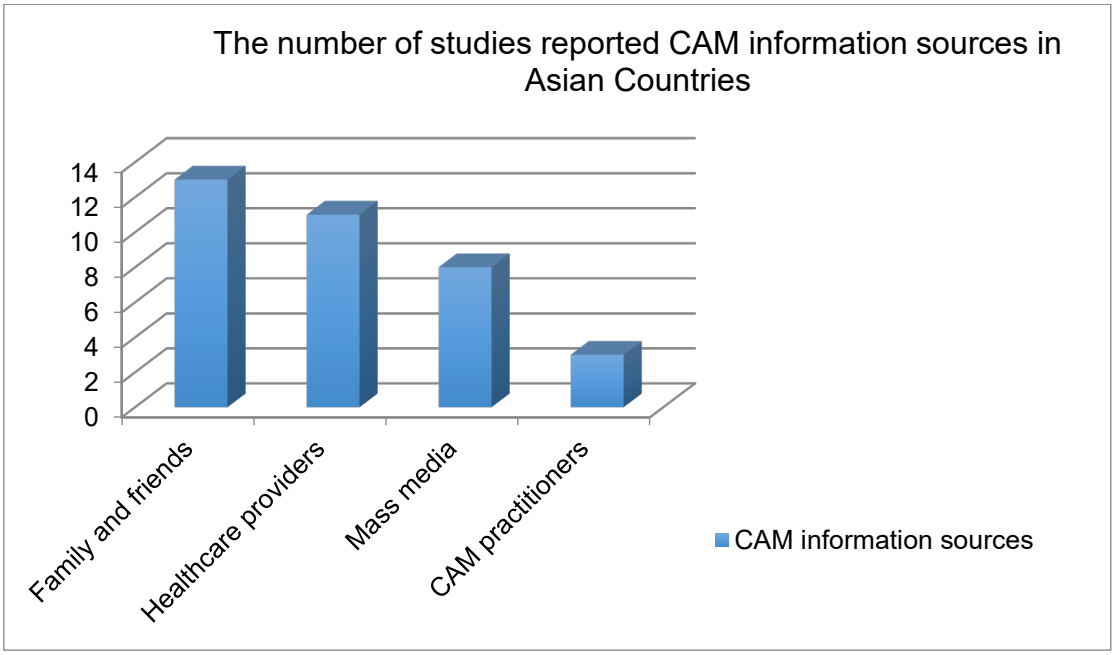


Figure 3: The number of studies reported CAM information sources

The bar chart shows that women with breast cancer commonly obtained information about CAM from family and friends. In lower-middle income countries such as Bangladesh, Indonesia, Malaysia, Palestine, Turkey and Thailand, it was found that women with breast cancer utilised CAM based on recommendations and personal testimonies from their family and friends (Akhtar et al., 2018; Almasdy et al., 2018; Gül et al., 2014; Jaradat et al., 2016; Kalender et al., 2014; Knight et al., 2015; Muhamad et al., 2012). Particularly in Malaysia, family and friends were the foremost sources of information about CAM, as Malaysian women with breast cancer generally used CAM-based recommendations and influences from their family and friends (Knight et al., 2015; Muhamad et al., 2012; Mujar et al., 2017; Saibul et al., 2012; Shaharudin et al., 2011; Zulkipli et al., 2018). Saibul et al. (2012) found that the majority of Malaysian women with breast cancer in their study sought information on CAM from family and friends. Other studies also reported that Malaysian women with breast cancer often purchased CAM products from their family or friends who worked as medical assistants (Chui et al., 2014; Knight et al., 2015).

Furthermore, many women with breast cancer followed suggestions from their families and friends even though they did not believe in CAM (Muhamad et al., 2012). The women with breast cancer believed that their families and friends meant well wanting to support their breast cancer healing process. For instance, five of the 11 Malaysian women with breast cancer in a qualitative study, which was conducted by Muhamad et al. (2012), reported that recommendations or advice from close family including parents, spouse (husband) and the oldest brother or sister was such a blessing and form of guidance that it should be followed. Accordingly, they felt obliged to obey the family's advice (Muhamad et al., 2012). In addition, seven of the women reported that their friends persuaded them to seek CAM and introduced them to several popular traditional healers (Muhamad et al., 2012). A participant of a qualitative study in Thailand reported that she used herbal therapy for breast cancer based on the recommendation from her friend, who is a Thai traditional medicine doctor (Wanchai et al., 2016). This research participant's friend suggested she use herbal therapy as an alternative treatment for breast cancer (Wanchai et al., 2016). Recommendations from family and friends were one of the strongest influences on the use of CAM for breast cancer management in Asian countries (Muhamad et al., 2012; Wanchai et al., 2016). Overall, family and friends played an important role in the use of CAM for breast cancer management in Asian countries.

Healthcare CAM providers including oncologists, doctors, nurses and pharmacists were the second most common source of information about CAM. Nine studies reported that women with breast cancer were less likely to seek information about CAM from healthcare professionals compared to family and friends (Gulluoglu et al., 2008; Jaradat et al., 2016; Kalender et al., 2014; Knight et al., 2015; Saibul et al., 2012; Shaharudin et al., 2011; Wanchai et al., 2016; Wong et al., 2014; Yildirim, 2010). A survey study in Palestine found that there was only 1.4% of 115 women with breast cancer who received herbal therapy information from their doctors, and 2.7% of them obtained information from pharmacists

(Jaradat et al., 2016). Similarly, a study in Turkey, which was conducted by Kalender et al. (2014), found that there was only 18% of 122 women with breast cancer who used CAM based on their doctor's advice, while more than 80% of them followed their family and friends' recommendations. Another study in Turkey reported that 11% of 68 cancer survivors received information about CAM from healthcare CAM providers (Yildirim, 2010). There were only three studies that identified CAM practitioners as sources of information about CAM. Studies in Malaysia, Palestine and Singapore found a small number of women with breast cancer who used CAM based on CAM practitioners' recommendations (Jaradat et al., 2016; Saibul et al., 2012; Wong et al., 2014). Overall, healthcare CAM providers were not the primary sources of information about CAM for breast cancer management in Asian countries.

Other common sources of information on CAM were mass media. A cross-sectional descriptive study in Korea found that women with breast cancer mainly sought information about CAM from television, radio, newspapers, magazines and the internet (Kang et al., 2012). In higher income countries such as South Korea, internet access is well developed, so that Korean people including women with breast cancer can easily search for various types of information such as CAM information using internet search engines (Kang et al., 2012). In contrast, in lower-middle income countries such as Malaysia, the use of the internet as a source of information on CAM was less frequent due to financial constraints where women with breast cancer could not afford the additional expense of internet access (Knight et al., 2015). A survey in Malaysia reported that there was only 9% of 394 women with breast cancer who used the internet to seek information about CAM (Saibul et al., 2012). Another study in Malaysia also found that approximately 14% of women in their study obtained information about CAM through the internet (Knight et al., 2015). However, information about CAM that was published through the internet may be less reliable as the information provided is mostly from non-healthcare professionals (Kang et al., 2012). Kang et al. (2012)

cautioned that unscientific information on CAM may mislead women with breast cancer to make inappropriate decisions in selecting and using suitable CAM for breast cancer management. Other studies also cautioned that women with breast cancer might experience adverse effects or unsuccessful cancer therapies as a result of using incorrect CAM (Gül et al., 2014; Kang et al., 2012; Muhamad et al., 2012).

A lack of communication about CAM for breast cancer management between women with breast cancer and healthcare CAM providers was also identified in several reviewed studies. The majority of women with breast cancer in the reviewed studies concealed the use CAM from their healthcare providers (Gulluoglu et al., 2008; Hwang et al., 2015; Kang et al., 2012; Shaharudin et al., 2011; Wanchai et al., 2016; Wong et al., 2014; Yildirim, 2010). Studies in Lebanon, Malaysia, Singapore and Thailand reported that most women with breast cancer did not inform their doctors that they used CAM while undergoing breast cancer medical treatment (Naja et al., 2015; Wanchai et al., 2016; Wong et al., 2014; Zulkipli et al., 2018). The main reasons for women with breast cancer to hide the use of CAM were due to their being afraid of being disallowed or denied the use of CAM, and being discouraged to use CAM by their doctors (Naja et al., 2015; Wanchai et al., 2016; Zulkipli et al., 2018). Korean women with breast cancer perceived that informing their doctors of their CAM use was unnecessary as their doctors should not know that they used CAM, and healthcare providers may dislike the use of CAM (Huang et al., 2015; Hwang et al., 2015; Kang et al., 2012). In addition, women with breast cancer in Indonesia were found to hide the use of CAM because they did not trust their doctors (Azhar et al., 2016).

However, Can et al. (2012) and Kang et al. (2012) argued that disclosing CAM use to healthcare providers is essential due to particular CAM, such as herbal medicine or dietary supplements, possibly interacting with medical breast cancer treatment. The use of inappropriate CAM due to lack of communication between healthcare professionals and

women with breast cancer may negatively impact on the outcomes of breast cancer treatment (Can et al., 2012; Kang et al., 2012). Disclosing the use of CAM to healthcare professionals may enhance women with breast cancer's understanding about the benefits of using scientifically based CAM, and increase women with breast cancer's awareness of the risks of side effects that might occur from using inappropriate CAM (Kang et al., 2012; Zulkipli et al., 2018). Some studies suggested that healthcare professionals, particularly oncologists and nurses, should be more proactive in initiating discussions about CAM, and respecting women with breast cancer's intention to use CAM (Azhar et al., 2016; Hwang et al., 2015; Naja et al., 2015). It was expected by women with breast cancer that healthcare professionals, particularly doctors, being not judgemental and discouraging in the use of CAM for breast cancer, and if this was the case then women with breast cancer would be reluctant to discuss CAM use (Kang et al., 2012; Wanchai et al., 2012). Healthcare professionals would be required to pay special attention to CAM users, identify the need for supportive therapy such as CAM, support women with breast cancer to use scientifically based CAM, and provide accurate CAM information from reliable sources (Azhar et al., 2016; Chui et al., 2015). However, Yildirim (2010) found that healthcare professionals in Turkey were hesitant and lacked confidence to openly discuss CAM with women with breast cancer due to their lack of sufficient training related to CAM. Healthcare professionals need to increase their knowledge of CAM. A greater understanding of scientifically based CAM for breast cancer would enable healthcare professionals to provide accurate information and discuss CAM with women with breast cancer who were interested in using CAM as a part of their breast cancer management (Huang et al., 2015).

The literature supports the concept that sources of information about CAM and disclosure of CAM use to healthcare CAM providers is essential. Furthermore, in order to achieve optimum breast cancer treatment outcomes, the literature suggests that women with breast cancer should utilise CAM based on accurate information from credible information sources,

and discuss CAM use with healthcare CAM providers. Trust and effective communication between women with breast cancer and healthcare CAM providers also needs to be well maintained so that the use of CAM for breast cancer management can be used in an appropriate manner. However, there is a lack of research exploring this concept. Therefore, more qualitative studies are required to explore women with breast cancer's lived experiences in obtaining information about CAM, specifically in Indonesia as the phenomena of CAM use for breast cancer management has not been investigated.

2.7. Discussion of the results from the reviewed studies

The results from the selected studies related to the use of CAM for breast cancer management in Asian region countries have been synthesised and analysed. It was evident from the reviewed studies that the use of CAM for breast cancer management was prevalent, particularly in women with breast cancer who were undergoing breast cancer medical treatment such as chemotherapy and radiotherapy. This literature review demonstrated that the use of CAM for breast cancer in Asian countries was mainly influenced by socioeconomic factors such as personal income, education levels and age as discussed below.

Personal income determined the use of CAM and the type of CAM that was used for breast cancer management. The use of CAM as a complementary therapy to medical cancer treatment was prevalent in higher income countries in Asian regions such as Hong Kong, Korea, Singapore and Taiwan (Fong et al., 2014; Hwang et al., 2015; Lee et al., 2014; Wong et al., 2014). This result is in line with studies in Western countries including Australia, Germany, Ireland and the United States, which found the use of CAM was prevalent in women with breast cancer with higher personal income as they had health insurance cover for CAM and could afford to pay out-of-pocket CAM costs (Andersen, Sweet, Zhou, & Standish, 2015; Fox et al., 2013; Greenlee et al., 2009; Kremser et al., 2008). In Western

countries women with breast cancer with higher income used yoga, acupuncture, massage therapy, reflexology, dietary supplements and natural products provided by certified professional therapists to improve their physical and emotional wellbeing during breast cancer treatment (Brems, Barnett, Parret, Metzger, & Johnson, 2013; Chandwani et al., 2014; Fox et al., 2013; Kremser et al., 2008; Lambe, 2013; Tautz, Momm, Hasenburg, & Guethlin, 2012).

However, the use of CAM as a complementary therapy among women with breast cancer at a lower income level was less frequent because they could not afford the additional CAM cost (Knight et al., 2015; Wanchai et al., 2016). In addition, whilst most women with breast cancer with a higher income used CAM to manage psychological symptoms including anxiety and sleep disorders (Andersen et al., 2015; Fox et al., 2013; Greenlee et al., 2009; Hübner & Hanf, 2013; Huebner et al., 2014; Kremser et al., 2008), those who had a low personal income used CAM as their main treatment before they sought medical cancer treatment, or as an alternative medicine to substitute medical cancer treatment for breast cancer (Azhar et al., 2016; Kalender et al., 2014; Muhamad et al., 2012; Wanchai et al., 2016). Many poor women with breast cancer in lower-middle income countries preferred to try CAM and sought medical cancer treatment when they found CAM was unsuccessful (Azhar et al., 2016; Muhamad et al., 2012).

Low personal income can create financial constraints and prevent poor women with breast cancer from accessing medical cancer treatment. The availability of cancer care facilities and health supports from the government in most lower-middle income countries are also limited. For example, cancer care facilities in Indonesia are generally provided by state public hospitals and are located in metropolitan cities, which requires additional travel and accommodation expenses being added to medical cancer treatment costs specifically for women with breast cancer in rural and remote regions (Ministry of Health Republic of

Indonesia, 2016; Raut & Chakrabarti, 2013). Alternatively, women with breast cancer with financial constraints used CAM such as herbs from their garden, massage therapy provided by uncertified therapists, folk medicine, and spiritual therapy as a main therapy for breast cancer (Azhar et al., 2016; Jaradat et al., 2016; Kalender et al., 2014; Muhamad et al., 2012; Wanchai et al., 2012). Such CAM were deemed to be more accessible and affordable breast cancer treatment options while waiting for access to medical cancer treatment. However, there was no evidence to date that CAM can be used as a main therapy to cure cancer. Using CAM to treat breast cancer instead of medical cancer treatment may lead to cancer cells growing to advanced stages, resulting in a decline in quality-of-life and delayed healing. Delays in seeking breast cancer medical treatment impact on healing time durations, and result in higher medical treatment costs. Therefore, it is important that women with breast cancer understand the actual function of CAM for breast cancer management.

Education levels influenced knowledge, beliefs and attitudes toward the use of CAM for breast cancer management. This literature review identified that women with breast cancer with lower education levels particularly in lower-middle income countries were more likely to use CAM based on their cultural beliefs, and sought CAM information from mass media rather than from healthcare professionals (Can et al., 2012; Chui et al., 2014; Gül et al., 2014; Muhamad et al., 2012). It appeared that women with breast cancer with lower education levels had inadequate knowledge about CAM as they perceived CAM to be natural, effective and safe therapy to treat breast cancer. Having this understanding, the women with breast cancer preferred to use CAM as their main therapy, refused medical cancer treatment, and trusted traditional healer more than healthcare professionals (Azhar et al., 2016; Sirisupluxana et al., 2009; Wanchai et al., 2012). A lack of knowledge caused women with breast cancer to doubt their ability to make their own decisions in selecting CAM options, and relied on family and friends' recommendations. However, the use of CAM by women with breast cancer with higher education levels was mostly found in higher income

countries (Bower et al., 2015; Brems et al., 2013). Highly educated women with breast cancer used CAM as complementary therapy and openly discussed it with healthcare CAM providers (Lambe, 2013; McLay, Stewart, George, Rore, & Heys, 2012).

The United Nations Educational, Scientific and Cultural Organisation stated education transforms lives (UNESCO, 2017). Education increases knowledge and influences health behaviour (UNESCO, 2017). It is essential for women with breast cancer to have adequate knowledge about breast cancer and CAM as it would assist women with breast cancer to make informed judgements in searching for information about CAM from reliable sources, receiving or refusing recommendations from others, and seeking CAM from professional therapists (Azhar et al., 2016; Knight et al., 2015; Sirisupluxana et al., 2009). However, studies investigating women with breast cancer's knowledge about CAM for breast cancer management, particularly in the Indonesian setting, do not exist. Thus, qualitative studies exploring women's knowledge regarding CAM for breast cancer are required.

Another contributing factor to the use of CAM for breast cancer in Asian countries was age. This literature review found that CAM was mainly used by women with breast cancer aged younger than 60 years. This finding is supported by a previous systematic review that found that women with breast cancer at a younger age were more attracted to use CAM, as they were more enthusiastic in seeking breast cancer treatment to extend their life expectancy (Wanchai, Armer, & Stewart, 2010). This finding implied that women with breast cancer at a younger age have a strong motivation to recover from breast cancer. Having positive motivation would help women with breast cancer to achieve optimum treatment outcomes.

Overall, the use of CAM in Asian countries is an essential part of breast cancer management. The discussion of the results from the reviewed studies has clarified how financial situations, knowledge and age influence the use of CAM, particularly for women with breast cancer in lower-middle income countries. The use of CAM may impact on quality-

of-life and breast cancer treatment outcomes. Therefore, there is a need to explore women with breast cancer's lived experiences, understanding, knowledge and attitude towards the use of CAM for breast cancer, especially in lower-middle income countries such as Indonesia. A number of knowledge gaps emerged from the reviewed studies. The knowledge gaps will be addressed by this interpretive phenomenological research.

2.8. Identified knowledge gaps

Three main knowledge gaps were identified in the literature review. These gaps relate to the type of existing relevant literature, knowledge, awareness and attitudes towards CAM, and the outcomes from using CAM. These knowledge gaps are discussed below.

The majority of the reviewed studies were quantitative studies that investigated the use of CAM for breast cancer which is based on numerical data to make generalisations. The quantitative studies mainly described prevalence and determining factors related to CAM use, evaluated quality-of-life scores from using CAM, and investigated the effects of particular CAM on breast cancer. Most of the studies provided information on the type of CAM that had been used for breast cancer, reasons to use it and sources of information about CAM. The four included qualitative studies explored why Malaysian women with breast cancer sought traditional healers, the meaning of CAM from a Thai perspective, cultural and social factors that influenced women with breast cancer to use CAM in Thailand, and performance care practice in CAM among Thai breast cancer survivors. There is a deficit of rigorous research on women with breast cancer's experiences and CAM providers' perceptions of the use of CAM for breast cancer in Asian countries particularly in Indonesia. Understanding the use of CAM for breast cancer in Indonesia was found to be lacking. There were only two quantitative studies included from Indonesia, which were focused on predictors of CAM use by women with breast cancer. Individually, women with breast cancer in Indonesia have unique experiences regarding CAM use because of the plurality of

socioeconomic status, culture, religion and beliefs. There is a significant gap in the existing literature and body of knowledge. This gap leads to the research question: What do Indonesian women with breast cancer experience and what are CAM providers' perceptions of the use of CAM for breast cancer management? Therefore, an interpretive phenomenological study is a suitable method to address this the gap. This methodology will be discussed in depth in subsequent chapters.

It is known from the literature review that CAM use for breast cancer in Asian countries was commonly influenced by women with breast cancer's personal income and education levels. However, there is a lack of understanding in regard to women with breast cancer's knowledge and understanding of CAM use for breast cancer management. As previously explained, knowledge may impact on women with breast cancer's awareness and attitudes toward the use of CAM. Those with higher education levels were more likely to use scientifically-based CAM that they obtained from professional CAM practitioners. In contrast, women with breast cancer with lower education levels mostly believed in CAM information from less reliable sources and sought CAM from unprofessional CAM providers. In addition, the reviewed studies showed that women with breast cancer used CAM as an alternative medicine for breast cancer although there was no scientific evidence that CAM could cure breast cancer. It is crucial for women with breast cancer to be aware that misuse of CAM and inappropriate integration of CAM and medical cancer treatment may cause harm that leads to increased risk of breast cancer treatment failure and increased mortality rates for breast cancer. Quantitative studies have shown that women with breast cancer's knowledge, awareness and attitudes toward CAM impacts on breast cancer treatment outcomes, quality-of-life and survival rates. However, there is a huge gap in knowledge based on qualitative studies to assess women with breast cancer's knowledge, awareness and attitudes toward the use of CAM breast cancer in Asian countries particularly in Indonesia, which needs to be addressed. Additionally, CAM providers' knowledge and attitudes about

CAM for breast cancer have not been explored to date. The exploration of CAM providers' knowledge and attitudes toward CAM could provide greater understanding about the quality and safety of CAM used by women with breast cancer for breast cancer management.

The reviewed studies identified that women with breast cancer in Asian countries used CAM either as complementary therapy or the main treatment for breast cancer management. It is evident from a number of studies in this literature review that CAM has potential benefits for maintaining women with breast cancer's physical and psychological wellbeing while undergoing breast cancer treatment. Some of the cross-sectional studies statistically reported that WBC who used CAM had a higher score in quality-of-life scores than non-CAM users. Other controlled trial studies in this literature review identified potential therapeutic effects of several CAM on breast cancer. These positive outcomes suggest that CAM could be considered as part of breast cancer management. However, the results of the reviewed quantitative studies have not provided any understanding of what it is like to use CAM for breast cancer management. Women with breast cancer may experience different outcomes from using CAM, but research based on women with breast cancer's personal lived experiences of CAM use to date is absent. Additionally, the use of CAM for breast cancer in Indonesia, as described in Chapter One, is urgently required due to limited access to medical cancer treatment. Thus, it is important to understand what women with breast cancer specifically feel and experience about the outcomes of CAM use including the benefits and disadvantages. Greater understanding about outcomes from using CAM experienced by women with breast cancer could contribute to improving CAM practice and breast cancer care in Indonesia.

Overall, qualitative design studies exploring women with breast cancer's lived experiences and CAM providers' perceptions with the use of CAM for breast cancer management need to be conducted. The exploration may discover what women with breast cancer know about

CAM, what type of CAM they use, and what they feel and experience related to benefits or negative side effects from using CAM for breast cancer management. The findings from qualitative research may generate new ideas to conduct further clinical trial studies investigating the safety and effectiveness of CAM that have been used by women with breast cancer for breast cancer management. The scientific evidence from rigorous research can contribute to the development of CAM guidelines for breast cancer management, especially in the Indonesian context. Ultimately, the use of CAM for breast cancer management based on scientifically evidenced recommendations could improve the quality of life of women with breast cancer and increase survival rates.

2.9. Chapter summary

This chapter has presented the use of CAM for breast cancer management in Asian countries based on an integrative literature review process. This literature review chapter explains the process of generating insights and knowledge gaps regarding CAM use for breast cancer. By using an integrative review framework, the process began with formulating the guiding question, searching and selecting the most relevant literature for this study. Relevant data from 48 selected studies were extracted and appraised using the JBI critical appraisal tools. The results of the selected studies were synthesised and resulted in four main categories including the use of CAM for breast cancer, sociodemographic factors, type, efficacy and safety of CAM used for breast cancer, and sources of information about CAM. These results were discussed and knowledge gaps were identified. The reviewed studies indicated that age, education levels, and personal income were factors that related to CAM use. There was also evidence that CAM could improve the quality-of-life of women with breast cancer. However, the majority of the evidence presented in this reviews is based on quantitative studies. Qualitative research is required to complete and complement missing evidence of women with breast cancer's lived experiences and CAM providers' perceptions of the use of CAM for breast cancer management. Additionally, CAM therapists also play an

important role in providing CAM for breast cancer management, but research exploring CAM therapists' knowledge and attitudes toward CAM has not been conducted to date. Therefore, this study, within an interpretive phenomenological framework, explores the identified knowledge gaps in research regarding the use of CAM for breast cancer management particularly in Indonesia. This study focuses on exploring women with breast cancer's lived experiences and CAM providers' perceptions regarding the use of CAM for management in Indonesia. This study focuses on the phenomenon of CAM use for breast cancer management based on women with breast cancer's lived experiences and CAM providers' perceptions as it is demonstrated by themselves.

The methodology underpinning this current study will be explained in the next chapter (Chapter Three). This will be followed by Chapter Four, which will explain the research activities in this study. The findings of this study are presented in two chapters, Chapter Five and Chapter Six. Chapter Five presents the findings of women with breast cancer's lived experiences and Chapter Six provides the findings of CAM providers' views about the use of CAM for breast cancer management. The discussion of the findings of this study will be presented in Chapter Seven. Chapter Eight of the thesis concludes this study and provides the implications of this study for the healthcare system, nursing practice, CAM education and further research, policy makers, CAM providers and women with breast cancer in Indonesia.

CHAPTER THREE: PHILOSOPHY OF PHENOMENOLOGY

3.1. Introduction

The previous Chapter Two provided a review of existing relevant literature related to the use of CAM for breast cancer management in Asian countries. The literature review described what is currently known about CAM use for breast cancer and identified gaps in knowledge that requires further research. There has been little research exploring the lived experiences of women with breast cancer and CAM providers' perceptions related to the use of CAM for breast cancer management. Therefore, this study aimed to gain a greater understanding and generate the meaning of women with breast cancer's lived experiences and CAM providers' views on the use of CAM for breast cancer management. Understanding women with breast cancer's experiences and CAM providers' views will provide new insight and knowledge in the field of CAM use for breast cancer management (Kiyimba, Lester, & O'Reilly, 2019). Knowledge is essential for the development of theories, protocols, evidence-based nursing, and to improve the quality of breast cancer care in clinical practice (Munhall, 2012).

This chapter explains the phenomenological approach that was applied to assist in answering the research requestion 'What are women with breast cancer's experiences and CAM providers' views in the use of CAM for breast cancer management?' This chapter begins with an explanation of the research paradigm followed by the philosophical underpinnings of phenomenology, and concludes with a discussion of the phenomenological framework that is applied to understand the meaning of the lived experiences of women with breast cancer and CAM providers' views of the use of CAM for breast cancer management.

3.2. Qualitative research paradigm

Given the research question, the purpose of this study was to gain an understanding of the meaning of women with breast cancer's lived experiences and CAM providers' views related to the phenomena of CAM use for breast cancer management. A qualitative research approach was found to be the most appropriate research design, as this study did not intend to investigate or to generalise findings about the use of CAM for breast cancer based on statistical information. The qualitative research approach provides various methods to seek the truth and understand the '*realness*' of people's lives by examining their experiences, perspectives, perceptions and everyday social activities (Kiyimba et al., 2019). This research approach allows the health researcher to gain a holistic understanding of the phenomena under investigation particularly in health research, with a person-centred focus on patients, healthcare CAM providers and other care CAM providers (Kiyimba et al., 2019).

In this study context, a qualitative research approach assists the researcher to explore the phenomena of CAM use for breast cancer management by listening to women with breast cancer and CAM providers' voices, describing and interpreting the meaning of their everyday lived experiences and social practices (Kiyimba et al., 2019; Munhall, 2012). The most common qualitative research methodologies used in nursing and healthcare are phenomenology, ethnomethodology, symbolic interactionism, grounded theory and constructivism (Maltby, 2010). Of all the qualitative research methodologies, phenomenology is considered as the most suitable research methodology to understand the lived experiences of women with breast cancer and CAM providers' views in the use of CAM for breast cancer management. Phenomenology was selected because it is a research design to explore lived human experiences (Neubauer, Witkop, & Varpio, 2019). The section below presents the philosophy of phenomenology and its movements.

3.2. Phenomenology

Phenomenology is one of the traditional qualitative research approaches that is widely used by healthcare professional researchers, including those in nursing and midwifery (Schneider, 2016). This approach is designed to understand a phenomenon by exploring specific human experiences and revealing the meaning of phenomena (Neubauer et al., 2019). Accordingly, health professional researchers consider phenomenology as a framework to guide the research process that focuses on understanding experiences of a phenomena related to health and illness, treatment and care (Schneider, 2016). The phenomenological research approach is commonly used by nurses to broaden their understanding of human phenomena, which is relevant to nursing practice (Matua, 2015; Wilson, 2015).

The term phenomenology is derived from '*phenomenon*' and '*logos*' (Heidegger, 2010, p. 27-32) . The word '*phenomenon*' comes from the Greek word '*phaenesthai*', which means '*to flare up*, *to show itself*, *to appear*' (Heidegger, 2010, p. 27). The meaning of the expression *phenomenon* is established as what shows itself in itself, what is manifest (Nelms, 2014). The phenomenon is what appears in consciousness (Heidegger, 2010; Moustakas, 1994). The basic meaning of '*logos*' is discourse, but then it was interpreted by the researcher as reason, judgement, concept, definition, ground and relation (Heidegger, 2010, p. 30). Logos also means '*what is being talked about'* in discourse (Heidegger, 2010, p.31). Accordingly, the formal meaning of phenomenological research is to let what shows itself be seen from itself, just as it shows itself from itself (Heidegger, 2010).

The science of phenomena means that it grasps its objects in such a way that everything to be discussed must be directly indicated and directly demonstrated (Horrigan-Kelly, Millar, & Dowling, 2016). In other words, phenomenology is the investigation of the essence or the nature of material things or things that appear (Heidegger, 1962). The term phenomenology

was first used by some precursors in the 18th century such as René Descartes (1596-1650), Immanuel Kant (1724-1804), Georg Wilhelm Friedrich Hegel (1770-1831), and Friedrich Nietzsche (1844-1900) (van Manen, 2016). Later in the early 20th century, Edmund Husserl (1859-1938) and his colleague Martin Heidegger (1889-1976), and Hans Georg Gadamer (1900-2000) established and developed the phenomenological movement (Dowling, 2007; van Manen, 2016). Other earlier European philosophers Ernst Mach (1838-1916) and Carl Stumpf (1848-1936) also contributed to the historical development of the phenomenology movement (Fisette, 2019; Stumpf, 1930). The following sections present the movement of phenomenology as philosophy and methodology.

3.2.1. Edmund Husserl: Transcendental/descriptive phenomenology

Edmund Husserl (1859-1938) was a mathematician who was generally regarded as the intellectual founder of phenomenological philosophy, who developed transcendental phenomenology, which is also known as descriptive phenomenology (Dowling, 2007; Paley, 1997). This philosopher, who had a Jewish family background, defined phenomenology as a descriptive philosophy of the essence of pure experience, which aims to capture experience without interpreting, explaining or theorising (van Manen, 2016). Husserl phenomenology adopted epistemology, the theory of the nature of knowledge, justification and the relationally of belief (Nelms, 2014; Paley, 1997). He questioned the knowledge of the ‘object’ that was obtained through consciousness awareness (Schneider, 2016). Husserl had a strong desire to discover phenomena from the essence of things (Moustakas, 1994). Husserl also emphasised that “essence” was the thing that made phenomenon appear from the individual conscious experience presented to the world (Moustakas, 1994; Polit, 2014; Schneider, 2016). Thus, it can be concluded that essence refers to the true nature of the phenomenon being studied. Based on Husserl’s ideas, descriptive phenomenology involves two major concepts: bracketing and intuiting (Polit, 2014).

Husserl constructed the concept of bracketing or reduction, which was based on *epoche* which he adopted from Descartes (1596-1650) a French mathematician, philosopher and psychologist who developed the first systematic account of the body/mind relationship (van Manen, 2011). The term *epoche* comes from a Greek word meaning to refrain from judgement, to abstain from or stay away from the everyday, ordinary way of perceiving things (Moustakas, 1994; van Manen, 2016). The concept of *epoche* allows things to purely and naturally show themselves as the essence of the things, and describes the things as itself (van Manen, 1990). Husserl developed the *epoche* concept, which required the elimination of suppositions and the raising of knowledge above every possible doubt (Moustakas, 1994). He believed that mood, thoughts, memories and emotions should be separated or bracketed out in order to focus on conscious awareness of objects (Schneider & Whitehead, 2013).

Another of Husserl's phenomenological concepts is intentionality. Husserl (1931), as cited in Moustakas (1994), claimed that intentionality is a consciousness of thought toward a thing. Husserl was concerned about the concept of intentionality when he attended a descriptive psychology lecture given by Franz Brentano (1973) (Dowling, 2007; Moustakas, 1994). In his lecture, Brentano explained consciousness as intentional; it is directed toward objects; it always contains content that is intentional (Fisette, 2019). Brentano mentioned that the difference of external perception only relates to physical phenomena, and internal perceptions of mental phenomena (Moustakas, 1994). He believed that the phenomena of external perception cannot be proven to be true, and the phenomena of internal perception possesses actual existence as well as intentional existence (Moustakas, 1994). According to Brentano, the natural sciences investigate physical phenomena such as sensations, and the human sciences investigate mental phenomena particularly perception, memory, judgement and mental presentation (Moustakas, 1994). However, Husserl disagreed with Brentano's belief that a relationship always exists between perception and reference

(Moustakas, 1994). Based on Brentano's lecture and writings, Husserl developed his ideas regarding the intentional nature of consciousness, the necessity of self-evidence, the value of inner perceptions and the dependence of knowledge on self-experience (Spiegelberg, 1960). He focused on pure phenomenology, essence, pure consciousness and pure ego (Moustakas, 1994; Spiegelberg, 1960). In short, descriptive or transcendental phenomenology is a scientific study of the phenomena of things that appear or show as themselves from essence in consciousness, or back to the things themselves.

Descriptive phenomenology (also described by Husserl) provided a description of human experience of "things" in everyday life, such as hearing, seeing, believing, feeling, remembering, deciding, evaluating and acting (Moustakas, 1994; Polit, 2014). Paley (1997) noted that Husserl's phenomenology was applied in nursing research by a group of nurses including Parse (1981), Oiler (1982), Omery (1983), Ray (1985), Cohen (1987) and Reeder (1987). He argued that nurse researchers often misinterpret the three central ideas of phenomenological reduction, phenomena and essence in descriptive phenomenology (Paley, 1997). The application of Husserl phenomenological methods in nursing research was found to be frequently inconsistent to the original idea (Paley, 1997).

Based on Husserl's descriptive phenomenology, a researcher must set aside all opinions, beliefs, pre-assumptions, knowledge and understanding in relating to the thing that is being studied (Paley, 1997). In this study context, bracketing and intentionality are not possible because this researcher is a nurse who possesses general understanding and knowledge in relation to the use of CAM for cancer management. The researcher might make assumptions based on her existing knowledge so that the "essence" or pure description as believed by Husserl would not be achieved. In addition, this current study aimed not only to describe the lived experiences of women with breast cancer and CAM providers' views in the use of CAM for breast cancer but also to understand the meaning of the women with

breast cancer's lived experiences and CAM providers' views. Therefore, Husserl's phenomenology was deemed an inappropriate approach for this study.

3.2.2. Martin Heidegger: Hermeneutic phenomenology

Martin Heidegger was a theology student who turned to the study of philosophy, mathematics and physics at the University of Heidelberg (Neubauer et al., 2019; van Manen, 2016). This German philosopher was a student of Husserl who argued against Husserl's transcendental phenomenology concept (Horrigan-Kelly et al., 2016; Olafson, 1975; Reiners, 2012). Heidegger focused on understanding the meaning of things rather than its pure description as suggested by Husserl's phenomenology (Dowling, 2007; Heidegger, 1962, 2010; van Manen, 2016). Heidegger believed phenomenology should be used to explore the ontological question 'what is the meaning of being?' instead of the epistemological question, which seeks to know a being or the experience of the phenomena (Converse, 2012; Heidegger, 1962). In his publication of *Being and Time*, Heidegger critiqued Husserl's phenomenological concept of *epoche* or bracketing and intentionality (Olafson, 1975). He argued that bracketing things was impossible particularly if the researcher was entangled with a thing or an experience being study for some time or moment (Heidegger, 1962).

Heidegger perceived that humans could not avoid their assumptions when looking at a phenomena, just like subject and object are inseparable (Olafson, 1975). Instead of bracketing pre-assumptions, he suggested researchers to have explicit pre-assumptions about the object and study it (Heidegger, 2010). Heidegger rejected the notion of intentionality or consciousness that was 'directedness' toward an object or things as he was concerned with human existences and lived experiences (Heidegger, 2010). Based on this belief Heidegger developed the concept of human existence as *Dasein* or 'being in the world' (Heidegger, 2010). The word *Dasein* derives from German words of *da*

meaning *here* and *sein* meaning being (Olafson, 1975). The concept of *Dasein* allows questioning of human beings existence in the world, their behaviour and interaction with the world in a certain manner (Heidegger, 1962, 2010). As such, Heidegger's idea of 'being in the world' offers a way to discover and understand meanings of everyday life human lived experience. Therefore, hermeneutic phenomenology was considered to be used in this study as this study aimed to understand meaning of CAM use based on the lived experiences of women with breast cancer and CAM providers.

In order to understand the meaning of humans lived experiences, Heidegger proposed the hermeneutic circle concept. The word of '*hermeneutic*' originates from the Greek word '*hermeneuein*' meaning 'to interpret' (Heidegger, 1962). Hermeneutic came from Greek mythology with Hermes, who was believed to be a messenger and interpreter between God and humankind (Heidegger, 1962). Hermes had the ability to transform messages from God into human language so that they could understand messages from God (Heidegger, 1962). Based on the hermeneutic concept, Heidegger constructed the hermeneutic circle, an interpretative framework to gain understanding of phenomena or human's lived experience (Reiners, 2012). Heidegger developed the hermeneutic circle or 'fore-structure' involving three interrelated modes of interpretation: 'fore-having', 'fore-sight', and 'fore-conception' (Mackey, 2005). Fore-having means having pre-understanding about a thing that is being studied makes an interpretation possible. Fore-sight demonstrates that pre-understanding generates a point of view from which an interpretation will be made, and fore-conception concerns having some expectation of what might be anticipated in an interpretation due to pre-understanding or prejudice (Heidegger, 1962). The hermeneutic circle describes a circular movement of reading the text from the part of the text to the whole of the text, and back to part of the text again continuously for the process of interpretation (Mackey, 2005).

3.2.3. Hans-Georg Gadamer: Fusion of Horizons

The hermeneutic circle concept was then extended further by Hans–Georg Gadamer, a former pupil of Husserl and Heidegger at the University of Freiburg (van Manen, 2016). In his publication *Truth and Method*, Gadamer emphasised that prejudices are not negative; instead, they are deeply embedded in historical consciousness. He rejected the concept of bracketing because he strongly believed that prejudice cannot be removed from consciousness (Gadamer, 1975). In addition, each individual prejudice or perception is tied to gender, culture, social, historical contexts, hence, these need to be considered in an interpretative process (de Chesnay, 2014; Dowling, 2007; Gadamer, 1975; Vessey, 2009). Furthermore, Gadamer viewed language as an essential part of the interpretation process to achieve understanding (Wiercinski, 2019). Language had the power to create and recreate multiple meanings from the text (van Manen, 2016). He believed that all human understanding occurs through language, which is transformed into text (Vessey, 2009). It is important that the researcher remains open to other person's world and lived experience, as this can bring new things from dialogue with the other person (Vessey, 2009).

The hermeneutic circle described a circular movement back and forth from the part of the text to the whole in an interpretation process. At this point, Gadamer believed that the hermeneutic reading process of the text may change understanding over time, resulting in endless interpretation and indefinite outcomes (Vessey, 2009; Wiercinski, 2019). The hermeneutic circle also shifted prejudice of the past to become new understandings of the present time or in the future (Gadamer, 1975). Based on his fundamental idea, Gadamer introduced the fusion of horizon concept, an interaction or dialogue between a researcher and text in an interpretation process to reveal understanding (de Chesnay, 2014; Dowling, 2007; Vessey, 2009; Wiercinski, 2019). The horizon is the range of vision that can be seen by the researcher from a particular

standpoint (Gadamer, 1975). He stated that a person who has no horizon does not see far enough and hence overvalues what is nearest to them (Vessey, 2009). Gadamer emphasised the term horizon was not to limit understanding but to condition understanding, which always draws the researcher toward new understandings (Vessey, 2009). Therefore, the fusion of horizon means the fusion of the researcher's horizon, or pre-understanding, in the past and the horizon of text generates new understanding and expands the researcher's horizons. However, the fusion of horizons concept was not utilised in this study as this study sought to understand women with breast cancer's experiences in the use of CAM as it is lived. Accordingly, this study considered applying hermeneutic phenomenology with life existential reflections offered by van Manen.

3.2.4. Max van Manen: Phenomenology of practice

Max van Manen is a Dutch Emeritus Professor in research methods who has had a major influence in the world of contemporary phenomenology. He was born in the Netherlands in 1942, achieved his academic qualifications in the same country before migrating to Canada in 1967 (Errasti-Ibarrondo, Jordán, Díez-Del-Corral, & Arantzamendi, 2019). Inspired by Heidegger and Gadamer's hermeneutic phenomenology, van Manen introduced phenomenology of practice (Errasti-Ibarrondo et al., 2019). In the Dutch school, van Manen's phenomenology is known as a combination of descriptive and interpretive phenomenology (Errasti-Ibarrondo et al., 2019). His writings described human's lived experience using the phenomenology developed by Husserl and interpreted the meaning of lived experience following Heidegger's phenomenology (Dowling, 2007). Van Manen introduced five existential life themes of lived self-others, lived body, lived time, lived space, and lived things to guide the researcher in phenomenological writing (van Manen, 1990, 2016). These existentials demonstrate a fusion of the objectivist hermeneutic circle, pre-understanding and the researcher's role in the research process (van Manen, 1990, 2016).

It is important for nurse researchers using this methodology to have adequate understanding about the philosophy of phenomenology that underpins their research (Reiners, 2012). A deeper understanding of phenomenological philosophy and methods assist nurse researchers to produce scientifically rigorous phenomenological studies (Matua, 2015). Phenomenology provides a guide for nurses to conduct research that has the ability to generate in-depth insight and useful meaning into nursing practice (Converse, 2012). The five existential concepts offer a guide to nurse researchers facing the difficulties of bracketing, and reflects the ongoing transformation of phenomenology as a methodological approach (Dowling, 2007). Therefore, van Manen's phenomenology of practice is popular in medical and nursing phenomenological studies (Dowling, 2007). Errasti-Ibarrondo et al. (2019) acknowledged the phenomenology of practice as a valuable and appropriate research methodology for nursing research, specifically in studies seeking to understand a patient's lived experience. The phenomenology of practice provides a guide to produce new horizons, understanding and knowledge from rigorous phenomenological texts, where the phenomenological texts have the ability to contribute greatly to improving nursing practice (Errasti-Ibarrondo et al., 2019).

However, Errasti-Ibarrondo et al. (2019) claimed several limitations that need to be considered in conducting van Manen's phenomenological approach. First, lived experiences are ineffable and immense in nature; hence, it is impossible to understand fully and absolutely a phenomenon (Errasti-Ibarrondo et al., 2019). Secondly, the pedagogical value and power of phenomenological texts are often underestimated, and sharing a global vision of the phenomena studies with the scientific communities is difficult, due to misreading, misunderstanding and inconsistency in conducting the phenomenology of practice (Errasti-Ibarrondo et al., 2019). Another limitation of van Manen's phenomenological framework is its time consuming nature, because the phenomenology of practice framework consists of six research activities (van Manen, 1990).

Furthermore, Paley (2018) argued that van Manen's phenomenology of practice was harder to fathom, resulted in misreading and misattribution that abound in van Manen's articles. Paley (2018) also claimed that van Manen's phenomenology does not refer to genuine phenomenology, which is commonly based on the phenomenological philosophical tradition. In addition, Zahavi (2019) argued that van Manen's approach promotes various confusions regarding the nature of phenomenology. Zahavi (2019) critiqued van Manen (2017b) writing of '*Phenomenology with original sense*', which claimed that phenomenology is the study of the lived meaning of an experience, and the phenomenological question is 'What is this experience like?'. Zahavi (2019) viewed that van Manen's understanding about phenomenology is untrue and irrelevant to the original sense of phenomenology. In his article *"Getting it Quite Wrong: van Manen and Smith on Phenomenology"*, Zahavi (2019) explained his objection to the way van Menen's characterised the phenomenology of practice approach as phenomenology, despite the approach being aligned with the philosophical phenomenology thinkers like Husserl, Heidegger and Merleau-Ponty (Zahavi, 2019). Unlike van Manen's ideas, Zahavi (2019) believed that the aim of phenomenological research study is not to simply let the experience show itself as it is lived through. Instead, phenomenological research aims to disclose, disentangle, explicate and articulate those components and structures that are implicitly embodied in the pre-reflective experience (Zahavi, 2019).

van Manen rebutted Zahavi's critiques on his phenomenological understandings (van Manen, 2019). Through his article titled "*Rebuttal: Doing Phenomenology on the Things*", van Manen (2019) defended the term 'original' that he used in his article, which was critiqued by Zahavi (2019). van Manen stated that it was not meant to solely or primarily refer to Husserl's fundamental works. The 'original' term referred to the commanding works of past and present leading phenomenological thinkers, that were original in the sense of unique and recognised in the primary literature (van Manen, 2019). van Manen (2019)

viewed that Zahavi adopted a stricter orthodox philosophical position as he said was ‘anchored to Husserl’. According to van Menen’s view, Zahavi’s writings were less relevant to the concerns of professional practitioners even to the everyday lives of readers with a philosophic interest (van Manen, 2019). The reason offered was that professional practitioners and clinicians have real-world concerns and real-life interests (van Manen, 2019). Nevertheless, these potential limitations and critiques did not impede the application of van Manen’s phenomenological framework in this study.

van Manen’s phenomenological approach was used as a framework in this study. There were several reasons why this approach was chosen for this study. Primarily, van Manen’s phenomenological framework offered a suitable guide that allowed this researcher to describe and interpret the meanings of women with breast cancer’s experiences and CAM providers’ views on the use of CAM for breast cancer management. The second reason was, the van Manen’s approach is contemporary, unique, practical, informative and systematic, based on this researcher’s point of view. Another more important reason was this framework guided this researcher to produce a rich and deep phenomenological text of women with breast cancer’s experiences and CAM providers’ views in the use of CAM for breast cancer management in Indonesia. The phenomenological text from this current study provides valuable insight and knowledge that could contribute to improving both oncological nursing care and CAM practices in Indonesia, specifically in Batam and Bandung.

3.3. van Manen’s hermeneutic phenomenological framework

In his book titled *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*, van Manen (1990) introduced practical approaches that may assist in conducting a hermeneutic phenomenology study. The practical approaches involved six research activities (van Manen, 1990) that will be described in-depth in the following sections. These are 1). Turning to a phenomenon, 2). Investigating experience as we live it rather than as

we conceptualise it, 3). Reflecting on the essential themes which characterise the phenomenon, 4). Describing the phenomenon through the art of writing and rewriting, 5). Maintaining a strong and oriented pedagogical relation, and 6). Balancing the research context by considering the parts and whole.

3.3.1. Turning to a phenomenon

Phenomenological research aims to transform lived experience into a textual expression of its essence; hence, it starts and ends with lived experience (van Manen, 1990). Lived experience can only be recalled and reflected through language (van Manen, 1990). The research activities at this stage include explaining the researcher's self-orientation to the phenomenon of interest (p. 100), formulating phenomenological question (p. 17) and explicating assumption and pre-understanding (p. 101).

Phenomenological inquiry is a creative attempt to capture certain phenomena of life in a holistic, analytical, evocative and precise, powerful and sensitive linguistic description (van Manen, 1990). Orienting to a phenomena refers to approaching an experience with a certain interest (van Manen, 1990). At this stage of orienting to the phenomenon, the researcher needed to focus carefully on possible questions of human experience that could be the topic for phenomenological investigation (van Manen, 1990). In this context, the researcher for this study identified women with breast cancer's experiences and CAM providers's views on the use of CAM for breast cancer management as a true phenomenon that human beings live through and as a particular area of interest in the lifeworld.

A phenomenological question may arise through certain experiences or ordinary experiences that may bring the researcher to a sense of wonder (van Manen, 2016). Phenomenology asks simple questions such as, 'What it is like to have a certain experience?', or 'What is the nature, meaning, and uniqueness of the experience as it is given in consciousness?' (van Manen, 1990, 2016). A phenomenological question must be

clear, understood, lived by the researcher and evoke the reader's sense of wonder about the nature of the phenomenon that is being studied (van Manen, 1990). Therefore, the research question in this phenomenological study was: 'What are women with breast cancer's experiences and CAM providers' views on the use of CAM for breast cancer management in Indonesia?'

van Manen (1990) claims that assumptions, pre-understanding, suppositions and the existing bodies of scientific knowledge lead to an interpretation about the nature of the phenomenon before it is grasped with a significant phenomenological question. In order to allow the phenomenon to show itself in different ways, the researcher needs to identify pre-existing knowledge and understanding about the phenomenon that being studied (van Manen, 2016) . The method of *epoche* and reduction provide access to gain the structures of meaning of a phenomenon (Heinonen, 2015). The *epoche* or bracketing method suggests that the researcher stays away from or parenthesizes existing understanding and presumptions about the phenomena (van Manen, 2016). Reduction is an attentive turning to presumptions or remembrance pre-understanding about the phenomena in an open state of mind (Heinonen, 2015). According to van Manen (1990), existing assumptions, pre-understanding, beliefs, and assumptions should not be forgotten or ignored; instead, they should be explicated and reflected on as the researcher's initial pre-understandings and assumptions potentially influence the interpretation process. The researcher needs to return to the pre-understanding and assumptions to validate or ensure that the phenomena appears or shows itself (van Manen, 2016). Thus, it is important that the researcher in this study explicates her assumptions and pre-understandings about the use of CAM for breast cancer management in Indonesia (p. 101).

3.3.2. Investigating experience as we live it rather than as we conceptualise it

The object and the source of phenomenological research is the lifeworld, the world of lived experience (van Manen, 1990). The lifeworld of lived experience is given or borrowed from other peoples' experiences from sources such as interviews, observation, and language analysis (van Manen, 1990, 2016). Borrowing other peoples' lived experiences allows the researcher to become more experienced with the phenomena in a vicarious way (van Manen, 2016). In human science research, the data are human experiences or other peoples' lived experiences that are collected as examples of possible human experiences in order to reflect meaning that may be inherent in them (van Manen, 2016). It is important to be aware that oral or written discourse lived experience descriptions given by other people will never be identical to their lived experience (van Manen, 1990, 2016). This is because the lived experiences have already been transformed into recollections of experiences, reflection on experiences, descriptions of experiences, taped interviews about the experiences or transcribed interviews about the experiences (van Manen, 1990, 2016).

In order to understand the deeper meaning of human experience, there is a need to borrow other people's experiences and their reflections of their experiences (van Manen, 1990). The other people's experiences can be obtained through protocols of writing or lived-experience descriptions, interviewing or personal life stories, and observing or close observation (van Manen, 2016). In addition, other people's lived experience can also be collected from experiential descriptions in literature, from biographies (as a resource for experiential material), diaries, journals, logs and arts (as a source of lived experience), as well as consulting phenomenological literature (van Manen, 1990). In this phenomenological study, examples of women with breast cancer's lived experiences and CAM providers' views in the use of CAM were gathered through in-depth interviews. The research activities in

gathering lived experiences in this study included ethical clearance applications, participant recruitment and interviews, which are explained in Chapter Four.

3.3.3. Reflecting on the essential themes that characterise the phenomenon

Phenomenological reflection or interpretation aims to understand the essential meaning of a phenomenon. Meaning is multi-dimensional and multi-layered; hence, it can never be grasped in a single definition (van Manen, 1990, 2016). Meaning can only be communicated textually by organising the narrative text of the phenomenon (van Manen, 1990). Working out the narrative text of the phenomenological descriptions and interpretations to identify themes is the challenging part of the phenomenological research process (van Manen, 2016). In this study, thematic analysis, isolating thematic statements, and composing linguistic transformations were conducted to generate essential themes for interpretation. Lifeworld existential methods were also applied to guide reflection. The thematic analysis and reflection are explained in greater detail in the forthcoming Chapter Four.

3.3.4. Describing the phenomenon through the art of writing and rewriting

van Manen (1990) states that hermeneutic phenomenological writing is the process of creating a text to communicate meaning that is embedded in the participants lived experience descriptions. The process of phenomenological writing or the vocative aims to express the non-cognitive, ineffable and phatic aspects of meaning of the phenomenon (van Manen, 2016). The writing process of lived experience descriptions may require a conducive physical environment as it would allow the writer to enter the world opened up by the words, and the space of the texts (van Manen, 2016). The space of words may transport the writer away from everyday reality into the reality of the texts (van Manen, 2016). Accordingly, the phenomenological writing process in this study was undertaken in a comfortable quiet working space hence the writer could enter the space of the text and immerse herself into the texts. Moreover, van Manen (2016) believed that successful phenomenological writing should have mesmerising consciousness effects to evoke the

world, and to provide insights and understandings. He suggests that the more vocative a text, the stronger the meaning is embedded in the text.

3.3.5. Maintaining a strong and oriented pedagogical relation

van Manen (1990) explains that phenomenological human science texts should maintain a strong and oriented relationship to the phenomenon. Researchers need to be sensitive to the purpose of the research, their role as researchers, and able to write an oriented, strong, rich and deep text where the voice of the professional is heard (Errasti-Ibarrondo, Jordán, Díez-Del-Corral, & Arantzamendi, 2018). The text needs to be oriented to the research, writing about awareness of the relationship between content and form, speaking and acting, and text and textually (van Manen, 1990). The text needs to be strongly constructed so that the researcher is able to gain the strongest interpretation of a certain phenomenon, and gain clarity about a certain notion (van Manen, 1990). Strong text interpretation produces meaning, understanding, knowledge, interpretation and formulation to the orientation of the researchers' profession (Errasti-Ibarrondo et al., 2018; van Manen, 1990). The text needs to be rich in order to provide rich statements, and rich descriptions of the lived experience that is being studied (van Manen, 1990, 2016). The text also needs to be deep so that the researcher can gain in-depth insight, understanding and meaning of the phenomenon or lived experience that is being studied (van Manen, 1990, 2016). The researcher needs to be aware of the relationship between this research and nursing pedagogy (Errasti-Ibarrondo et al., 2018, 2019). The phenomenological writing of women with breast cancer's lived experiences and CAM providers' views in the use of CAM from this study should stand with nursing knowledge and education. In order to maintain a strong and oriented pedagogical relationship to the phenomenon, the researcher continually reminded herself of the research question and discussed this phenomenological text with her academic supervisors.

3.3.6. Balancing the research context by considering parts and whole

At this final stage, van Manen (1990) reminds the researcher to ensure that research activity follows certain directions and procedures in conducting human science research. This includes preparing the research proposal in narrative form with a significant research question and methods, to consider the effect and ethics of human science research, and anticipate potential challenges and situations that the researcher may encounter while conducting the research study that draws on human subjects (van Manen, 1990). In addition, working with the phenomenological text back and forth from the part to the whole repetitively may lead to loss of sight of what the researcher is trying to achieve and the rationale (van Manen, 1990). To ensure the balance of the research context in this study, the researcher printed out the thesis chapters in hard copy, read them, and evaluated the flow and connection of all parts of the research context.

Overall, van Manen's phenomenology of practice framework provided practical step-by-step procedures to conduct this phenomenological research study from the beginning to the end. The framework helped the researcher develop the research question, guided data collection on the lived experiences of women with breast cancer and CAM providers' views, guided the description of the experiences, guided the interpretation of embedded meaning of the lived experiences in the use of CAM, and guided the writing the phenomenological text.

3.4. Chapter summary

The aim of this study was to understand the lived experiences of women with breast cancer and CAM providers' views in the use of CAM for breast cancer management in Indonesia. Hermeneutic phenomenology was identified as the most suitable philosophy to underpin this study. The hermeneutic phenomenological approach allowed deep description of women with breast cancer's lived experiences and CAM providers' views of the use of CAM for

breast cancer management, and in-depth interpretation of meaning of this phenomenon. Specifically, van Manen's contemporary hermeneutic phenomenological framework was used as a guide to uncover women with breast cancer's experiences and CAM providers' views in the use of CAM for breast cancer management. The application of van Manen's methods are explained in the following Chapter Four. After this presentation, Chapter Five presents the thematic analysis findings of women with breast cancer's lived experiences in the use of CAM, followed by Chapter Six that presents the thematic analysis findings of CAM providers' views.

CHAPTER FOUR: PHENOMENOLOGICAL METHODS

4.1. Introduction

This chapter describes the application of van Manen's phenomenological approach in order to explore women with breast cancer's experiences and CAM providers' views of the use of CAM for breast cancer management in Indonesia. A phenomenological approach was selected as it is the most appropriate research design because the phenomenological approach enabled this researcher to answer the question 'What are women with breast cancer's experience and CAM providers' views in the use of CAM for breast cancer management?' The research activities conducted were based on this design, and explicated as directed by van Manen's approach (4.2) explicating pre-understanding, (4.3) gathering lived experiences, (4.4) thematic analyses, (4.5) writing phenomenological text, and (4.6) issues of rigour. All these activities are explained in detail below.

4.2. Explicating pre-understanding

The researcher's orientation to the lifeworld is that of healthcare practitioner. She is a registered nurse, and had a close relative who died of breast cancer, who had used CAM. The researcher often encountered cancer patients including women with breast cancer who use CAM for cancer management. The researcher asked herself: 'What are women with breast cancer's experience and CAM providers' views in the use CAM for breast cancer management?' This curiosity generated the researcher's intention to pursue the exclusively singular aspect of phenomena about CAM usage in a scientific manner.

In this phenomenological study, the researcher is a nurse who interacted with women with breast cancer who were patients with cancer. In the day-to-day activity of interacting with patients, health practitioners including doctors and nurses need to be sensitive to the variety of ways patients may experience their world. Health practitioners should ask simple

phenomenological questions to assist their understanding that patients have various and differing lived experiences, values and predicaments.

The researcher developed simple phenomenological questions to investigate women with breast cancer's lived experiences and CAM providers' views of a phenomenon that was of particular interest to the researcher. The phenomenological question in this study was: 'What are women with breast cancer's experience and CAM providers' views in the use of CAM for breast cancer in Indonesia?' The women with breast cancer were asked to share their lived experiences in the use of CAM for breast cancer management. Additionally, CAM providers' knowledge and views on the use of CAM for breast cancer were explored, to gain greater depth in understanding of the phenomenological research question in this study. The question for the CAM providers was: 'What do CAM providers know about the use of CAM for breast cancer management in Indonesia?'

In phenomenological inquiry, reflecting personal experience is often a good starting point prior to investigating other peoples' experiences (van Manen, 1990) . The researcher may have clues for orienting to the phenomenon by recognising the structure of one's own experience of phenomenon (van Manen, 1990). van Manen (1990) states that the phenomenologist knows that one's own experiences are also possible experiences of others by drawing on personal descriptions of lived experiences. The researcher's personal experience description, as a starting point of this phenomenological research, is presented in italic font below:

Reflecting my experience working as a clinical nurse in a medical-surgical ward at a small suburban hospital in Indonesia in 2006, I often encountered cancer patients who used CAM as part of their cancer management. During my clinical experience, I noticed many hospitalised patients commonly used CAM although they were undergoing medical cancer treatments such as surgery, chemotherapy and radiation therapy. One day, I attended a 52

year-old woman with advanced stage breast cancer who was admitted for surgical removal of her breast tumour. When I was performing the physical assessment on her, I found her mouth, tongue and lips were an abnormal dark red colour. I asked the woman what particular food or drink with red colour she had consumed. The woman said that she had been regularly consuming an herbal potion to treat her breast cancer three days prior to hospitalisation. Five hours after the physical assessment, the patient vomited blood and her breast tumour ruptured. I suggested that she stop consuming the herbal potion and just take the prescribed medicine during her hospitalisation. However, the woman insisted on continuing to consume the herbal potion and claimed that the herbal potion removed the breast cancer cells through her vomiting and the bleeding from her ruptured breast tumour. She kept vomiting blood and her breast tumour bleeding worsened. The woman's health condition deteriorated and she passed away before the breast tumour could be surgically removed. This experience drove my curiosity and question why people with cancer including women with breast cancer were interested in the use of CAM. I was unfamiliar with what it was like to use CAM for breast cancer management. This experience led me to believe that CAM was a potentially harmful treatment.

I also witnessed my aunt (my father's younger sister) die for inappropriately treated breast cancer. She lived in a village where medical cancer treatment was not available. It took approximately six hours travel by public shuttle bus from her village to a public hospital in the capital city. She travelled once to the hospital and was recommended to undergo breast tumour surgery followed by chemotherapy. Due to her fear of surgery and financial constraints, she was compelled to use traditional medicine from a shaman as an alternative medicine for her breast cancer. She consumed herbal potions, applied grated herbs and oil onto her breast tumours, and massaged the breast tumours using a duck egg from a shaman, who had used prayer with it. As a nurse, I encouraged her to undergo surgery and chemotherapy but she refused my recommendations. Five years later (using traditional

medicine during that time), her breast tumours ulcerated and the cancer spread into her lungs. In a critical health condition, her family brought her back again to the hospital but it was too late for the medical cancer treatment. She passed away from untreatable breast cancer which had been unsuccessfully treated using traditional medicine at the age of 55 years.

Similarly, my uncle (my father's younger brother) died of colorectal cancer due to delayed medical cancer treatment. He lived on a rural small island in Indonesia where oncology and medical cancer treatment were not available. His colon abscess was treated by a digestive surgeon as an intestinal perforation. In addition to medical treatment, he consumed herbal medicine, traditional medicine from a shaman and charcoal therapy. However, his heath condition worsened after several major laparotomy surgeries to remove intra-abdominal abscesses due to intestinal perforation. He was referred to a hospital in the capital city for further cancer assessment, and his medical diagnostic test results indicated that he had advanced colorectal cancer. In order to gain access to medical cancer treatment, he took two-hour flights from the island to the capital city incurring high travel and accommodation expenses. Another option for access to medical treatment was travel to other nearby countries such as Malaysia or Singapore which also would have required expensive associated costs. He took Xeloda (chemotherapy tablet) and kept consuming herbal medicine, traditional medicine from the shaman and charcoal therapy with little effects. Finally, his quality of life declined. His poor health condition, meant he was unable to travel to the capital city so he travelled to Malaysia which took only 45 minutes by ferry. He had a couple radiotherapy cycles in a hospital in Malaysia. However, it was too late for him to undergo radiotherapy. He passed away at the age of 47 years in the hospital in Malaysia due to severe sepsis associated with colorectal cancer.

These experiences shaped the researcher's understanding that all CAM therapies provided unrealistic expectations. Based on these experiences, the researcher assumed that CAM was not effective in treating cancer; instead, it could worsen health conditions and decrease quality of life. The researcher had never researched scientific evidence about the efficacy or the safety of CAM. She had no idea what her patients and relatives experienced with the use of CAM. The researcher often doubted her assumptions and pre-understandings about the use of CAM for cancer management. These experiences left the researcher with questions and a curiosity of what it was like to use CAM for cancer management, specifically what are women with breast cancer's experiences and CAM providers' views within the use of CAM. Additionally, knowledge and understanding about what is known about the phenomenon that is being explored through this hermeneutic phenomenological research was sought. Thus, there was a need to highlight other women with breast cancer's lived experiences and CAM providers' views about the use of CAM for breast cancer management.

4.3. Gathering lived experiences

The research activities required to gather the examples of women with breast cancer's lived experiences and CAM providers' views in the use of CAM for breast cancer management in Indonesia were: ethical considerations, determination of research settings, recruitment of participants as sources of lived experiences, participant selection, and the phenomenological interview process, which are explained below.

4.3.1. Ethical considerations

Ethical issues must be considered by any researcher in order to prevent participants from potential harm that may occur during the data collection and the data analysis process (Kiyimba, Lester, & O'Reilly, 2018). Ethical permission to conduct this study was sought from the Social and Behavioural Research and Ethics Committee (SBREC) at Flinders University

as the principal researcher is a PhD candidate at this education institution. The ethics application was submitted in August 2017 and the final approval was received in November 2017 with the project number 7792 (Appendix 2, p. 303). Permission letters for data gathering were also obtained from the chair of the cancer support groups in Indonesia (Appendix 3, p. 306) and Appendix 4, p. 307).

This study applied the four central principles of the deontological approach to maintain the integrity of the data collection and the data analysis (Kiyimba et al., 2018). These include respects for autonomy, promotion of justice, ensuring beneficence, and ensuring non-maleficence (Kiyimba et al., 2018). Respecting the autonomy of participants is critical to the ethical conduct of gathering the data (Kiyimba et al., 2018). In order to respect the autonomy of the participants, the researcher introduced the study, explained the research objectives, provided written and verbal information about the recruitment process, and obtained informed consent, explaining that participants had a right to withdraw from the study at any time, and had freedom from any coercion. All the information in relation to respect for the participants' autonomy was written in several documents such as the letter of introduction, information sheet and consent forms. These documents were prepared in English and translated into Bahasa, the national language of the participants. To promote the principle of justice, the researcher treated all the participants in fair and equitable ways. For example, the participants were recruited without prejudice and discrimination against specific groups. Ensuring beneficence and non-maleficence in this study were demonstrated by minimising potential physical and psychological harm. For example, the researcher informed the participants that their anonymity and confidentiality were maintained by applying pseudonym on their identity. Providing anonymity and confidentiality also encapsulated the non-maleficence principle, as the information given by the participants was protected by applying a pseudonym and storing the information on the principle researcher's protected hard disk.

Further details about the application of ethical principles are presented in the interviewing process section.

There were no anticipated major burdens or risks to the participants in this study as this study aimed to explore their life experiences related to the use of CAM. Studies have found sharing experiences with health care CAM providers to be therapeutic and help to reduce psychosocial distress (Chochinov et al., 2013). However, if the participants were upset or emotionally distressed during the interviews, the researcher would immediately stop the interviews and would not recommence gathering their lived experience unless the participant agreed.

4.3.2. Research setting

The examples of lived experiences were gathered from two cancer support groups in Indonesia. The cancer support groups were non-profit organisations established to support cancer patients and survivors. The cancer support groups specifically provide information about cancer and its treatment, as well as emotional and physical support to people with cancer. These organisations regularly organise health education activities related to cancer such as cancer seminars and cancer prevention campaigns. The majority of the cancer support groups' members were patients with cancer and their families, cancer survivors, and healthcare workers who were interested in cancer management. Membership of cancer support groups was free of charge and those who were working for these associations were volunteers.

The first research setting was a cancer support group (CSG) located in Batam, the largest city in the province of Riau Islands, Indonesia (Dinas Kesehatan Provinsi Kepulauan Riau, 2018). Batam is the closest region of Indonesia to Singapore. The northern side of the island is bordered by Vietnam and Cambodia. The Western side is bordered by Malaysia and Singapore. The first inhabitants in Batam were Malay, and now this city is inhabited by a

heterogeneous mixture of people who have migrated from other provinces including Javanese, Bataknese, Minangkabau and Chinese (Dinas Kesehatan Provinsi Kepulauan Riau, 2018). The total population of this city in 2018 was 2,231, 721, comprising of 1,140, 011 (51%) males, and 1,091,710 (49%) females with approximately 28,674 people living under the poverty line (Dinas Kesehatan Provinsi Kepulauan Riau, 2018; Putra & Abbas, 2019). The majority of the population religion was Islam (71%), followed by Christian (22%) and Buddhism (7%) (Dinas Kesehatan Provinsi Kepulauan Riau, 2018). The common language in daily use is Bahasa as this is the official national language in Indonesia (Dinas Kesehatan Provinsi Kepulauan Riau, 2018). Other languages used by people in Batam city were Malay, Batak, Minangkabau, Javanese and Chinese languages such Hokkien, Teochew and Mandarin (Dinas Kesehatan Provinsi Kepulauan Riau, 2018).

Batam was selected as one of the research sites due to the fact that a cancer care facility was recently established in this city. There are 20 community health centres, three government public hospitals and 18 private hospitals in Batam (Ministry of Health Republic of Indonesia, 2018). The number of cancer patients in Batam city is growing; however, cancer care facilities are limited (Dinas Kesehatan Provinsi Kepulauan Riau, 2018). According to the Kepulauan-Riau health profile report in 2018, there were only two oncologists and four chemotherapy rooms in the government public hospital to provide cancer care for more than 1000 cancer patients including 550 women with breast cancer (Dinas Kesehatan Provinsi Kepulauan Riau, 2018). Cancer care facilities were not commonly provided in private hospitals in Batam (Dinas Kesehatan Provinsi Kepulauan Riau, 2018). In addition, there were more than 119 CAM practices in Batam; however, the number of registered professional CAM providers in Batam remains lacking (Ministry of Health Republic of Indonesia, 2019). It was anticipated that the women with breast cancer and CAM providers who lived in Batam would have unique lived experiences and views in the use of CAM for breast cancer.

The second research setting was a cancer support group located in Bandung, the capital city of the West Java province in Indonesia. Bandung is the fourth most populous city in Indonesia with an estimated population of 2.5 million in the year 2017 (Dinkes Jabar, 2017). The majority of Bandung's population is Sundanese decent and about 91.70% of the total population is Muslim (Dinkes Jabar, 2017). Bandung is one of the well-developed cities in the West Java province where most of the cancer care facilities are provided in hospitals. Further, a referral centre at a public hospital for the West Java region is located in Bandung (Dinkes Jabar, 2017). This hospital provides cancer care for poor patients who participate in the government subsidised national health insurance program (Dinkes Jabar, 2017; Donadear, 2012). As a referral centre for the 27 cities included in the West Java province, this public hospital is extremely crowded, and waiting lists are lengthy resulting in cancer treatment being less accessible (Donadear, 2012). The majority of cancer support group members receive cancer treatments in this public hospital. Women with breast cancer in Bandung may have more access to cancer care treatment so it was anticipated that they may have different lived experiences, and the CAM providers may have dissimilar views in the use of CAM for those women with breast cancer and CAM providers in a remote region like the city of Batam. The figure below shows the research settings of this study.

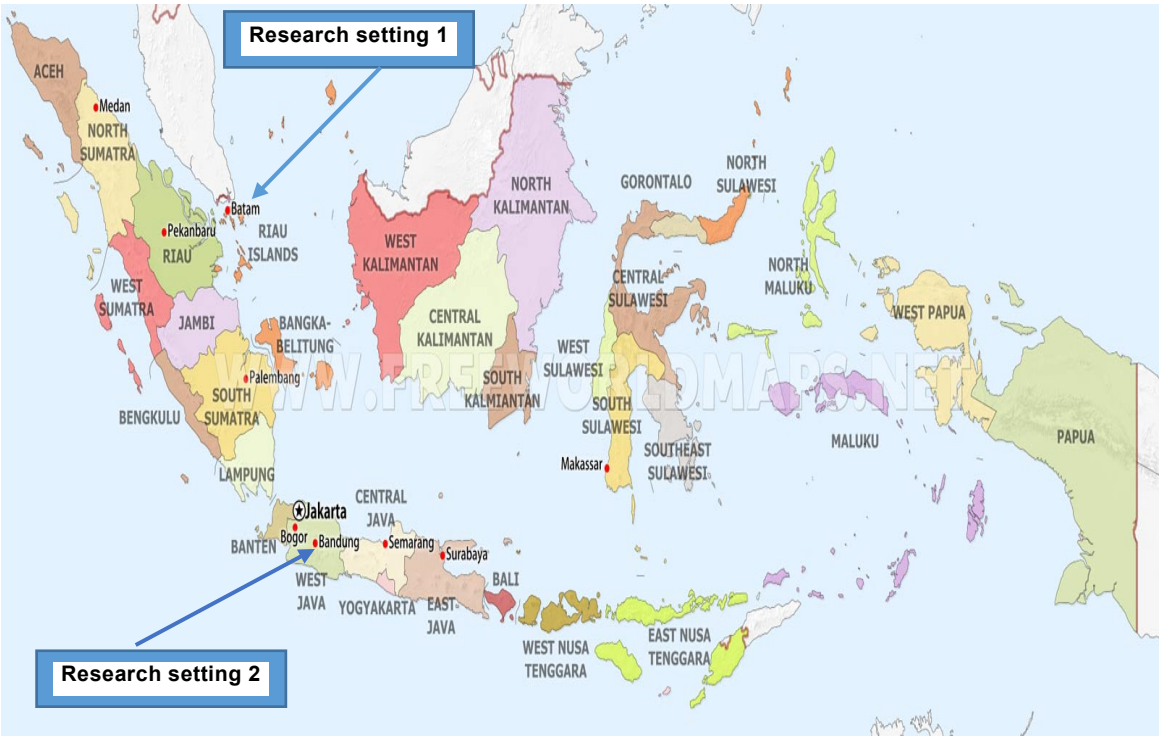


Figure 4. Research settings map.

Batam and Bandung were considered as the research sites for this study due to the fact that the researcher was born and grew up in Batam, and worked in Bandung. The researcher is familiar with the Bahasa language and has prior knowledge about the culture, and socioeconomic situation, as well as the healthcare system in both cities. These benefits assisted the researcher to articulate the meaning of lived-experience descriptions that were provided by the participants from these cities.

4.3.4. Recruitment

This phenomenological study aimed to explore the lived experiences and views in the use of CAM for breast cancer management. Therefore, it was essential that the examples of lived experience were obtained from participants who had experiences related to the phenomenon. Accordingly, a group of women with breast cancer who had used CAM for breast cancer management were sought to share their lived experiences for this

hermeneutic phenomenological study. In addition, CAM providers were also asked to share their perceptions about the use of CAM for breast cancer management in Indonesia.

A purposive sampling technique was adopted to recruit the potential participants. This technique allowed the researcher to select participants with experience of the phenomenon and who were be able to provide in-depth information. Another approach that was used to recruit the potential participants was the snowball or chain sampling technique. The snowball sampling technique was time-effective and practical as it allowed the researcher to ask the early participants to refer this study to other potential participants (Kiyimba et al., 2018; Polit, 2014; Sutton & Austin, 2015). In addition, this approach also assisted the researcher to recruit CAM providers who provided CAM treatment used by the women with breast cancer in this study. The recruitment was conducted from the end of November 2017 to the end of January 2018. The recruitment process was completed once adequate rich experiential materials had been achieved.

To begin the recruitment process, the researcher sought information and identified relevant cancer support groups within both the Riau Island province and the West Java province. There was only one cancer support group available in Batam and there were four well-known cancer support groups in Bandung. These cancer support groups were contacted via email and mobile phone as per details provided on their official websites. The introduction letter (Appendix 5, p. 308) and the information sheet (Appendix 6, p. 309) were attached to the initial email that was sent to the cancer support groups. Recruitment permission was received from the chief of a cancer support group in Batam and the chief of a cancer support group in Bandung (see Appendix 3 and 4 for the permission letters).

Approved recruitment posters about the study (Appendix 8, p. 314) were displayed on notice boards around the CSGs' office once permission had been gained from the chief of cancer support groups. Packages of an introduction letter, information sheet, consent form, and

contact sheet were provided at the cancer support groups' office. The researcher was invited to attend the cancer support group regular meetings and activities and was given the opportunity to explain the details of the study. The cancer support groups' members, particularly women with breast cancer who were interested in participating in this research, were required to collect a package containing the letter of introduction, information sheet, contact sheet and consent form that had been provided in the cancer support groups office. The potential participants were requested to complete a contact sheet provided in the research package, then submit the completed contact sheet into a secure box provided in the cancer support groups' office. Afterwards, the researcher collected the completed contact sheets, and contacted the prospective participants by telephone or text messages in order to arrange a suitable time, date and place for the interviews. The potential participants were also invited to initially contact the researcher on the telephone number that was specifically provided for this project.

In order to recruit CAM providers, the researcher obtained the CAM providers contact details and mail address from the women with breast cancer in this study who used their services, and the local newspaper that advertised CAM treatments in Batam and Bandung, Indonesia. The packages of the introduction letter information sheet, contact sheet, and consent form were sent through mail or directly delivered to CAM practices. The potential participants in this study were requested to contact the researcher via a specific phone number for this project, to arrange a suitable time and place to conduct the interview. The researcher also sent reminders to the CAM providers to contact the researcher if they would like to be involved in this study.

4.3.5. Participants

Hermeneutic phenomenology aims to gather an insight, or notion, of a certain example of a lived experience description (van Manen, 2016, 2017a). Unlike other qualitative studies that

keep collecting data until data saturation is reached, phenomenology methodology does not look at how many times a certain word or ideas are expressed by informants or participants (Townsend, 2013; van Manen, 2016). In-depth conversations are the main data sources in phenomenology studies (Errasti-Ibarrondo et al., 2018; van Manen, 1990, 2016). The in-depth conversations provide full access for the researcher to enter the participants' world experience as it is lived (Polit, 2014; van Manen, 1990, 2016). Phenomenological research may benefit from a few or a great many experiential data sources; in contrast, a large number of interview transcripts may produce shallow reflection (van Manen, 2016). Therefore, it is important that a phenomenology study contains just the right amount of experiential material that generates reflective phenomenology text (van Manen, 2016). Thirty seven women with breast cancer expressed their interest to participate in this study and they were selected based on inclusion criteria as follow:

1. Women who had been diagnosed with breast cancer at any stage
2. Had experiences in the use of CAM for breast cancer management
3. Able to communicate in Bahasa (Indonesian national language), and
4. Willing to voluntarily participate in this study.

Four of the women with breast cancer were excluded from this study due to having had no personal lived experience related to the use of CAM. Thirty-three women with breast cancer met the inclusion criteria and were ready to be interviewed. However, seven of the women with breast cancer withdrew from the study due to personal reasons and their poor health condition impacted on chemotherapy treatments. In total, 21 women with breast cancer voluntarily participated in this study. Ten of the women with breast cancer resided in Batam and 11 of the 21 women with breast cancer resided in Bandung. Most of the women with breast cancer were breast cancer survivors who had completed their breast cancer treatment, and some of them were undergoing chemotherapy and radiotherapy treatments.

Five of the women with breast cancer did not use any medical cancer treatment to treat their breast cancer. Table 6 (p. 113) shows the demographic characteristics of the women with breast cancer who participated in this study.

Table 6: Demographic Characteristics of Women with Breast Cancer

No	Participant's pseudonyms	Age (years)	Stage of cancer	Level of education	Occupation
1	Rosi	49	III	High school	Housewife
2	Yuni	42	II	Primary school	Housewife
3	Yani	41	IV	Primary school	Housewife
4	Lia	43	IV	High school	Islam spiritual teacher
5	Ina	29	IV	High school	Canteen keeper
6	Riris	51	IIIB	High school	Housewife
7	Desi	59	I	High school	Retail shop owner
8	Widya	52	IIB	Bachelor degree	Restaurant owner
9	Asih	52	IV	High school	Cleaner
10	Lani	59	III	Primary school	Unemployed
11	Sumi	51	IV	Primary school	Unemployed
12	Wati	57	III	Primary school	Unemployed
13	Lina	42	II	Diploma	Housewife
14	Retno	64	III	Diploma	Housewife
15	Intan	52	III	Bachelor degree	Housewife
16	Anik	65	I	Diploma degree	Editor
17	Sari	23	III	Diploma	Casual teacher
18	Bunda	53	IIIA	Bachelor degree	Volunteer
19	Dini	38	II	Diploma degree	Housewife
20	Indah	49	IIIA	Bachelor degree	Wedding gallery owner
21	Encik	57	I	Bachelor degree	Volunteer

The other group of participants were CAM providers who provided CAM therapy for women with breast cancer in this study. Fourteen CAM providers contacted the researcher to confirm their interest in sharing their views about the use of CAM for breast cancer. However, four of the CAM providers cancelled their participation in this study due to their limited time. In total, 10 CAM providers participated in this study based on the inclusion criteria including current provision of CAM for breast cancer and willing to voluntarily participate in this study. Seven of the CAM providers practiced in Batam and the other three practiced in Bandung. The demographic characteristics of CAM providers are presented in Table 7 (p. 114) below.

Table 7: Demographic Characteristics of CAM Providers

No	Participants 'pseudonyms Age range 35-65	Education/ Qualification	Types of CAM practice	Length of Practice (Years)
1	Lim	High school	Acupressure Herbal therapy	3
2	Jamilah	High school	Cupping therapy Herbal therapy	10
3	Aris	High school	Cupping therapy Herbal therapy	15
4	Rangga	Primary school	Chinese herbal medicine	30
5	Riska	High school	Germanium stone therapy	8
6	Aji	Master degree	Detox therapy (bloodletting) Herbal therapy	5
7	Riko	Primary school	Chinese herbal medicine	15
8	Kinanti	High school	Herbal therapy	20
9	Dinah	Primary school	Massage and herbal therapy	23
10	Nanik	High school	Herbal therapy	10

4.3.6. The phenomenological Interview

The phenomenological interview method is used to explore and gather experiential material that will be used as a source for phenomenological reflection, and to develop a richer and deeper understanding of a human phenomenon (van Manen, 2016). Guerrero-Castaneda, Menezes, and Ojeda-Vargas (2017) stated that a phenomenological interview allows the researcher to meet the phenomenon that is being lived by a person who determines the characteristics of the phenomenon with their consciousness. Therefore, phenomenological in-depth interviews between the participants and the researcher were conducted in order to gather the sample of lived experience descriptions in the use of CAM for breast cancer management.

The selected participants from both groups of women with breast cancer and CAM providers were asked to read through and signed the consent form prior to the interviews (Appendix 7, p. 312). The researcher again explained to the participants that their privacy and

confidentiality would be maintained, as well that they were free to withdraw at any time from this study without any consequences as written in the consent form. The participants were given the opportunity to ask questions and address any uncertainties.

The face-to-face 45-to 60- minute in-depth interviews were recorded using a digital audio recorder. The researcher regularly ensured that the digital audio recorder functioned well before recording each interview. Additionally, a mobile phone voice recorder was also used as a recorder backup. The interviews were conducted in Bahasa, the official language in Indonesia, which the researcher and the participants used daily to communicate in. It was essential for the researcher to develop trust with the participants as the phenomenon that was being studied may explore sensitive matters (van Manen, 2016). In order to build trust, the researcher developed a relationship with the participants by sharing information using a friendly approach and used conversational language. van Manen (2016) also suggested that the researcher needs to be mentally prepared before starting the interviews to keep the phenomenological intent of the interview clearly in mind, and to try to obtain concrete stories of particular situations and events. These strategies helped the researcher to obtain productive interviews of experiential material.

The researcher developed a semi-structured open-ended questions schedule to guide the interviews. The interview questions ranged from general to specific questions. The general questions for women with breast cancer included their demographic data such as age, educational background, stage of breast cancer, length of time diagnosed with breast cancer and occupation. For the specific questions, the women with breast cancer were asked to share their experiences in the use of CAM and knowledge. For instance, ‘Could you tell me about your experience of using CAM?’, and ‘Could you tell me what is it like, or what it feels like to use CAM?’ Similarly, the interviews with the CAM providers commenced with a brief discussion about their demographic data including age, educational background, type of

CAM that they provide and the length of CAM practice. The CAM providers were specifically asked about their experiences and understandings of CAM for breast cancer management. For example, ‘Could you tell me your understandings about CAM for breast cancer management?’ Other prompts were used to further explore their experiences such as, ‘How did it make you feel?’, ‘Can you tell me what you mean by that?’ and ‘Can you tell me more about this aspect?’. Most of the interviews lasted approximately 60 minutes in duration. Four interviews with the women with breast cancer were more than 60 minutes in length due to the women with breast cancer requiring rest time. The researcher offered the participants breaks from the interview due to their health condition being impacted by chemotherapy side effects. Some women with breast cancer periodically interrupted their interviews but were happy to continue when they felt comfortable and relaxed. The researcher employed active listening skills during the interviews, repeated the last statement where necessary when the participants seemed to be blocked to stimulate their memories, and asked specific instances or examples for clarity.

The date, time and place for the interviews were chosen by the participants based on their preference and convenience. Most of the interviews with the women with breast cancer were undertaken in the living room of their house during the day. Similarly, the CAM providers preferred their house as the interview location as the house was connected with their practice facility. Some of the CAM providers invited the researcher to observe their clinics and instruments that they used to administer CAM therapy, as well as to witness how they provided CAM to their patients. A couple of interviews with women with breast cancer and CAM providers were conducted in informal settings such as coffee shops and cafes. Finally, the researcher thanked the participants for their contribution to the study and informed them to contact the researcher if they were willing to validate the accuracy of the transcripts. None of the participants contacted the researcher regarding transcription validation.

4.4. Thematic analysis

Thematic analysis is the process of recovering structures of meanings and themes that are embodied and dramatized in human experience presented in a text (Sundler, Lindberg, Nilsson, & Palmér, 2019). A theme refers to an element or matter that occurs frequently in the text (van Manen, 1990, 2016). Grasping and formulating a thematic understanding allows free of 'seeing' meaning rather than a rule-bound process (van Manen, 1990). In order to conduct the thematic analysis process, the recorded conversations between the researcher and the participants were transcribed and translated from Bahasa into English by the researcher who is bilingual in these languages.

Transcription was conducted to generate texts as the source of meaning of the phenomenon. Kiyimba et al. (2018) claimed that transcription is the first stage of analysis where the researcher can become familiar with the data. In this phenomenological study, the first analysis begun when the participants started to describe and make sense of their experiences. Transcriptions in this study were considered as the second stage of analysis. The researcher undertook the transcriptions herself in order to immerse herself in the data, although the transcription process was time consuming. However, an enormous amount of work was required to transcribe the interviews and was a challenge in this study. A total of 31 interviews with women with breast cancer and CAM providers were transcribed verbatim by the principal researcher. Each transcript of a 60-minute conversation took more than eight hours for the transcribing process and resulted in 15 to 30 pages being translated into English. The translation was undertaken by the researcher as she considered the translation process to be the third stage of analysis. The researcher obtained translation accuracy certification from the Social and Behavioural Research Ethics Committee, Flinders University to undertake the translations. Additionally, in order to maintain the accuracy of the translations, some of the transcriptions were translated and reviewed by two professional translators (Indonesian and Australian).

The thematic analysis was conducted using manual approaches such as isolating thematic statements and composing linguistic transformations as suggested by van Manen (1990). According to Sohn (2017) and van Manen (2016), qualitative data analysis software (NVivo) is considered to be an inappropriate tool for data analysis in phenomenological research. The reason given was that codifications, conceptual abstractions and empirical generalisations that are offered by the data analysis software could not produce adequate phenomenological understanding and insight (Sohn, 2017; van Manen, 2016). Conceptual abstraction cannot capture lived experiences that were going to be described (van Manen, 1990). In addition, the use of data analysis software may have prevented the researcher from being deeply immersed in the texts or from being-in-the world of the phenomena (Sohn, 2017). In this study, the lived of experiences of women with breast cancer and CAM providers' views were analysed to determine themes, or categorical statements, of experiential structures that made up the experiences.

4.4.1. Isolating thematic statements

Isolating thematic statements refers to the uncovering of thematic aspects from the lived experience descriptions (van Manen, 1990). van Manen's three approaches, such as the holistic reading approach, the selective reading approach, and the detailed reading approach, were applied to isolate thematic aspects or to identify themes of the lived experience descriptions (van Manen, 2016). According to van Manen (2016) these approaches assist in exploring insights and themes at the level of the whole story, at the level of each separate paragraph and at the level of each sentence, phrase, expression or single word. At the holistic reading level, the researcher read the transcripts as a whole to capture significant phenomenological meanings of the participants' lived experience in the use of CAM. An example of the application of the holistic reading approach, is as follows:

> *My family encourage me to use herbal therapy. I feel guilty if I don't follow their suggestion. My parents have sent the herbal therapy from far away. Why don't I use it? I use herbal therapy because of my family's desire. Every day my mother calls me, she asks me whether I have taken herbal therapy or not. Yeah, I know it's not easy for my family to get the herbal therapy. It takes time to order and send it from my village to here (Batam). It takes a few days (Ina, p. 13, line 374-392).*

An overall theme for the above experiential description was: 'A women used CAM with support from family'.

The next level of the thematic analysis was the selective reading. In the selective reading approach, each paragraph of the transcripts was re-read again several times to identify specific phrases or statements to reveal significant phenomenological meaning. The statements that seemed particularly essential were highlighted and extracted for the next level of analysis with the detailed reading. An example of the application of the selective reading approach on the text, is as follow:

> *My family encourage me to use herbal therapy. I feel guilty if I don't follow their suggestion. My parents have sent the herbal therapy from far away. Why don't I use it? I use herbal therapy because of my family's desire. Every day my mother calls me, she asks me whether I have taken herbal therapy or not. Yeah, I know it's not easy for my family to get the herbal therapy. It takes time to order and send it from my village to here (Batam). It takes a few days (Ina, p. 13, line 374-392).*

The highlighted sentences from the text above were deemed to be thematic of the experience of using CAM for breast cancer management: 'My family encourage me to use herbal therapy', 'I feel guilty if I don't follow their suggestion', and 'I use herbal therapy because of my family's desire'. The potential phenomenological meaning that was captured from the selected sentences was that the woman's family had a strong influence on the use of CAM.

The last level of the thematic analysis process was the detailed reading approach. In the detailed reading approach, the researcher read every single sentence and asked what the sentence revealed about the experience that was being described. An example of the application of the detailed reading approach, is as follows:

Sentence 1: My family encourage me to use herbal therapy.

Sentence 2: I feel guilty if I don't follow their suggestion.

Sentence 3: I use herbal therapy because of my family's desire

The researcher then reflected on what each sentence revealed about the experience of using CAM for breast cancer management. Sentence 1 showed that the use of CAM involved family. Sentences 2 and 3 indicated that the use of CAM was to respect her family's recommendations.

4.4.2. Composing linguistic transformations

Composing linguistic transformations is a creative hermeneutic process of writing notes and paragraphs on the basis of reading and other research activities (van Manen, 1990). This procedure is a part of research activities that capture the thematic statements of the identified themes in more phenomenologically sensitive paragraphs (van Manen, 1990). The themes that emerged through the thematic analysis process are only abstractions of the interpretive descriptions; thus, phenomenological reflective writing should be constructed (van Manen, 2016). In this study, the themes that emerged from the descriptions of the lived experiences of women with breast cancer and CAM providers' views descriptions were transformed into major themes and sub-themes, and were used for reflective writing and phenomenological interpretation.

4.4.3. Lifeworld existential concepts as guides to reflection

According to van Manen (1990), phenomenological research aims to explore the structure of the human lifeworld as experienced in everyday situations and relations. In his recent publication of *Phenomenology of Practice*, van Manen suggested that the existential methods are helpful in assisting with the exploration of aspects of meaning of the lifeworld, and of the particular phenomena that is being studied in a heuristic manner (van Manen, 2016). The existential methods are relationality (lived self-other),

corporeality (lived body), spatiality (lived space), temporality (lived time), and materiality (lived things) (van Manen, 2016). As universal themes of life, these five existentials belong to everyone's lifeworld and repeatedly occurs throughout the literature of phenomenology (van Manen, 2016). In this study, the five existential themes were used as a guide to reflect the structure of the women with breast cancer and CAM providers' themes of lifeworld on the use of CAM for breast cancer management.

4.4.3.1. Relationality – Lived Self-Other

The existential theme of relationality or lived self-other guides reflection of how the self and others are experienced with respect to the phenomenon that is being studied (van Manen, 2016). In this phenomenological research, the concept of relationality reflected how women with breast cancer and CAM providers experience connections or relationships with others in relation to the use of CAM. For example, women with breast cancer reported that they used CAM based on family' support, recommendations from relatives and friends, and their beliefs in God and spiritual leaders. In another example, CAM providers claimed that they provided CAM based on knowledge that was inherited by their ancestors. The relationships with God, family, ancestors, friends, and spiritual leaders experienced by women with breast cancer and CAM providers in relation to the use of CAM as mentioned in those examples were reflected as lived self-other.

4.4.3.2. Corporeality - Lived Body

van Manen (1990) stated that corporeality or the lived body is a phenomenological fact that we are bodily in the word. The corporeality or lived body concept guides the reflection to ask how the body is experienced with respect to the phenomenon that is being studied (van Manen, 2016). In this study, corporeality was used to reflect what the women with breast cancer and CAM providers physically felt and experienced in relation to the use of CAM for breast cancer management. For example, some of the women with breast cancer experienced negative sides from using CAM such as a sore throat, and vomiting,

and the benefits of CAM included analgesic effects and increased in physical strength from using CAM. Both the negative sides and the benefits from using CAM that women with breast cancer experienced were reflected through a lived body. None of the CAM providers had physical experience in relation to providing CAM for breast cancer management.

4.4.3.3. Spatiality – Lived Space

The concept of spatiality guides reflection in the investigation of how space was experienced with respect to the phenomenon that is being studied (van Manen, 2016). In this study, the concept of spatiality was used to reveal what women with breast cancer and CAM providers experienced about space in regard to the use of CAM. For example, travel distance to access medical treatment, the need for temporary accommodation, and financial constraints in the use of CAM for breast cancer management experienced by women with breast cancer and CAM providers were reflected by this researcher as lived space.

4.4.3.4. Temporality – Lived Time

van Manen (1990) stated that temporality or lived time is our temporal way of being in the world. The horizons of an individual's temporal existence are constituted by the dimension of past, present and future time (van Manen, 1990). Every person experiences time differently. As suggested by van Manen (2016), the existential theme of temporality is a possible guide to ask how time is experienced with the phenomenon. In this study, the concept of temporality guided the reflection of how time was experienced by women with breast cancer and CAM providers in relation to the use of CAM for breast cancer management. For example, the waiting time period in accessing medical treatment, and CAM response time toward breast cancer healing process were reflected as lived time.

4.4.3.5. Materiality – Lived Things

The fifth life existential concept is materiality or the lived thing. According to van Manen (2016), the existential theme of materiality could assist in reflection to ask how things are

experienced in relation to phenomena that are being studied. In everyday life, experience that related with a thing may contribute an essential meaning (van Manen, 2016). In this study, the theme of lived things reflected particular things that women with breast cancer and CAM providers experienced in relation to the use of CAM for breast cancer management. For example, the types of CAM that women with breast cancer used and CAM providers provided for breast cancer, instruments that CAM providers utilised to administer CAM, and sources of information that women with breast cancer used to search for information about CAM.

4.5. Writing phenomenological text

van Manen (2016) describes the vocative methods of writing that may assist within the phenomenological writing process. The vocative methods include the revocative (lived throughness), the evocative (nearness), the invocative (intensification), the convocative (pathic) and provocative. In this study, the vocative methods were applied to write the thematic analysis findings and to present the existential reflection discussion to the reader. Figure 5 (p.123) below shows the vocative methods applied in this phenomenological writing of women with breast cancer's experience in the use of CAM for breast cancer in Indonesia.

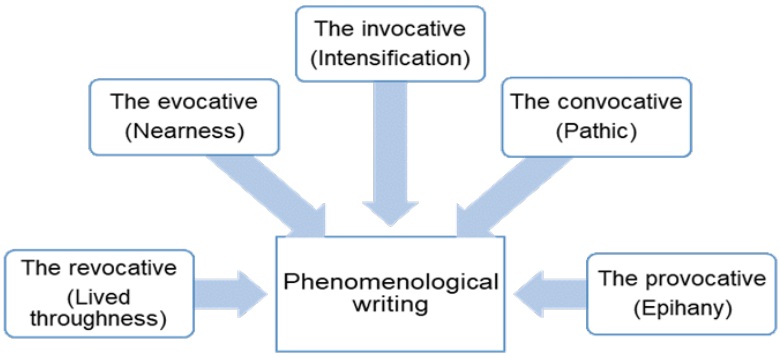


Figure 5: The vocative methods for phenomenological writing

The revocative or lived throughness method allows the quality of the text to bring an experience vividly into presence through the power of experiential anecdote, expressive narrative or qualitative imagery (van Manen, 2016). In this study, the researcher brought the women with breast cancer and CAM providers lived experiences in the use of CAM vividly into presence through the detailed written lived experience descriptions. The lived experience descriptions were written using the revocative method to bring the reader to sense the presence of the experience, closeness, propinquity or proximity in place or time of the phenomenon in this study.

The evocative method, or nearness, guides the texts to speak to the reader in an addressive manner, and it creates a sense of nearness and intimacy with the phenomenon (van Manen, 2016). The term of ‘evoke’ is derived from “evocare”, which means to call forth, to call out, to bring out, or to recreate imaginatively through word or image (van Manen, 2016). The evocative method brings experience vividly into presence for phenomenological reflection, and carries the thing into closeness and contact (van Manen, 2016). In this study, the language of evocative texts speaks to the reader, and induces a feeling of being in touch with the phenomenon of CAM use. A sense of nearness with the phenomenon of CAM use facilitates an understanding of what it is like to use CAM for breast cancer management by reflecting on the meaning that is inherent in texts of women with breast cancer’s lived experiences and CAM providers’ views.

The invocative method of writing allows the researcher to invoke the power of language to make words more intense, memorable and quotable so that the reader is able to experience the phenomenon (van Manen, 2016). In this phenomenological writing, the researcher was sensitive to the ways that words and expressions had a certain desirable intensity when they were composed with strong embedded meaning. In this study, invocative words of women with breast cancer’s lived experience and CAM providers’

views descriptions draw the reader into the experience, generating a strong feeling of the experience and creating an image of what it is like to experience the use of CAM for breast cancer management.

The convocative method of writing allows the texts that possess the em(pathic) power to appeal to the reader (van Manen, 2016). According to van Manen (2016), phatic linguistic devices tend to make phenomenological text more memorable, more worthy and more capable of memorisation. The vocative texts bring the reader to understand meaning embedded in the lived experience through an emotive rather than cognitive aspect (van Manen, 2016). In this study, the phatic words and expressions occurred in the discussion of the women with breast cancer and CAM providers' lifeworld existential reflections of relationality, corporeality, spatiality, temporality and materiality.

Another method of phenomenological writing is the provocative method. The aim of the provocative method of writing is to articulate the kind of ethical predicaments that are suggested in the phenomenon that is being studied, and what the active normative responses such as advice, policies, and tactful practices are (van Manen, 2016). This method allows the texts to have a provocative quality in which its deeper meaning may exercise and provoke a transformative effect to the reader (van Manen, 2016). In this study, the women with breast cancer and CAM providers' lived experience texts tended to provoke certain actions that may lead to improve healthcare services for breast cancer in Indonesia and maintain the quality-of-life for women with breast cancer. The provocative method was applied in writing the implications for the healthcare system, nursing practice, CAM education and research, policy maker, women with breast cancer and CAM providers as presented in Chapter Eight of this thesis.

Overall, the phenomenological writing process can be the most challenging dimension of the phenomenological inquiry process as espoused by van Manen (2016). It is a reflexive

activity that involves ones' total physical and mental being (van Manen, 1990). The researcher is the writer and the first reader to experience the presence of the experiential texts (van Manen, 2002, 2016). The application of the vocative writing methods, particularly the revocative (lived throughness) and the evocative (nearness), brought the researcher in this study to turn the women with breast cancer and CAM providers' lived experience descriptions into a life of her own. These methods allowed the researcher to capture a deeper sense of meaning embedded within the women with breast cancer and CAM providers lived experience description written texts. However, the researcher also physically and emotionally sensed the unpleasant feelings as experienced and reflected by the women with breast cancer in the texts. Writing a phenomenological text in this study enabled the researcher to leave the ordinary world and entered the participants' world to seek insight and understand meaning of their lived experiences regarding the use of CAM for breast cancer management.

4.6. Issues of rigour

Cypress (2017) defined rigour as the strength of the research design and the appropriateness of the method used to answer research question. It is critical to understand rigour in qualitative research, and it is the responsibility for qualitative researchers to ensure the rigour of a research study (Cypress, 2017). Rigour or trustworthiness equates to the concept of validity and reliability in quantitative research (Cypress, 2017; Krefting, 1991). Rigour describes the criteria of 'goodness' in qualitative research, and trustworthiness is considered as quality and authenticity of the findings of qualitative research (Connelly, 2016; Cypress, 2017; Emden & Sandelowski, 1998; Krefting, 1991).

Guba (1981) and Lincoln and Guba (1986) first introduced trustworthiness as a central concept to appraise the rigour of qualitative research. Their proposed framework considered four main aspects for assessing the trustworthiness. The four crucial aspects of

trustworthiness in qualitative research are credibility, transferability, dependability and confirmability (Connelly, 2016; Cypress, 2017; Emden & Sandelowski, 1998; Guba, 1981; Krefting, 1991; Schwandt, Lincoln, & Guba, 2007). Credibility refers to confidence in the truth of the findings of a study (Cypress, 2017; Guba, 1981). Transferability refers to the degree to which the findings can be applied in other settings or other groups (Connelly, 2016; Cypress, 2017; Guba, 1981; Lincoln & Guba, 1986). Dependability is the stability and consistency of the data overtime and conditions (Connelly, 2016; Cypress, 2017; Guba, 1981; Lincoln & Guba, 1986). Confirmability refers to the neutrality or the congruence of findings between two or more independent people (Connelly, 2016; Guba, 1981; Lincoln & Guba, 1986; Polit & Beck, 2011).

However, the notion of rigour in hermeneutic phenomenological research is different to other common qualitative studies (Cypress, 2017; De Witt & Ploeg, 2006; Errasti-Ibarrondo et al., 2018). In human science research, such as this hermeneutic phenomenology study, rigour is demonstrated through a uniqueness of strong moral and spirited sense of the study (De Witt & Ploeg, 2006). Unlike, other qualitative studies that commonly establish validity and reliability through ensuring trustworthiness, van Manen (2016) claims that the validity of a phenomenological study has to be achieved in the appraisal of the originality of insight and soundness of the interpretive process demonstrated in the study. He suggested that a high-quality phenomenological text cannot be summarised, and the phenomenological quality of the text must be evaluated by meeting with it, going through it, encountering it, consuming and being consumed by it (van Manen, 2016).

van Manen (2016) identifies seven criteria to appraise phenomenological research as listed below:

1. **Heuristic questioning**: Does the text induce a sense of contemplative wonder and attentiveness?

2. **Descriptive richness**: Does the text contain rich and recognisable experiential material?
3. **Interpretive depth**: Does the text offer reflective insights that go beyond the taken-for-granted understandings of everyday life?
4. **Distinctive rigour**: Does the text remain constantly guided by a self-critical question of distinct meaning of the phenomenology or event?
5. **Strong and addressive meaning**: Does the text "speak" to and address our sense of embodied meaning?
6. **Experiential awakening**: Does the text awaken prereflective or primal experience though vocative and presentative language?
7. **Inceptual epiphany:** Does the study offer us the possibility of deeper and original insight, and perhaps an intuitive or inspirited grasp of the ethics and ethos of life commitments and practices?

The hermeneutic phenomenological research evaluation criteria above were addressed using the four terms of the expressions of rigours framework proposed by De Witt and Ploeg (2006). The expressions of rigours framework was developed based on van Manen's ideas, the theoretical interpretive phenomenological nursing literature, and Madison's criteria of rigour for hermeneutic phenomenology (De Witt & Ploeg, 2006). According to this framework, the expressions of rigour for hermeneutic phenomenological research are balanced integration, openness, concreteness, and resonance (De Witt & Ploeg, 2006). These four expressions of rigour that describe the quality of the hermeneutic phenomenological text in this research are discussed in detail in the next section.

4.6.1. Balance integration

Balance integration refers to the response to identify weaknesses of hermeneutic phenomenological research text (De Witt & Ploeg, 2006). In this study context, balance integration was expressed by three criteria. The first characteristic was to articulate if the general philosophical theme was suitable for the researcher and the research topic. For example, the topic of this study was to understand women with breast cancer's lived experiences and CAM providers' views in the use of CAM for breast cancer management. The principal researcher is a tertiary educated registered nurse (in Indonesia) who has post-graduate academic qualifications and skills to conduct scientific research related to healthcare including the exploration of the lived experiences of women with breast cancer and CAM providers' views in the use of CAM for breast cancer management. The philosophy that underpinned this research was hermeneutic phenomenology where this methodology was considered to be the most appropriate methodology to answer the research question.

The second characteristic of balance integration is in-depth intertwining of philosophical concepts within the study's methods and findings (De Witt & Ploeg, 2006). This characteristic was demonstrated by the use of the in-depth interview method to gather the lived experiences of women with breast cancer and CAM providers' views in this study. The findings of the study have been revealed through thematic analysis and existentials reflection as suggested by van Manen's phenomenological framework.

The third characteristic is a balance between the voice of study participants and philosophical explanation (De Witt & Ploeg, 2006). This characteristic refers to the description and interpretation of the lived experiences of women with breast cancer and CAM providers' views based on the philosophical underpinning of this study.

4.6.2. Openness

Openness is the second expression of rigour in this hermeneutic phenomenological research. van Manen (2016) claims that a certain openness is required in the writing and reading of a phenomenological text, and the measure of the openness needs to grasp and express something and also measure its deep nature. Openness as a rigour in this study was established by explicating the researcher's preunderstanding and assumptions about the use of CAM for breast cancer management. This approach allowed the phenomenological text to speak as it is lived through, and made known prejudice on the phenomenon that was being study.

4.6.3. Concreteness

Concreteness means that the hermeneutic phenomenological text concretely situates readers to the context of lived experience that is being studied, and also connects with experience in their lifeworld (van Manen, 2016). In this study, concreteness was established by writing the phenomenological text with the revocative method or lived thoroughness. This method allowed the researcher to bring experiences vividly into the presence through the power of expressive narrative. The phenomenological text of this study was written with rich description using vocative language, to bring readers closer to the lived experiences of women with breast cancer and CAM providers' views in the use of CAM for breast cancer management as provided in Chapters Five and Six.

4.6.4. Resonance

Resonance is the fourth proposed expression of rigour in this hermeneutic phenomenological research. This expression embraces the experiential or felt effect of reading the phenomenological text (De Witt & Ploeg, 2006). van Manen (2016) described this effect epiphany or the sudden perception or intuitive grasp of the life meaning of thing of reading the phenomenological text. Resonance in this phenomenological research refers to writing a strong vocative text-particularly the findings-in a way that is

easy to understand by readers. This facilitated an experiential effect for the readers, allowing for the grasping of meaning of something, and the potential to provoke actions from reading the phenomenological text of women with breast cancer's lived experiences and CAM providers' views in the use of CAM for breast cancer management as presented in the following Chapter Five and Chapter Six.

4.7. Chapter summary

This chapter has provided an overview of the research activities based on van Manen's hermeneutic phenomenological framework, in order to gather the examples of women with breast cancer's lived experiences and CAM providers' views in the use of CAM for breast cancer management in Indonesia. The research activities began with the explication of the researcher's preunderstanding about the use of CAM for breast cancer management, followed by presenting the data collection methods of the lived experience examples process. The processes for gathering examples of lived experience included ethics applications, determination of research settings, recruitment of the participants and the interview process. The processes for gathering lived experience examples obtained by interview were explained. This was followed on by an explanation of how the obtained lived experiences were written into phenomenological text for interpretation. Finally, this chapter concluded with an explanation of how the rigour of this hermeneutic phenomenological research was considered and applied. Examples of the lived experience of women with breast cancer in the use of CAM for breast cancer management are provided in the following Chapter Five of this thesis. Chapter Six of this thesis presents examples of CAM providers' views in providing CAM for breast cancer management in Indonesia. A discussion of the lived experiences of women with breast cancer and CAM providers' views are presented in Chapter Seven. The final chapter of this thesis, Chapter Eight, concludes this study and provides implications from

this study for healthcare systems, nursing practice, CAM education and further research, policy makers, CAM providers and women with breast cancer in Indonesia.

CHAPTER FIVE: FINDINGS (PART 1)
THE LIVED EXPERIENCES OF WOMEN WITH BREAST CANCER

5.1. Introduction

The previous chapter presented the methodology and methods that underpinned the exploration of the lived experiences of women with breast cancer and CAM providers' views in the use of CAM for breast cancer management in Indonesia. Details of the data collection and the process of thematic analysis were also presented in the previous chapter. The thematic analysis results will be presented in two findings chapters. This chapter focuses on the findings to the research question: 'What are women with breast cancer's experiences in the use of CAM for breast cancer management in Indonesia?'. The following findings chapter (Chapter Six) will report CAM providers' views in providing treatment for women with breast cancer in Indonesia.

Four main themes and 13 sub-themes emerged from the data analysis of the lived experiences of women with breast cancer. The first main theme identified was '*Access, affordability and support to medical treatment*'. The sub-themes of the first major theme were '*Limited access and financial constraints*', '*Lack of knowledge and awareness about breast cancer*', '*Fear of medical treatment'*, and '*Family influences*'. The second major theme was '*Beliefs in CAM treatment*' and the sub-themes were '*Unfounded beliefs*' and '*Believing in CAM based on religion and personal experience*'. The third main theme was '*Feeling the potential benefits of CAM*'. The third main theme has four sub-themes: '*Pain relief*', '*Increase physical strength and immune system*', '*CAM is safer and more affordable than medical treatment*' and '*Cancer prevention'*. The fourth main theme of women with breast cancer's lived experiences in the use of CAM was '*Acknowledging the negative aspects of CAM*', and

the sub-themes were '*Potential toxicity and unpleasant taste*', '*The futility of CAM'*, and '*Doubting the safety and legality of CAM*'. The detail of each main theme and sub-themes that emerged from the lived experiences of women with breast cancer in the use of CAM for breast cancer management is presented in the following sections.

5.2. Theme 1: Access, affordability and support for medical treatment

This main theme describes the participants' experiences in accessing medical treatment for breast cancer. Access refers to obtaining cancer medical treatment. Affordability relates to the women with breast cancer's ability to pay for medical treatment costs, and other expenses related to their breast cancer treatment. Support refers to any encouragement provided to use CAM that women with breast cancer received. Lack of access, an inability to pay for medical treatment, and family influences were identified as factors that delayed or prohibited the women with breast cancer's access to medical cancer treatment. These factors contributed to the women with breast cancer opting for CAM therapies for their primary breast cancer management rather than medical treatment. The details of each of the factors will be explained under four sub-themes. The sub-themes include: having limited access and finances, a lack of knowledge and awareness about breast cancer, fear of medical treatment and family influences.

5.2.1. Limited access and financial constraints

Limited access and financial constraints were identified as factors commonly identified by the women with breast cancer in regard to accessing medical treatment, particularly those who lived in remote areas. Many of the women with breast cancer stated that distance and costs had an effect on their ability to access medical treatment, particularly those who resided in rural and remote areas. They were aware that the cancer medical treatment facility had recently been established a few years prior. However, many of these women had been diagnosed with breast cancer a considerable time prior to the cancer facility being

established. Consequently, some of the women with breast cancer in rural settings travelled to nearby countries such as Singapore and Malaysia for surgery and chemotherapy. In terms of finances and time, medical treatment in Johor, Malaysia and Singapore, as identified by the participants, was more affordable and accessible compared to medical cancer treatment in Jakarta, Indonesia. There were only two of the women with breast cancer who could afford medical treatment overseas. The rest of the women with breast cancer in this region had to use CAM as an alternative medicine for breast cancer management. The following excerpts describe the limited access to medical cancer treatment in the remote area of Batam.

> *The doctor said I must immediately seek cancer treatment in Jakarta or wherever since there was no medical cancer treatment available in Batam. I was very confused. Finally, I went to Johor, Malaysia. (Widya, participant 8, woman with breast cancer, Batam, p. 5)*

> *Cancer treatment in Singapore was very expensive. Then I met a friend in Batam, she was a breast cancer survivor as well. We had a conversation and I asked where she obtained breast cancer treatment. She said she had breast cancer treatment in Malaysia. Finally, I had treatment in Malaysia together with her. We mostly had chemotherapy and radiotherapy together…The breast cancer treatment in Malaysia was cheaper than in Singapore and Jakarta. That's why I decided to have medical treatment in Malaysia. (Desi, participant 7, woman with breast cancer, Batam, p.3 & 4)*

In contrast, seven of the 10 participants who lived in a remote location could not access cancer medical treatment in other cities or overseas due to financial constraints. According to the demographic data, the majority of the women with breast cancer in this study had no personal income, because they were unemployed due to their breast cancer condition. The women with breast cancer stated they relied on their family's support for their medical treatment. However, the financial support from their family was very limited. While living away from home for medical treatment, the women claimed the financial support was insufficient to cover medical treatment costs, other related expenses, travel costs to other cities or overseas, as well as accommodation and meal expenses. Thus, financial constraints led the women with breast cancer to utilise CAM as their primary treatment for breast cancer management.

Some of the participants utilised alternative medicine for more than ten years, due to their inability to afford medical treatment in other cities or overseas. Despite the recent availability of cancer medical treatment in the region and healthcare support for those on lower incomes, the women with breast cancer used alternative medicine because they could not afford the additional related medical treatment expenses. As mentioned by the participants, they needed a companion such as their husband or another family member to travel with them. This companion would require meals, travel and accommodation expenses, resulting in additional expenses. Consequently, the custom of a family member or relative companion while in hospital was a factor to be considered when making decisions for medical treatment. Additionally, the poor women with breast cancer from the remote area had to travel from their village to a public hospital, located in the capital city. Traveling to this hospital was unavoidable as healthcare support from the Indonesian government was only available at general referral public hospitals in metropolitan areas. Despite the free cancer medical treatment, the women with breast cancer had to spend money on travel, accommodation and meals during the treatment and this proved to be expensive as stated below.

> *I didn't want chemotherapy … If I had chemotherapy, where would I get the money from...? Chemotherapy is free, but while I was in hospital, I would need extra money to buy food for my kids. Then I would need my husband to accompany me in hospital. The only family I have is my husband. If he accompanied me in hospital, who will work for us? My kids are still studying. My husband only works as a labourer, building construction labourer. So, I don't want chemotherapy because of my financial situation. (Asih, participant 9, woman with breast cancer, Batam, p.7)*

> *I couldn't seek treatment in a private hospital because I have no money. Now I am grateful to have healthcare support from the government. But sometimes I couldn't afford travel expense to come here (hospital). The travel expense from my village to get here for two years of treatment is not little. That's why I always come only by myself to reduce the travel, accommodation and meal expenses. (Wati, participant 12, woman with breast cancer, Bandung, p. 8)*

Participants found that medical cancer treatment was expensive. Poor living conditions meant the women with breast cancer were unable to afford the costs of the medical treatment and other additional expenses. Accordingly, they used CAM as an alternative

medicine temporarily, until they had enough money to cover the medical cancer treatment costs. One of the participants stated:

> *Women seek alternative treatment for many reasons. The first reason is financial problems. The medical treatment effect is instant but at that time, I had not enough money to afford it. I needed to prepare money for my medical expense and living cost during the treatment… While I was saving money for medical treatment, I had to take action to reduce the pain… I used an alternative treatment because I did not have enough money and was not ready to undergo medical treatment. So, for me, an alternative treatment is a substitute therapy while waiting for medical treatment. (Lina, participant 13, woman with breast cancer, Bandung, p. 4, 5 & 8)*

> *…due to financial limitation, I manage the pain by consuming white turmeric, soursop leaves and ants plant extract. (Sari, participant 17, woman with breast cancer, Bandung, p. 3)*

The excerpts above highlights the financial constraints that compelled the women with breast cancer to choose CAM as their primary breast cancer management. The high cost of medical cancer treatment, expenses associated with an accompanying person and the travel distance to the hospital were the main issues affecting women with breast cancer's inability to access medical cancer treatment.

The women with breast cancer mentioned that the waiting period for access to medical cancer treatment at the general public hospital was lengthy. Although West Java is the most populous province in Indonesia and the majority of people with cancer live in this province, access to cancer treatment was limited. Therefore, because of long waiting lists, the women with breast cancer sought and used alternative medicine rather than not having any treatment whilst waiting for access to medical cancer treatment, as highlighted in the excerpt below:

> *The waiting list in hospital also took time…I was nearly giving up because I didn't get a chemotherapy schedule for a long time. I was nearly giving up. It was very difficult to get a chemotherapy schedule as the waiting list was very long. After chemotherapy, I had to wait two months for a radiotherapy schedule, so that I used herbal therapy while waiting for it. (Sumi, participant 11, woman with breast cancer, Bandung, p. 6 & 7)*

The excerpt above indicated that the use of CAM was associated with limited medical cancer treatment facilities in the region which resulted in prolonged waiting durations for access to

medical treatment. In turn this compelled the women with breast cancer to use CAM for breast cancer management.

This sub-theme has provided evidence of limited access to cancer treatment, and the inability to afford medical costs and other related expenses, as well as how long waiting lists had a direct impact on women with breast cancer's use of CAM as this treatment was more accessible and affordable than medical treatment. In addition to limited access, financial constraints and long waiting lists, a lack of knowledge and awareness about breast cancer, medical treatment and CAM therapies were identified as other factors that prevented women with breast cancer from accessing medical treatment, encouraging them to use CAM therapies.

5.2.2. Lack of knowledge and awareness about breast cancer

This sub-theme demonstrates how insufficient knowledge of breast cancer and its treatment could significantly prevent women with breast cancer from accessing medical treatment. The women with breast cancer believed that a breast tumour could become more aggressive if it was treated by invasive medical treatments such as surgery. The women with breast cancer believed this medical procedure would stimulate the cancer root causing the cancer cells to grow faster. One of the participants mentioned that breast cancer cells had genders. If the gender was male, it meant that the cell was benign and could be removed. In contrast, if the breast cancer cell was female, it meant that the cancer cell was aggressive and could not be removed, as it would cause the cancer cells to grow faster and spread into other organs. This understanding led some of the women with breast cancer to avoid medical treatment and to choose CAM instead. Samples of the participants' misconceptions about breast cancer and medical treatment are described in the following excerpts.

> *There are two types of cancer cells - there is male and there is female. If the cancer cell is male, there won't be any problems with the surgery…The male cells aren't as aggressive as the female one. (Yani, participant 3, woman with breast cancer, Batam, p.1 & 2)*

> *Cancer is like a tree. If we pruned a tree, the roots would grow stronger. Similarly, if we trimmed a plantation or flower, the branches and leaves will be growing faster. I don't want my cancer to grow and get bigger. (Lia, participant 4, woman with breast cancer, Batam, p. 2)*
>
> *I believe that when the cancer is touched by a blade, the cancer cell will be growing fast and spreading. (Indah, participant 20, woman with breast cancer, Bandung, p.6).*

Unfounded beliefs and limited knowledge about breast cancer had a significant impact on the use of CAM for breast cancer management. The women with breast cancer selected CAM instead of medical cancer treatment because they had no clear understanding about breast cancer or its treatment, nor about CAM therapies.

Many of the women with breast cancer reported that they were unfamiliar with early breast cancer detection and screening such as mammography and breast self-examination (BSE). Three of the participants admitted they lacked knowledge of BSE and failed to identify abnormalities in their breasts because they performed BSE incorrectly. The unfamiliarity with breast abnormalities led to the inability of women with breast cancer to recognise early breast cancer symptoms. One of the participants claimed:

> *I didn't understand how to do breast self-examination. When I slept face down side, I felt something fid breast but there was not anything I slept on. Finally, I spoke to my mom. I asked her what happened to my breast. (Sari, participant 17, woman with breast cancer Bandung, p. 1)*

The women with breast cancer's lived experiences indicated their lack of knowledge about breast cancer and its early detection, led them to ignore early breast cancer symptoms. Many of the women with breast cancer assumed that their breast abnormalities were symptoms of general disease, which caused delays in further breast examination.

Four of the participants ignored or were not concerned about the severity of their early breast cancer symptoms. Instead of seeking medical examination, the women with breast cancer treated their symptoms with CAM therapies such as massage therapy, herbal potions or by applying ointment onto their breasts. By the time they sought a medical examination and

treatment, the breast cancer was at an advanced stage as two participants stated in the following:

> *Before my lump got bigger, I had felt a light sharp pain in my breast, but I just ignored it. I thought it would go by itself. Most elderly said a breast lump is only gas that stuck in the breast, so that I was not concerned about this. Then when I was too tired of doing my daily activities, I had a fever and the lump got bigger. Finally, I went to hospital to check the lump. Doctors in two hospital said it was only a mammary gland inflammation, but it ended up being breast cancer. (Yuni, participant 2, woman with breast cancer, Batam, p. 9)*

> *The nipple discharged a very little amount of white fluid like breast milk. I cleaned it but after three days, it came again. Sometimes it was like a crust. I removed the crust and it caused a stinging pain. The doctor said it was a breast cancer symptom. I thought it wasn't early breast cancer symptom. But I did not care and was not concerned about it until a malignant tumour occurred. The doctor said to me "You come to me when you are dying" … The doctor asked me why I came to see him after the lump ruptured and worst. The lump was actively festering. (Ina, participant 5, woman with breast cancer, Batam, p.11)*

The apparent lack of knowledge and awareness regarding breast cancer and treatment, as well as CAM therapies, resulted in the women with breast cancer becoming less discerning when selecting appropriate treatments, with most of the women with breast cancer in this study assuming that their breast cancer symptoms could be naturally treated by using CAM. Therefore, CAM was selected as their first treatment option to cure their breast cancer symptoms, even though the majority of women with breast cancer confessed they had no clear understanding of the CAM that they used. An example of one of participants who identified the risk of CAM is presented below.

> *I don't know exactly what the plant was. It was dried plant roots that I have to boil with water then drink the extract. He [the sinshe] also gave me herbal capsules. Surely, I had herbal treatment from five different shinses…What I remember, the sinshes gave me herbal capsules which I didn't exactly know what that the capsule was filled with. One of the sinshe gave me a lot of dried plant roots… In my experience, the sinshe given me a lot of plant roots, which I had no idea what plant it was. But because I desired to get cure, I just trusted it. I surely didn't know about the roots and whether it could stimulate the cancer cells growing or spreading into other organs. It was surely risky. (Widya, participant 8, woman with breast cancer, Batam, p. 3 & 8).*

The excerpt above exemplifies that there was no consideration given by the women with breast cancer towards the efficacy and safety of CAM prior to using it. The women were unaware of the actual efficacy of herbal therapy as a treatment for breast cancer and the

possible toxic effects. The CAM treatments were hastily used to achieve a perceived immediate cure of symptoms.

Overall, lack of knowledge and awareness toward breast cancer and medical treatments, as well as limited understanding about breast self-examination, and CAM therapies, led to delayed medical treatment or no medical treatment for these women with breast cancer. This meant that the cancer progressed to an advanced stage where there was fear of medical treatment.

5.2.3. Fear of medical treatment

The majority of the women with breast cancer expressed fear or suspicion of medical cancer treatments particularly surgery and chemotherapy. Feelings of fear developed as a result of women with breast cancer hearing testimonies from other people who had negative experiences of using medical cancer treatment. Many of the women with breast cancer expressed their fear towards the side effects of medical treatment, as they had witnessed family members, friends and other women die following surgery. These negatives experiences led the women with breast cancer to refuse or delay surgery. They preferred using alternative medicines instead of seeking medical treatment, as they believed that alternative medicine could shrink their breast tumour naturally. The following excerpts demonstrate the decision of women with breast cancer to use herbal therapy due to being fearful of medical treatment:

> *I used herbal therapy because I was afraid of medical treatment effects. Therefore, I trusted alternative treatment. It's because I heard what people said about the side effects of medical treatment …I chose alternative therapy as my first cancer treatment option because I was afraid of myths related to breast cancer. It is said that the tumour can become more aggressive it is touched by a surgical blade. It can attack the other organs. Therefore, it is important to shrink the tumour until it naturally disappears. Do not awake the sleeping lion up. (Widya, participant 8, woman with breast cancer, Batam, p. 4 & 8)*

> *I was afraid of surgery because many of my close friends died not long after they had breast tumour removal surgery. I became really paranoid. Even my best friend's mother and sister passed away of breast cancer in three months…The professor suggested to have surgery, but I was still afraid. I remembered, I had a friend whose breast lump disappeared by an using alternative treatment. I tried the alternative treatment that she*

used. I was given ginger therapy. Grated ginger was tapped onto my breast. (Lina, participant 13, woman with breast cancer, Bandung, p. 2)

The negative feelings and fear emerged because the women with breast cancer had heard about unsuccessful medical treatment from other people. The participants' lived experiences demonstrated that they were more afraid of the surgery than the breast cancer progressing into advanced stages.

Another frightening medical cancer treatment for the women with breast cancer in this study was chemotherapy. Six of the 21 women with breast cancer in this study only used CAM as a single therapy for breast cancer management as they were afraid of chemotherapy. The women with breast cancer indicated they were concerned about the side effects of chemotherapy more than the effectiveness of the treatment. According to the interview data, the women with breast cancer often received frightening information and negative testimonies from other people who had undergone chemotherapy. Some participants described how people around them with cancer suffered and died due to the side effects of chemotherapy. This caused them to be afraid and, resulted in them postponing their chemotherapy or refusing to have it as the following excerpts highlight:

Medical treatment including surgery, chemotherapy and radiotherapy must have side effects… I heard from women who have had chemo and radiotherapy, the side effects are hair loss, burnt skin, and nails colour becoming dark. I used alternative therapy. I did not experience those effects. My hair, skin and nails were fine. No side effects at all… What? Chemotherapy? I am not sure about chemotherapy. I don't know why. I have seen many people around me die of chemotherapy. One of my sisters had cancer. She had chemotherapy for one year then she died. I also heard one of our community members passed away due to chemotherapy she had for breast cancer... It seems that all medical treatments that she had were not helpful …I have never heard people died because of using alternative therapy for breast cancer. In contrast, I know many people passed away after using medical treatment. That makes me scared. I am not brave enough to use medical treatment, that's why I chose alternative medicine (Lia, participant 4, woman with breast cance,r Batam, p. 9 & 11)

Actually, I should have chemotherapy and radiotherapy, but I said, "I don't want chemotherapy. I am afraid of it." The doctor couldn't force me …My friends who refused chemotherapy live longer than those who underwent chemotherapy. They can eat normally. But those who had chemotherapy, they couldn't eat due to mouth ulcers and vomit. Chemotherapy reaction is very hot. It is administered into the body to kill cancer cells. But the healthy cells also get destroyed. Like one of friends, her nails were off, and the hands' skin got burnt. She looks older than her age…. But if the age is over than 60

years old, it is better to not have chemotherapy. I think if I have chemotherapy I will die and if I do not have chemotherapy I will die as well. So then I prefer not to have chemotherapy rather than suffering from its side effects, like my friend's experienced from the cancer support group. Having chemotherapy or not, I will surely die so I am better enjoying my life without medical treatmen.t (Anik, participant 16, woman with breast cancer, Bandung, p. 4, 7& 8)

The participants clearly indicated fear towards the adverse effects of chemotherapy refusing treatment and opting for alternative medicine instead. According to the participants who chose this, CAM had no harmful side effects and could not cause immediate death. They expected CAM could increase their lifespan and prevent suffering from the negative effects of medical cancer treatment. The lack of information about any advantages of chemotherapy hindered women with breast cancer from accessing medical treatment.

The majority of women with breast cancer in this study revealed they continued using CAM, after or along with their medical treatment. However, the use of CAM was kept hidden from healthcare professionals as the participants did not want to stop it. Consequently, some of the women with breast cancer independently combined CAM and medical treatment against the advice of their healthcare professionals. Some of the women with breast cancer secretly consumed herbal potions whilst having chemotherapy treatment in hospital, and often misled their doctor about their chemotherapy, and alternative treatment use as explained in the following statements:

I didn't tell the doctor that I used herbal therapy. I couldn't do it. The doctor would be disappointed at me because I used both his treatment and herbal therapy. So, the doctor didn't know about it. I brought the herbal potion and drank it in the hospital while undergoing chemotherapy. The doctor didn't know and didn't ask about it. He never asked me what treatment that I have used before I sought medical treatment… I didn't tell the doctor about the herbal therapy. I didn't speak to the doctor because I was afraid and I didn't feel confident. (Lani, participant 10, woman with breast cancer, Batam, p. 5).

I kept going to a doctor at the hospital, but I didn't tell him that I stopped taking the hormonal medicine which have been given to me. The doctor gave me hormonal medicine, but I didn't report that I have discontinued taking it. I didn't tell the doctor that I used an alternative treatment instead…I did the breathing exercise and prayed. I believe those are my medicines. After four months, I went back for a medical check-up to the same doctor as the doctor suggested having eight cycles of chemotherapy, every two-three weeks, so I counted when my appointment schedule to see him was. Then the doctor asked me, 'Where did you have your chemotherapy? Was it in the general public hospital?' I answered, 'No doctor, I had chemotherapy in America'. I didn't have the

confidence to speak up to the doctor that I use an herbal potion as a chemotherapy. (Bunda, participant 18, woman with breast cancer, Bandung, p. 5 & 6).

Furthermore, the participants expressed that they did not discuss the use of CAM with health professionals because they were never asked about it and were reluctant to initiate any discussion as exemplified in the following excerpt:

Apparently, the doctor did not know that I drank an herbal potion while I was having chemotherapy because I didn't speak to him about it. The doctor didn't ask what therapy that I used either … I didn't speak to nurses that I drank an herbal potion. The nurses didn't ask me either, so I didn't tell them. (Intan, participant 15, woman with breast cancer Bandung, p.4)

Fear of disclosing the use of CAM to health professionals indicated the women with breast cancer lacked confidence and trust in the health professionals which led to their use of CAM being hidden whilst undergoing medical cancer treatment. Hiding the use of CAM from health professionals meant the women with breast cancer were unaware of any potential harmful interactions that may occur from the use of CAM, when combined with medical treatment.

This sub-theme represented evidence of fear of medical treatment as one of the many reasons why women with breast cancer were inclined to use CAM for breast cancer management rather than medical treatment. This fear was influenced by others who had experienced negative effects from medical treatment. Hiding the use of CAM from healthcare professionals indicated the women with breast cancer were unaware of potential negative effects of CAM that could interfere with chemotherapy efficacy, and worsen their health condition. Aside from a fear of medical treatment, support from and influences of family members were strongly related to whether the women with breast cancer used CAM for breast cancer management.

5.2.4. Family influences

Family influence was identified as another factor that deterred women with breast cancer from accessing medical treatment. The women with breast cancer stated family members

were more supportive of the use of CAM than the use of medical treatment. In this study, family influence refers to both advice and financial aid that women with breast cancer received from their husband, parents, children or siblings.

A woman's husband was identified as the family member who played the most important role in the determination of which breast cancer treatment the women with breast cancer would use. Almost all of the participants in this study claimed they used CAM based on their husband's suggestion. Some of the women with breast cancer stated that they refused surgery because their husbands disagreed with the breast tumour removal surgery. How the women with breast cancer's husbands influenced the use of CAM for breast cancer management is demonstrated in the following excerpts.

> *…my husband and I read articles about Chinese traditional herbal medicine for cancer from the internet. My husband offered for me to try a Chinese herbal medicine for cancer in another city. There is a clinic that provides Chinese treatment for cancer without chemotherapy and surgery…Then I discussed it with my husband. My husband suggested that I use his treatment immediately. Then I underwent cancer treatment in that clinic. (Indah, participant 20, woman with breast cancer, Bandung, p.2)*

> *My husband stated, 'Don't go for surgery straight away'. He suggested to pray first, to request Allah shows the best treatment option. My husband disagreed with the tumour removal surgery even though I was ready for it. But I had to respect my husband's decision and I had to get his permission for the surgery. I asked my husband why he disagreed if I have surgery. Whether he was afraid of what I would become because I lost my breast? Actually, he was not afraid of it. But he would agree, if the surgery is the only way treatment that I should have. My husband said, 'We are not searching for other treatment options'. I became uncertain to have surgery due to my husband's disagreement… My family supported me in making the decision to use alternative treatment. (Bunda, participant 18, woman with breast cancer Bandung, p. 3).*

Influences from other family members, including parents and siblings also significantly contributed to the use of CAM for breast cancer treatment. Sometimes family members supported the women with breast cancer by giving them recommendations based on testimonies from other people who had used CAM. These recommendations and testimonies influenced the treatment options the women with breast cancer chose. As mentioned by some participants, their parents or sister provided CAM therapies for them. The relatives encouraged the women with breast cancer to consume CAM and stated CAM

would have positive outcomes. The excerpts below indicated how relatives influenced the women with breast cancer to use CAM.

> *My parents sent benalu kopi [loranthus] from Samosir my village to Medan (the capital city of North Sumatra), then from Medan to Batam. I didn't pay anything for it. My mother gave money to my uncle who use benalu kopi (loranthus) to get benalu kopi for me from the forest in the village. Sometimes she gave IDR 20.000 (AUD $2.00) to my uncle for a big shopping bag of benalu kopi [loranthus]…Honestly, I use herbal therapy because my mother sent it to me. I am appreciating her effort to support me. I would not feel not good if I didn't use it…My sister recommended I drink moral berry leaf extract. She knows someone who has recovered from cancer by taking moral berry leaf extract. So, I had drunk moral berry leaves before I drink benalu kopi [loranthus] extract (Ina, participant 5, woman with breast cancer, Batam, p. 4 & 8).*

> *…The oncologist said that I need to have surgery [biopsy] to take a sample of the tissue for pathology analysis. The sample will be sent to Jakarta. I said 'Yes. I agree'. But then my sister rang me. She encouraged me to refuse biopsy... Come on, discharge from the hospital" …She gave me several herbal therapy products… (Lia, participant 4, woman with breast cancer, Batam, p.2 & 3).*

Overall, family influences deterred these women with breast cancer from accessing medical treatment, with the participants choosing to use CAM over medical treatment based on the influences of their family members. This meant the women with breast cancer were very dependent on their families for support and lacked confidence in making decisions about medical treatment. The participants also obeyed family's expectations of showing respect and appreciation of their support.

In summary, this first main theme of access, affordability and influences on the use of CAM over medical treatment by women with breast cancer included a number of factors. A lack of available cancer treatment facilities and the prohibitive cost of medical treatment, as well as lengthy waiting times, all influenced the women with breast cancer's access to and preference for CAM treatments. The access to medical treatment facilities was also limited by travel distance, which caused additional travel and accommodation expenses. These issues compelled the women with breast cancer to use CAM as their primary breast cancer treatment, particularly women with breast cancer in rural areas. According to the participants, CAM was more accessible and affordable compared to medical treatments. In addition, a lack of knowledge and awareness about breast cancer, fear and sceptical

attitudes towards medical treatment, as well as family influences also played a vital role in the use of CAM over medical treatment. The women with breast cancer's belief in CAM is presented as the next main theme.

5.3. Theme 2: Beliefs in CAM treatment

The second main theme of beliefs in CAM treatment described the faith or trust in the use of non-evidence-based CAM treatment. Having belief in CAM treatment was identified as one of the most common reasons why these participants used CAM. The analysis indicated beliefs in CAM were constructed by recommendations to women with breast cancer from communities, friends, acquaintances, CAM therapists and social media. Most of the participants stated they were given recommendations to use CAM for breast cancer management based on unfounded beliefs from lay sources. In addition, participants identified religious beliefs as their guide to use CAM as the primary treatment for breast cancer management, believing it to be the most effective treatment for breast cancer. The participants strongly supported the use of CAM and recommended CAM to other women who had breast cancer. The following sub-themes demonstrated the women with breast cancer's unfounded beliefs based on religious beliefs and other influences toward the use of CAM treatment for breast cancer.

5.3.1. Unfounded beliefs

Unfounded beliefs refer to the women with breast cancer's beliefs in rumours or non-evidence-based recommendations by lay people regarding the use of CAM for breast cancer management. Almost all the participants reported they had been recommended to use CAM for their breast cancer management. These recommendations to use CAM were generally received from friends, people who had previously had cancer, acquaintances, uncertified CAM therapists and sales marketing people, as well as from social media. A strong motivation was the implication they could get an immediate cure, and this contributed to their

belief in CAM as the best option. Some participants stated they had tried every available CAM treatment that claimed to cure breast cancer such as herbal therapy, soursop leaves extract, loranthus extract, traditional Chinese medicine and alkaline water. The following statements below demonstrate the participants' beliefs in the use of CAM.

> *I heard from my friends that soursop leaves can shrink the breast lump, it can even cure breast cancer. (Retno, participant 14, woman with breast cancer, Bandung, p. 2).*
>
> *Many people said that if having cancer, I should drink bitter taste herb extract. I received recommendations from other people and friends who have experienced the use of herbal therapy. (Wati, participant 12, woman with breast cancer, Bandung, p.5.)*
>
> *I have a friend who bought a water filter to produce alkaline water. My friend said alkaline water has been proven to be effective to cure lung problem. There are many people who found their lungs clear and normal after drinking it. Alhamdulillah,[3] they were no longer needing medical treatment. I trusted her because she is my friend, so I followed her suggestion. I drank alkaline water. (Yuni, participant 2, woman with breast cancer Batam, p. 7).*
>
> *My brother produced soursop herbal capsules by himself. This herbal therapy has proven to be effective on his wife who had breast cancer. His wife had breast cancer diagnosed by an internist, surgeon and oncologist… But then his wife consumed soursop herbal capsules. She believes and is sure that the herbal therapy would work. After two weeks consuming the soursop herbal capsules, she had a medical check-up in hospital. The medical examination result showed that the cancer has gone. Even the doctor was so surprised to see the cancer has disappeared…This made me believe in and be confident in using soursop herbal therapy. All my friends' experiences in using herbal therapy made me to believe it… I know the evidence of efficacy of herbal therapy from my family experiences who has first used herbal therapy. If I did not see the evidence, I would not believe it. This is real, I witnessed that the herbal therapy helped my family and friends. (Yuni, participant 2, woman with breast cancer Batam, p. 8 & 10.)*
>
> *The first time I got it the [Mahkota Dewa] fruit from my neighbour. I saw it at my neighbour's house. I thought that the fruit must be delicious as the colour is red. My neighbour said that Mahkota dewa is a cancer medicine. I was so surprised. She encouraged me to take the fruit. I took it home, I sliced it then I consumed it. (Lani, participant 10, woman with breast cancer Batam, p.4)*
>
> *What made me trust the traditional Chinese herbal medicine was patients' testimonies about the use of the treatment in that clinic. Sometimes I used my feelings. I felt that all the people in that clinics are a good people. (Indah, participant 20, woman with breast cancer, Bandung, p.6).*

The participants accepted and followed the unfounded belief-based recommendations unconditionally, without considering whether the recommendations from their friends were

[3] Alhamdulillah is an Arabic phrase meaning "praise be to God".

worthy. As such, the women with breast cancer undertook CAM in place of medical treatment and, in most cases the cancer progressed to an advanced stage.

The participants believed and used CAM based on other people's personal experiences and hearsay and they expected similar positive outcomes as those people had experienced. Believing in testimonies from other people signified that the participants were more trustful of other's beliefs and would rather use CAM than consult with qualified healthcare professionals.

Non-professional CAM providers including sinshe[4] and CAM sales marketing persons were identified by the participants as the other sources, where they were persuaded to use CAM as a cure for breast cancer. The sinshe and sales persons deceived the women with breast cancer by telling them that breast cancer was a common symptom that could be healed or cured with particular CAM treatments. Examples of these persuasions are exemplified in the following:

> *A germanium stone marketing seller delivered a germanium stone therapy brochure to my house. She said that one of our community members had recovered from cancer by using the germanium stone therapy. She convinced me that I should try the germanium stone therapy. (Lia, participant 4, woman with breast cancer, Batam, p. 4).*
>
> *The sinshe encouraged me to drink more herbal potion slowly. He [the sinshe] said that it [breast lump inflammation] wasn't cancer, instead it was just the swollen mammary glands. He always said, "You should be patient and patient". This statement was always the same. (Widya, participant 8, woman with breast cancer, Batam p.5)*
>
> *I knew that chlorophyll could cure cancer from a drug store salesman…I obtained a recommendation of snakehead fish capsule, which can accelerate wound healing processes from a door-to-door tofu seller (Ina, participant 6, woman with breast cancer, Batam, p.2 6 & 8).*

It was apparent from the analysis that there was a lack of ability to discern the claims of CAM made by other persons. The participants stated they confidently believed in the recommendations to use CAM by others and were unaware they may have been misled by these non-professionals. These beliefs in a cure for women with breast cancer led to them

[4] Sinshe is a traditional Chinese medicine healer

not consulting or to delaying medical cancer treatment, and all the while their breast cancer was progressing.

The internet and social media also had a strong influence on unfounded beliefs around CAM for the women with breast cancer. The participants used the internet to obtain information about CAM as well as viewing advertisements on television as is expressed in the following excerpts show:

> *… Yesterday I watched the efficacy of coffee tree plant parasites (loranthus) to cure cancer on YouTube. It was said that this herbal therapy is good and helpful (Ina, participant 5, woman with breast cancer, Batam, p.10)*
>
> *It's (information of moringa leaves) on Facebook. I found information that Moringa leaves can treat cancer from Facebook. It was posted that moringa leaves and the snake fish head can cure cancer. (Lani, participant 10, woman with breast cancer, Batam, p. 7).*
>
> *…I have seen on TV that sukun [bread fruit/artocarpus alitilis] leaf extract can be drunk for cancer therapy,as well as black sugar cane roots. The sugar cane stem can be eaten, and the roots can be boiled. The sugar cane root extract can be used to cure cancer. So, I tried those (Wati, participant 12, woman with breast cancer, Bandung, p.6).*
>
> *I found much information on the internet, I' am lways searching information from the internet. It was said that baking soda can cure cancer, but I think it doesn't make sense. I wasn't brave enough to try it. (Anik, participant 16, woman with breast cancer Bandung, p. 6).*
>
> *I obtained information about energy therapy from Google. I Googled it. I read a blog of a breast cancer survivor who use energy therapy. Then I chatted with her and then she suggested that I seek [name of the CAM clinic], which provides this therapy. (Dini, participant 19, woman with breast cancer Bandung, p.7, 215-217)*

As seen from the above statements, social media was another popular CAM information source among the women with breast cancer and was preferred rather than discussing breast cancer with healthcare professionals. This indicated that there was a lack of trust and confidence in healthcare professionals. Thus, utilising non-evidenced based CAM may have aggravated the women with breast cancer's health and accelerated the growth of breast cancer cells.

Overall, the women with breast cancer generally utilised CAM based on unfounded beliefs, hearsay and unscrupulous marketing. The women with breast cancer were unaware of

recommendations for the use of CAM from trustworthy information sources such as qualified healthcare professionals. Utilising CAM based on these unfounded beliefs and dubious sources of information often had a negative impact on the women with breast cancer with the breast cancer progressing to an advanced stage. Additionally, CAM use was kept hidden, and adverse effects and negative interactions may have occurred with other breast cancer medical treatments.

5.3.2. Believing in CAM based on religious beliefs and personal experience

Most of the participants followed Islam and the women with breast cancer indicated the use of CAM for breast cancer management was also related to their spiritual and religious beliefs, citing a strong faith in their God. The women with breast cancer believed that CAM should be used as the primary breast cancer management, because Allah had provided natural medicines for them through nature. Based on Islamic doctrine, medical treatment was to be used only if natural therapies did not successfully cure breast cancer. Herbs, stones and energy therapy were God's creations, and these could be used as natural medicines to treat cancer, as identified by the women with breast cancer. These naturally-based medicines were more trusted than medical treatment as they were traditional and had been in use for a long time before medical treatment existed. The use of CAM for breast cancer management is based on Islamic religious beliefs and is represented in the following excerpts.

> *Well, my husband stated that Rossulloh's[5] treatment is based on spiritual belief and Sunnah.[6] He reminded me that surgery should be the final way… He [Bunda's husband] read a book about Rossulloh's treatment, which claimed that medicines are natural and exist in nature. Allah created medicine in nature so that people need be back to nature. So, until now, due to beliefs and several forms of evidences, I believe that my doctor and medicine are from nature. For instance, with the breathing exercise, the oxygen comes from Allah. Medicine is affordable because Allah created it. May be, even if I only believed in mineral water that Allah gives me as my medicine, Insyallah[7] I will be cured. In fact, the therapy which is given to me is the alternative treatment. So, based on my personal*

[5] Rosulluloh means the prophet of God in Islam religion.
[6] Sunnah is Islamic religion doctrine.
[7] Insyallah means with God's will.

opinion, my medicine exists in nature. (Bunda, participant 18, woman with breast cancer, Bandung, p. 10-11)

Alternative medicine means healing from Allah, encouragement and belief. Alternative medicine shows that God's creations such as germanium stones and herbal capsule can truly save a human's life…Alternative treatment is therapy from nature. Stone, germanium stones are God's creation. (Lia, participant 4, woman with breast cancer, Batam, p. 5)

Religious beliefs had a strong influence on the use of CAM as alternative medicines to treat breast cancer among Islamic women with breast cancer in this study. There was a lack of understanding that not all natural-based medicines have been scientifically proven to be effective and safe for breast cancer management. The use of natural medicines as suggested by religious beliefs led the women with breast cancer to delay pursuing appropriate breast cancer treatment.

In addition to religious beliefs, CAM was also related to faith in God's will. The women with breast cancer emphasised healing was in God's will, and if God allowed them to be cured from breast cancer, they would be cured no matter what medicines they used. Accordingly, some of the women with breast cancer refused medical cancer treatment, and selected alternative medicine for breast cancer. These participants were very confident in using CAM, along with their faith in God that would cure their breast cancer. The women with breast cancer's stories below demonstrate how they surrendered the cure of breast cancer and their healing to God's will.

I believe it [the use of CAM] with my prayer. Whilst I was drinking herbal potion, I prayed to God. I said, 'God, you have provided fruits and vegetables. I don't understand what you will but people said it can be used to treat cancer'. Some medicines are made from leaves. So if God's will I am cured I will be cured. …As I have explained before, I feel my body healthier and stronger. It is beneficial for me. That's what I said, it's God's will. I am only human who can do my effort. All I surrender my life to God's hands. I asked God to let me live longer. I am so grateful now I have two years, three months life after surgery without chemotherapy. People said that there is a high risk of cancer cell relapse and spread into other organs if I have no chemotherapy for more than three years after surgery. I will accept the consequence. I keep taking juice therapy as my medicine and consuming heathy food. I feel that God helps me, I believe it. (Anik, participant 16, woman with breast cancer Bandung, p.7 & 8)

But I surrender everything to God's hands. All in God's hands…If it's God's will, it will. So, energy therapy is truly developing faith in God... Even using medical treatment or other

therapies, it will work if it is asked from God. So I use energy therapy to ask healing from God. Until now, I have no obstacles to use energy therapy. I believe this treatment is from God. If in the future I will be using medical treatment, I don't know. But until now, I believe that God wants me to use energy therapy…I support alternative therapy and other non-medical treatments as long as I use it with belief that only God heals. So it depends on itself. I have to be strongly believed that God is the only one who can heal. I required God to guide me where I have to seek the best treatments. Only God knows the best for me. Even if it uses medical therapy or non-medical treatment. There are many women who recover from cancer by using medical treatment, but this treatment is not working for other women. So, everything depends on what we require from God (Dini, participant 19, woman with breast cancer, Bandung, p. 7 & 8)

Having belief in God's will guided the women with breast cancer to use CAM as an alternative to medical breast cancer management. Using CAM and surrendering their life to God's will indicated their strong justification for not using medical treatment.

In summary, this second main theme of having unfounded beliefs in CAM treatment demonstrated most women with breast cancer in Indonesia utilised CAM for breast cancer management based on their strong beliefs. These beliefs were constructed by other people either through personal conversations or on social media. Persuasion was also evident from non-healthcare professionals, their religious beliefs, and their faith in God's will also helped to justify their belief in CAM as a cure for breast cancer. The women with breast cancer did not commonly discuss the use of CAM with healthcare professionals if they were receiving medical treatment. Consequently, delays in seeking medical treatment caused the breast cancer to progress and worsen the women with breast cancer's health condition. As a result, the women with breast cancer would delay medical treatment and ultimately spend more money on medical treatment for their breast cancer. The following main theme presented the potential benefits of CAM that the women with breast cancer experienced.

5.4. Theme 3: Feeling the potential benefits of CAM

The third main theme described several positive outcomes the women with breast cancer experienced from the use of CAM. These included alleviating pain, increasing their physical strength and immune system, having less side effects, and being more affordable than medical treatment. The participants also expressed that CAM could be used as adjunct

therapy to medical treatment or for cancer prevention. In this theme, the participants expressed what they felt about the potential benefits of CAM and how it could provide comfort and hope. One of the participants expressed the benefits of using CAM as follows:

> *One of positive values from using alternative medicine is cure. I have recovered now. The lump has shrunk, the pain has been relieved. I can eat and sleep well. I feel more fit, healthy and enthusiastic. (Lia, participant 9, woman with breast cancer, Batam, p. 9)*

The women with breast cancer's experiences of the potential benefits of CAM are explained in the sub-themes below.

5.4.1. Pain relief

According to the women with breast cancer's lived experiences, CAM was identified as an effective analgesic in reducing breast cancer pain. Three of the women with breast cancer explained how their pain was significantly relieved after using CAM such as soursop herbal capsules, Jamu,[8] white turmeric, ginger therapy, mixtures of herbal potions (e.g. soursop leaves and ant plant extract), meditation, touch therapy and prayer therapy. These are represented in the following excerpts:

> *Soursop herbal capsules can relieve my pain. Before taking it, I had very bad pain throughout all my body. Oh my God, no one could touch me, it was extremely painful. But now the pain is not the worst. I experienced positive effects from using herbal therapy. For example, it relieved my cancer pain. (Yuni, participant 2, woman with breast cancer, Batam, p. 8)*

> *The breast pain decreased approximately up to 50% after drinking Jamu. Similar to Jamu, ginger therapy could reduce my breast pain as well. Ginger is even more effective than others. The breast lump got smaller. Yes, there some changes I felt from using it. I felt hot sensation when the grated ginger was applied on my breast. The breast was very painful; the pain was relieved by the heat from the ginger. (Lina, participant 13, woman with breast cancer, Bandung, p. 4 & 7)*

> *I use these herbs as a temporary treatment to relieve the pain. I don't buy white turmeric frequently because the taste is very strong compared to another herbs. But for me, white turmeric is the most effective herbal to reduce pain…For me, as a 10 year-breast cancer survivor, herbal therapy is only to reduce the pain… According to my experience, totok therapy could reduce pain as well. Totok therapy includes a religious touch such as prayer. The touch is given based on Arabic characters. It gives relaxation. That's one of the positive effects. Yes, there is a positive effect of meditation. I felt that the pain is*

[8] Jamu is Indonesia herbal portion made from curcumas and herbal extracts. Jamu is commonly consumed in the morning as a form of health maintenance, and for treatment of particular diseases.

reduced after doing meditation. The pain is relieved. (Sari, participant 17, woman with breast cancer Bandung, p. 3, 4, 5 & 7)

The participants' personal experiences indicated CAM potentially had natural analgesic properties. However, the reduction of pain levels and the duration of the pain relief effect were not mentioned by the participants. Other potential benefits of CAM mentioned by the participants were increased physical strength and boosting their immune system. These potential advantages will be presented in the following sub-them.

5.4.2. Increased physical strength and immune system

Most of the women with breast cancer reported that they experienced a significant increase in their physical strength and immune system from using CAM. As explained by some participants receiving chemotherapy, the side effects caused fatigue, tiredness and weakened of their immune system. In order to reduce the side effects of chemotherapy, the women with breast cancer consumed CAM such as herbal extracts which they obtained from sinshe, honey and animal-based food supplements. For example, one of the participants revealed that consuming dog and snake meat soup or deer placenta capsules maintained her immunity, strength and energy during her chemotherapy. The women with breast cancer's physical endurance increased with the consumption of CAM as demonstrated in the following excerpts:

I felt very fatigued and tired. But after I drank the herbal extract from the sinshe, I felt more energy. That's it. Nothing effects on the breast cancer (Desi, participant 7, woman with breast cancer, Batam, p. 7)

I was recommended to drink dog meat soup. I think you have known that people in Medan eat dog meat…Yes, dog meat soup. I drank it. My leukocyte level has never fallen down since I have been consuming it. Indeed, I felt more energy after drinking dog and snake meat soup. I felt my body get warm…Well, that was helped my leukocyte at the normal level …In fact, after taking deer's placenta capsules, I felt stronger. I felt that I had more energy to manage my health condition. I still had nausea but not the worst (Riris, participant 6, woman with breast cancer, Batam, p. 5, 6 & 10)

I felt stronger after, in particular, after consuming honey. I didn't feel the chemotherapy effect as hot as before I consumed the honey… I have continuously consumed the honey since before surgery until now. But now I also take propolis plus (Encik, participant 21, woman with breast cancer Bandung, p. 3)

Two of the participants also explained that CAM could control the growth and kill cancer cells. One of those participants found her breast tumour did not increase in size compared to her friends' breast tumour who did not use CAM. Another participant consumed a mixed of fermented herbs and snake venom, which she obtained from a shaman. She consumed this herbal potion as an alternative treatment option to replace radiotherapy. She stated the herbal potion killed her breast cancer cells. Examples of these findings are presented in the following extracts:

> *I felt cancer cells were stopped growing after I consumed herbal therapy. I compared myself to my friend who had similar breast cancer surgery like me, but she didn't drink herbal therapy. The breast cancer relapsed and invaded into another breast…So I felt that my cancer cells are not growing because I am consuming soursop leaves and mangosteen peel extract. (Intan, participant 15, woman with breast cancer, Bandung, p.3 & 4)*

> *The therapist explained that the herbal potion is made from fermented swallow's nest, ants-plant, red fruit, noni fruit, and turmeric. All of those ingredients have to be fermented…The therapist explained that I would feel a hot sensation while taking the alternative radiotherapy. It was from the snake venom. Yes, the snake venom was used as an alternative radiotherapy. Then I searched literature related to the snake venom. There was an article that stated that snake venom can kill cancer cells. Until now I am still consuming the herbal potion and snake venom. Recently, it was detected that cancer cells reoccur. I called the therapist again to ask for more herbal potion. (Bunda, participant 18, woman with breast cancer, Bandung, p.10)*

Other participants reported their experiences of their breast lumps gradually shrinking, after drinking loranthus extract. This herbal therapy, according to the participants shown below, dried the pus from the infected breast tumour.

> *Well, I felt my breast shrunk after drinking sarindam or coffee tree plant parasites [loranthus] extract. This effect occurred in the day that I drunk the extract (Ina, participant 5, woman with breast cancer, Batam, p. 4)*

> *Sarindam/benalu kopi [loranthus] extract shrunk the breast lump and dried the pus. Yes, it could shrink the lump. My body felt better after drinking it. Now for health maintenance, I boil a little bit Sarindam kopi with water and drink the extract. It is similar to how I make the soursop leaf extract. Boil the leaves with a cup of water then drink the extract. (Lani, participant 10, woman with breast cancer, Batam, p. 6)*

The women with breast cancer's personal experiences above indicated that they believed that the consumption of CAM helped to shrink their breast lump and kill cancer cells. None of the participants were concerned about the safety of CAM and any toxic effects.

Overall, the women with breast cancer in this study utilised CAM to increase their physical strength and boost their immune system. Other CAM benefits that were identified from the women with breast cancer's lived experiences were safety and affordability.

5.4.3. CAM is safer and more affordable than medical treatment

Sixteen of the women with breast cancer stated that CAM was both safer and more affordable than medical treatment, as they did not experience immediate negative outcomes or adverse reactions from the use of CAM. The participants experienced CAM to be of benefit and did not identify any disadvantages. Four of the participants revealed that they did not experience any negative events from drinking soursop or herbal extracts as in the following statements:

> *I didn't feel any side effects from using herbal therapy. Herbal therapy is safe because it is natural. Instead of taking medical treatment, I prefer to use natural treatment - no side effects. (Ina, participant 5, woman with breast cancer, Batam, p. 7)*

> *I didn't feel side effects from drinking soursop leaf extract and tea plant parasite extracts (Wati, participant 12, woman with breast cancer, Bandung, p. 4)*

> *I didn't experience side effects from taking soursop leaf therapy. (Retno, participant 14, woman with breast cancer, Bandung, p. 3)*

> *There are no disadvantages of juice therapy and soursop leaf extract…I didn't feel any serious side effects from drinking juice therapy and soursop leaf extract. (Anik, participant 16, woman with breast cancer, Bandung, p. 4)*

Soursop leaf extract was considered to be safe, as none of the participants experienced adverse events from consuming this herb. The participants were unaware of any potential adverse effects that may arise from the long-term consumption of soursop leaf extract. For example, one of the participants was more concerned about the positive effects she experienced rather than changes in her renal function, which may have been due to the herbal potion. For this participant, this symptom was minor and was not of concern as indicated in the following:

> *I didn't feel a serious adverse effects of consuming soursop extract and other herbal therapy. But the herbal potion cannot be taken every day. I would be good if I take the soursop extract three times a week, because sometimes it affected my urination pattern.*

> *When I took it every day, I had frequent urination and the urine was smelled very stinky. But based on my experience during these 10 years of using herbal therapy, I feel more positive effects than negative effects. (Sari, participant 17, woman with breast cancer, Bandung, p. 4*

The excerpt above indicated some herbal therapy might safe as it did not cause immediate adverse effects. However, the consumption of herbal therapy could affect the renal system, as experienced by one of the participants and dismissed as minor when compared to the perceived benefits.

In addition to the safety aspect, affordability of CAM was mentioned by the participants as another favourable benefit of CAM. The women with breast cancer stated that the cost of naturally based CAM such as soursop leaves, honey and energy therapy were more affordable than medical cancer treatment, because it could be paid for in the form of a donation according to the participants' inability to pay. Therefore, the women with breast cancer were more likely to select less costly CAM in favour of conventional medical treatment as demonstrated in the following excerpt:

> *But energy therapy is more beneficial if it is compared with the price of other treatment that I have paid for. If I go to hospital and have chemotherapy, I would spend much more money than having energy therapy. For chemotherapy, I have to sacrifice my body, time and money. Therefore, I prefer energy therapy. The cost of energy therapy is not as expensive as chemotherapy's cost. It is more affordable than chemotherapy (Dini, participant 19, woman with breast cancer, Bandung, p. 6)*

The affordability of treatment was one of the main considerations for the participants when they made their decision in selecting treatment options. Particularly for those who had financial constraints, the cost of CAM was more affordable compared to medical treatment. This led the women with breast cancer to use CAM for breast cancer treatment. The participants appeared to be more concerned about the cost of treatment rather than any safety or effectiveness.

This sub-theme demonstrated potential benefits and affordability in the use of CAM for women with breast cancer. Furthermore, the participants described how CAM was commonly used to prevent cancer cells growing and to prevent a relapse.

5.4.4. Cancer prevention

Cancer prevention was identified as another benefit that the women with breast cancer experienced from using CAM that they believed in. Nine of the women with breast cancer reported they used CAM to prevent their breast tumour from rupturing and becoming infected, as well as preventing cancer cells from returning after completing surgery or chemotherapy. Herbal therapy was the most favoured CAM used as a cancer prevention measure by the participants as described in the following extract:

> *…the lump did not burst because I used herbal therapy. If I did not take herbal therapy, the lump would be burst and be infected. I don't want my lump to burst like one of my friends who did not use herbal therapy. Her lump burst and was infected, discharging blood, pus and lymphatic fluid. I anticipated those condition by using herbal therapy. (Yuni, participant 2, woman with breast cancer, Batam, p. 9)*

> *I consumed black cumin capsule to prevent cancer cells relapse…I take it for prevention purposes, not to heal breast cancer. (Riris, participant 6, woman with breast cancer Batam, p. 12)*

> *The herbal therapy can be used as a cancer prevention. I have had surgery and chemotherapy so that I use herbal therapy to prevent the cancer cells relapse. (Lani, participant 10, woman with breast cancer, Batam, p. 6)*

The participants indicated that CAM was used as an adjunct therapy to prevent the cancer from returning as well as to maintain their health and well-being after the completion of medical treatment, as well as preventing cancer from reoccurring.

In summary, benefits of CAM for these participants were prevalent in their choice of breast cancer treatment. Several types of herbs, animal-based food supplements, meditation and energy-based therapies were used to reduce breast pain, increase physical strength and boost the immune system particularly after having chemotherapy. As experienced by the participants, CAM provided comfort and improved health and wellbeing. The affordability of CAM led the women with breast cancer to prefer to use CAM rather than medical treatment.

The use of CAM was considered to be safe by the participants, as most of them had never experienced negative effects from using it. However, negative aspects of CAM were revealed by some participants in this study and these negative aspects of CAM are presented in the following main theme.

5.5. Theme 4: Acknowledging the negative aspects of CAM

In contrast to the previous theme, the fourth main theme illustrated acknowledgement by the women with breast cancer of negative aspects of CAM. These negatives effects of CAM included potential toxicity, unpleasant taste, a slow healing response and doubtful legality and safety concerns. These negative aspects of CAM led women with breast cancer to being disappointed in their CAM use and also raised concerns that CAM may not cure breast cancer. The women with breast cancer emphasised that CAM should only be used as an adjunct therapy to support medical treatment. Some participants turned to using medical treatment and also disagreed with the use of CAM as an alternative treatment for breast cancer. Details of each negative aspect of CAM identified by the women with breast cancer are described in the following sub-themes.

5.5.1. Potential toxicity and unpleasant taste

Minor side effects and an unpleasant taste from using CAM were referred to by the participants. The negative effects included burning on the skin and a hot sensation in the throat whilst consuming herbal potions such as soursop leaf extract. Other participants claimed that they felt burning pain and experienced skin redness on their breast when CAM providers applied herbal therapy externally onto their breast at the site of the tumour skin. The following excerpts indicated how the participants experienced side effects of the CAM treatments.

> *He [Traditional herbal therapist] heated some betel leaves then he placed it onto my breast tumour skin, arms and legs. I felt it burning my body's skin. My breast skin was red. It burnt. (Ina, participant 8, woman with breast cancer, Batam, p. 14).*

Well after surgery and chemotherapy, I consumed soursop leaf extract. But when I drank the soursop extract, I felt like burnt in my throat. It might have a strong effect on me… I drank [the] herbal remedy for a long period of time. It might be an overdose. (Widya, participant 9, woman with breast cancer, Batam, p. 6)

…But when I drank it [soursop leaves] frequently, I got a sore throat like an irritation. I had to stop drinking it because I couldn't normally swallow after drinking the soursop extract…I stopped drinking soursop leaf extract because it caused a sore throat. I couldn't drink much water when I have sore throat… He tapped my breast, but it made more little lumps occur. Then he [he therapist] applied a grated cassava on to my breast to reduce the heat. Sometimes I felt a hot and stabbing pain like being puncture with many needles. The grated cassava and potato stuck on my breast. (Wati, participant 12, woman with breast cancer, Bandung, p. 3 & 4)

I felt a hot sensation in my body after taking the internal alternative radiotherapy that contained snake venom. The therapist explained that the hot sensation was from the snake venom. (Bunda, participant 18, woman with breast cancer, Bandung, p.10)

In addition to the external burning and sore throat, swallowing difficulties reduced the women with breast cancer fluid and food intake resulting in gradual decline of their overall health. These adverse effects increased the participants suffering and impacted on their quality of life.

In addition, some of the women with breast cancer reported more severe adverse events including nausea, vomiting, dizziness, burning pain in the stomach and constipation after consuming herbal therapies or natural therapies, such as baking soda. The participants discontinued taking those remedies immediately when the symptoms occurred. However, one of the participants claimed that she ignored the adverse effects due to her strong intention to get a cure for her breast cancer. Another participant reported she had kidney and liver disorders due to the consumption of a Chinese herbal medicine over a long period of time. Examples of the participants lived experiences related to the negative effects of CAM use are presented in the following excerpts:

The side effects of herbal therapy that I experienced were feeling sick, like vomiting, and nausea. But I think it's from my poor health and it's my body's reaction (Yani, participant 3, woman with breast, cancer Batam, p. 7)

I drank it all day. Sometimes I feel dizzy because of drinking it [soursop leaf extract]. But I keep drinking it because I want to get recover. (Lia, participant 4, woman with breast cancer Batam, p. 4)

Due to the effect of sarindam kopi[9] being very strong, I couldn't normally defecate after consuming it. The stool was solid. My stomach was distended. (Lani, participant 10, woman with breast cancer, Batam, p .4)

I have tried baking soda and honey, but I got a stomach upset from it. I felt a burning pain in my stomach. Logically, baking soda is alkaline, it should neutralise the gastric acid. But instead, I got a burning pain in my stomach. Since that, I am afraid to try it again. I just tried it only two times. (Retno, participant 14, woman with breast cancer, Bandung, p. 7)

…After 20 days of having the Chinese herbal [therapy] as a substitute to chemotherapy, my whole body become swollen like full of fluid. I did blood tests and the results showed that I had a liver and kidneys problem. I stopped the herbal therapy immediately … I thought it was a normal to experience side effects of the herbal medicine. (Indah, participant 20, woman with breast cancer, Bandung, p. 3 & 6)

The adverse events and effects of CAM indicated this treatment was not considered to be safe by some of the participants. Some of the herbal therapies were potentially toxic. One of the participants experienced kidney and liver problems from consuming the alternative medicines. Despite direct experiences of negative effects, most of the participants were unaware of any harmful effects of CAM and continued with their CAM therapy.

According to the women with breast cancer, the taste of herbal therapy was very bitter, and this unpleasant taste caused the participants to change their breast cancer management. The following excerpts illustrate how the women with breast cancer experienced unpleasant tastes from herbal therapies with some ceasing consumption while others persisted.

The taste of white turmeric extract is extremely bitter. I have a friend who drank it when she had a lump. She drank it every day even though it's very bitter. Alhamdulillah[10] the lump disappeared. That was what my friend said to me, so I also drank the white turmeric extract. But I didn't take it longer because I couldn't stand the bitter taste. (Wati, participant 12, woman with breast cancer, Bandung, p. 7)

I discontinued taking the moral berry extract because the taste is very bitter. I don't like it. I prefer benalu kopi [loranthus] extract because the taste is better than moral berry leaves extract…I discontinued taking it [the herbal potion] because I don't like the smell. It was smelled like ink…I picked the leaves and blended it with water. It was smelled very stink. When I drunk it, I felt it was like drinking chili sauce. It was very hot. (Ina, participant 5, woman with breast cancer, Batam, p. 8, 12 &15)

People suggested me to mash the young noni fruit, strain it then drink the extract. The aroma of the young noni fruit is very bad. I drank it one litter per day. (Lani, participant 10, woman with breast cancer, Batam, p. 3)

[9] Sarindam kopi is a coffee tree plant parasite (Loranthus paraciticus)
[10] Alhamdulilah in the Arabic language means Praise be to Allah (God)

Although some herbal therapies were unpleasant, some women with breast cancer persisted in consuming it, bearing the discomfort as they expected CAM would cure their breast cancer.

Overall, some of the participants ignored the adverse effects of CAM that they experienced. There was a lack of awareness of the potential toxic effects from the consumption of the herbal therapies that could be harmful and lead to serious health problems. Those who could not cope with the negative effects and the unpleasant taste of herbal therapy discontinued consuming it immediately due to an increase in their suffering.

5.5.2. The futility of CAM

Fourteen of the women with breast cancer in this study realised CAM were futile when they were not cured. Instead, cancer cells were growing and for some women, their breast cancer had metastasised into other areas of the body. The participants also claimed the use of CAM was wasting their money and their time, but this realisation did not come initially, only after trial and error.

Four of the women with breast cancer reported they did not experience any significant positive effects from using CAM, although they had used various types of CAM for a long period of time. According to these women with breast cancer, consuming herbal capsules and herbal potions was useless because there were not any obvious changes in the breast tumour nor the healing process as they expected. The women with breast cancer were dissatisfied and disappointed about the ineffectiveness of CAM. The following excerpts demonstrate the futility of CAM as revealed by the participants' statements in the following:

> *Time has gone, my breast did not heal until 10 years. (Rosi, participant 1, woman with breast cancer Batam, p.1)*

> *But the treatments were not well responded to. No effects. I thought, I better save my money to buy other medicine. Why should I waste money for shaman? (Ina, participant 5, woman with breast cancer, Batam, p. 14)*

I drank the herbal potion from each sinshe[11] for up to one month. When I found that there were no significant changes, I stopped and changed to other sinshe's treatment. In six months', time, I had sought treatment from all sinshes in Batam…It was only wasting money and time. When the cancer stage got to the advanced stage or stage 4, the cure would be more difficult…I didn't feel any reactions from using the herbal capsules even though its so many, approximately six different types of capsules. Every one of those was taken five to seven herbal capsules a day…There was no effect at all. I just felt very dissatisfied. (Widya, participant 8, woman with breast cancer, Batam, p. 3, 8, 9 &10)

I tried this herbal potion recipe for one year. It cost me one million rupiah a month…but it did not work, so I replaced it with another herbal medicine. (Asih, participant 9, woman with breast cancer, Batam p. 2)

…people said that herbal therapy can shrink the breast lump, so that I tried it. In fact, after I tried it, there were no positive outcomes. At the end, I admitted to hospital. …Until now nothing was changed. I didn't feel any changes while consuming soursop leaf and sarang semut [ant plant] extract. (Sumi, participant 11, woman with breast cancer, Bandung, p. 3)

The statements above, based on the women with breast cancer's experiences, referred to CAM as not being a cure for breast cancer. The ineffectiveness of CAM was admitted to by the participants after they had experienced usage for themselves where their cancer had progressed rather than regressed. As reported by the participants, their use of CAM delayed medical treatment, which led to the progression of their cancer. The use of CAM as a primary breast cancer treatment was futile according to some of the participants.

Most of participants' assumptions in the previous main theme contrasted to three of the women with breast cancer who expressed that CAM could not cure cancer. Instead of CAM shrinking their breast tumour, their breast tumour enlarged despite consuming herbal medicines, using prayer and water therapy. The participants sought medical treatment after they acknowledged that herbal medicine could not cure their cancer. The excerpts below describe how some women with breast cancer who used CAM came to the realisation that CAM was ineffective for cancer treatment.

But the more I took the herbal medicine, the bigger the breast lump grew…So over time the lump just got bigger. I just wanted it gone. How can it be? My lump just kept getting bigger… until it was the size of a quail egg. (Yani, participant 3, woman with breast cancer, Batam, p. 3)

[11] Sinshe is a Chinese traditional medicine healer.

After six months of consuming the herbal capsules, I checked my CA (cancer antigen) 3 level and found it increased to 1.4 U/mL. Later after eight months, the CA level rose to 6.4 U/mL…it [the cancer cells] was increasing instead of decreasing. So, I thought I shouldn't play with this. If the CA level increased up to 6.4 U/mL, the cancer could be metastasised…Obviously, the herbal therapy was not helping at all. According to doctors, cancer cells cannot be killed by herbal therapy. It might have a potential substance that can be used to treat cancer, but the reaction process is very slow. However, cancer cells develops very fast. This statement made me realise that herbal therapy could not cured cancer (Desi, participant 7, woman with breast cancer, Batam, p. 5 & 6)

I went to an Ustad.[12] He gave me only a glass of prayed water. He prayed over the water then I drank it. When I felt hot, the prayer water made me calm. After the prayer water was finished, the breast lump become swollen. The pain was relieved after drinking the prayer water. But then the pain occurred again. The pain was like burning and scratching. The prayer water effect did not stay longer. (Sumi, participant 11, woman with breast cancer, Bandung, p. 4)

CAM was not effective in curing the women with breast cancer and the delay caused their cancer to progress, grow and possibly spread. The use of ineffective CAM treatment for breast cancer meant their breast cancer was untreated.

Overall, some women in this study experienced negative outcomes of CAM therapies rather than positive outcomes. A large amount of money and time was wasted in the use of ineffective CAM treatment for their cancer. The use of futile CAM resulted in the breast cancer developing into advanced stages and this negatively impacted on the women with breast cancer and raised their awareness for the need for medical treatment for their breast cancer. The use of futile CAM had implications for the advancement of their cancer to the stage where it may have been untreatable by medical management.

5.5.3. Doubting the safety and legality of CAM

Some of the women with breast cancer had begun to question the safety and the legality of CAM practices after realising the treatment was ineffective. The failure of CAM treatment to cure their breast cancer led the women with breast cancer to be more discerning about regulations and standards for CAM treatments. Three of the participants emphasised that the government should control CAM treatment practices and registration in Indonesia, since

[12] Ustad is an Islamic spiritual teacher.

they had become aware of many questionable CAM practices provided in Indonesia. One of these women stated that some CAM therapists created a fraudulent CAM training certificate in order to register their practice and obtain a permit to provide CAM practices. The women with breast cancer's doubts toward the safety and legality of CAM therapies are represented in the following excerpts:

> *The government must control alternative treatment CAM providers' permit. For instance, when I was given plant roots to treat cancer, the government should know whether the safety of the plant roots have been scientifically tested or not. I think this procedure has not been included in the process of getting the alternative treatment registration. This can be a disadvantage for people with cancer. Therefore, the government should not legalise a doubtful alternative treatment provider. The procedures and medicines that are used in alternative treatment should be investigated and reviewed before the permit to run the treatment is given. It is important to offer evidence-based alternative treatment. (Widya, participant 8, woman with breast cancer, Batam, p. 9)*

> *But the safety of many alternative treatments might be doubtful. For example, the treatment that I received from a shaman in my village. He tapped my breast with herbal medicine. It caused more little lumps to occur. Then he [the shaman] applied grated cassava onto my breast to reduce the heat. Sometimes I felt a hot and stabbing pain like being punctured by many needles. (Wati, participant 12, woman with breast cancer Bandung, p. 4)*

> *So far, I know several alternative therapists who professed themselves to be medical doctors. I don't know whether it is true or not. They might have a fake certificate, which is created by using a Photoshop editor application. It is easy... But in fact, what I see, there are no new changes in the development of traditional treatment. The government has acknowledged this, but is not concerned about this. (Sari, participant 17, woman with breast cancer Bandung, p. 10)*

The women with breast cancer indicated there was a lack of control and surveillance toward the safety and legality of CAM treatment practices in Indonesia. The women with breast cancer felt that the use of questionable CAM practices harmed their health and the questionable CAM practices financially exploited them with futile CAM treatments. The therapists gained profits from the CAM practices, but the participants felt they did not gain any benefits.

One of the participants mentioned two names of the most famous CAM therapists who provided cancer treatment illegally. This participant claimed the CAM clinics owned by these therapists were closed by the local health department due to violating the CAM regulations

of Indonesia. Despite this, these two famous CAM providers continued to practice CAM therapies claiming publicly they could cure cancer. One of these CAM therapists advertised her CAM practice on television as one participant described below:

> *Due to sharing deceitful information, an alternative therapy practice was closed by the local health department. But I heard that the therapist of that practice still runs his practice illegally by moving from one place to other places. Another example of illegal alternative practice that I knew is provided by [name of the traditional healer therapist]. There were many women with breast cancer who used cancer therapy from her. They paid about IDR 3.000.000 (AUD$ 300) for the alternative treatment. This traditional healer was very famous. She has many alternative medicine clinics nearly everywhere. To gain more money from the traditional treatment practice, she paid a TV program to publish her treatment. Unfortunately, when she was on the TV program, she gave presentation using a patient's medical test results. Then she complained by professional medical doctors because she is not a medical doctor who has competency to do medical assessments. Then the local health department closed her clinics as well…I have spoken to a doctor about the alternative clinics. He [the doctor] said that the IDI [Indonesia Medical Doctors Association] cannot control alternative therapy practices because these practices were not registered as alternative medicines clinics. Instead, they were registered as midwives' practitioners or massage therapists. They registered their practice to the health department. This made illegal alternative medicine practices keep growing. As long as the therapists have money to support the business and customers, they will continuously be growing. One of the problems is the TV program in Indonesia is commonly be paid to publish and advertise the alternative practice. (Encik, participant 21, woman with breast cancer Bandung, p. 6 & 7)*

Some of the participants were aware that most of the CAM therapists in Indonesia were offering and providing ineffective cancer treatment for profit. These participants felt that they were being deceived by CAM therapists as they offered ineffective breast cancer treatments. Accordingly, the women with breast cancer in this study suggested that the Indonesian government needed to control unprofessional CAM practices particularly for cancer treatment. The excerpts below demonstrate the women with breast cancer's views of CAM practices as a business rather than an effective service.

> *Nowadays, many therapists are promoting and selling herbal therapy to gain personal profits. They offered treatments that have not proven to be effective. (Yuni, participant 2, woman with breast cancer, Batam, p. 4)*

> *Alternative therapy is not a proper cancer treatment. It only gives a false hope. It is essential that the government is concerned about the regulation of alternative treatment practice. Don't let the sinshes and shamans take profits for themselves by disadvantaging people who have cancer. The priority is the patients' life. (Widya, participant 8, woman with breast cancer, Batam, p. 12)*

People said that they spent more than hundred million rupiah for CAM treatment to treat breast cancer. For me, each visit cost me about IDR 7,500.000 [AUD$ 750]. It seemed that he [the CAM therapist] provides alternative therapy for business purposes rather than helping people. (Lina, woman with breast cancer Bandung, participant 13, p. 3)

The women with breast cancer indicated CAM therapists exploited them by giving them false hope and encouraging them to use ineffective cancer treatments. The CAM practices were profitable to the CAM provider but disadvantaged the women with breast cancer.

The growth of illegal CAM malpractice in Indonesia was a concern to some of the participants. According to one participant's view, CAM provider skills and competency standards should be certified, maintained and monitored by the Ministry of Health. Another participant mentioned that CAM treatments should be accountable under professional healthcare supervision. The participants' expectations on CAM safety and legality are demonstrated in the following excerpts:

Traditional medicine must have a standard. I would like the government to arrange regulations and rules as to the use of traditional medicine. So far, the government has given permission to particular traditional medicine. Somehow, each sinshe has different traditional medicine procedures. So, it is important to have a standard in the use of traditional medicine in Indonesia. Also, it is necessary that information related the use of traditional medicine should be published... I would like traditional treatment practices to be well supervised by the Ministry of Health. At least, a report can be made if any malpractice is found in the traditional treatment procedures. Traditional treatment has to maintain the safety procedures for consumers. I have seen this idea in the traditional treatment practices. It would be better if the traditional treatment practices have a registration or licence from the Ministry of Health. Each alternative medicine therapist must have a license from the Ministry of Health. It doesn't matter where was the therapists learned about the therapy but it is important that their competencies are recognised and certified by the Ministry of Health. (Sari, participant 17, woman with breast cancer Bandung, p. 9 & 10)

My expectation, alternative treatment or non-medical therapies have to work together with IDI[13] and medical specialists …It would be good if the use of supplement and non-medical therapy was under IDI and a medical specialist's supervision. Nowadays, there are many protests and complaints from alternative treatment malpractice victims. (Encik, participant 21, woman with breast cancer Bandung, p. 9 &10)

The participants' views indicated there was a concern about malpractice and the use of unprofessional CAM practices. Codes of conduct, guidelines, protocols and healthcare involvement in CAM practices in Indonesia are required, according to the participants, to

[13] IDI stands for Ikatan Dokter Indonesia, which means the Indonesian Medical Doctor Association.

ensure the safety and legality of CAM practices, as well as to prevent malpractice and exploitation. Overall, the sub-theme of doubtful safety and legality of CAM was described by the participants who expressed concern about CAM practice regulations and associated systems in Indonesia.

Overall, this fourth main theme described the women with breast cancer's concerns about the negative aspects of CAM therapies for breast cancer management. Some of the CAM treatments were identified by the participants to have potential toxic effects, as they experienced adverse events and effects from the use of CAM therapies. In addition to the risk of toxicity, particular herbal medicines were found to have unpleasant tastes and aromas. As a result, those issues generated uncomfortable feelings, increased financial hardship, as well as affected the women with breast cancer's health. Furthermore, this theme identified that some participants realised the futility of CAM treatment, with some CAM therapies having no obvious positive effects on their breast cancer or healing process. Using ineffective CAM treatment caused some of the women with breast cancer's cancer to grow and spread. Recognising the futility of CAM and the feeling of being exploited by CAM therapists raised the participants' awareness about the need for safety and legality of CAM practices in Indonesia. These women with breast cancer suggested that the government of Indonesia needs to ensure the safety and legality of CAM practices by maintaining and supervising CAM practice regulations, licensing and rules in Indonesia.

5.6. Chapter summary

This chapter presented four main themes and several sub-themes that focused on the women with breast cancer's lived experiences in the use of CAM treatments. According to the participants' experiences, CAM was used as a primary treatment for breast cancer due to financial constraints and limited access to medical treatment. Lack of knowledge and awareness about cancer, fear of medical treatment, family influences and having beliefs

about CAM treatment also contributed to their use of CAM. Herbal medicines were identified as the most common CAM used to relieve pain, increase physical strength and boost the immune system, as well as to prevent cancer cells growth and return. Most of the women with breast cancer perceived that CAM was more affordable and safer than medical treatment. However, complaints of the potential toxicity of CAM and adverse events and effects from the use of this treatment were also revealed by some women with breast cancer. These disadvantages of CAM raised concerns and awareness on the safety and legality of CAM practices. Ultimately, this chapter provided evidence that the women with breast cancer experienced that CAM could not cure their breast cancer, had negative effects and was costly both financially and for their health. The use of CAM therapies as alternative medicine led many of the women's breast cancer to develop into advanced stages and become incurable. Nevertheless, some potential benefits of CAM were identified where the woman considered CAM useful in reducing the side effects of medical cancer treatments.

The following chapter (Chapter Six) presents four main themes that describe CAM therapists' views, knowledge and attitudes toward the use of CAM for breast cancer management in Indonesia. This chapter supplements the evidence already presented of the women with breast cancer's lived experiences in the use of CAM for breast cancer management in Indonesia. The convergent and divergent views of women with breast cancer and CAM providers relating to the use of CAM for breast cancer management in Indonesia are also addressed in this chapter. Chapter Seven will discuss the findings of the research. The final chapter, Chapter Eight, concludes the thesis by presenting the implications of this study for healthcare systems, nursing practice, CAM education and further research, policy makers, CAM providers and women with breast cancer.

CHAPTER SIX: FINDINGS (PART 2)
VIEWS OF CAM PROVIDERS

6.1. Introduction

The previous chapter presented the findings of the investigation on the women with breast cancer's lived experiences in the use of CAM for breast cancer management in Indonesia. This findings chapter presents the CAM providers' perceptions, knowledge and attitudes toward the use of CAM for breast cancer management, providing greater depth in understanding of the findings of women with breast cancer's experiences and statements on CAM therapies for breast cancer management.

Using a thematic analysis approach, as discussed in the methodology chapter, Chapter Four, four main themes emerged from the interviews with CAM providers. The main themes from the interviews with CAM providers include (6.3) Characteristics of women with breast cancer who used CAM for breast cancer, (6.4) providing non-evidence-based CAM, (6.5) CAM providers' beliefs in the potential benefits of CAM, and (6.6) progressive and not-so-progressive attitudes toward CAM. Several sub-themes emerged under each of the main themes. These are supported by excerpts of the interviews throughout this chapter. The excerpts reflect the CAM providers' views, their knowledge and their attitudes. Demographic data of the CAM providers including age, education background, and the types of CAM treatment provided, as well as the length of time of their practices, are provided at the beginning of this chapter.

6.2. Demographics data of the CAM Providers

A total of 10 CAM providers voluntarily participated in this study. Seven of the CAM providers were in a remote area (Batam) and the other three CAM providers were in Bandung, the capital city of the West Java province. The participants' ages ranged from 35 to 65 years.

The average education level was high school. Three participants did not complete primary school. Only one of the participants had a master's degree in economic management. None of the CAM providers had any formal health education related background or certified qualifications in CAM therapies. Most of the CAM providers provided CAM therapies based on their perceived gifted healing abilities, their religion, and spiritual beliefs. These therapies include plant and animal-based therapies and bloodletting therapy. The participants' length of experience of practicing CAM varied from three to 30 years. The CAM providers' demographic characteristics indicate that the majority of CAM providers practiced CAM unprofessionally. The CAM providers' perceptions about the use of CAM for breast cancer management are presented in four main themes and several sub-themes below.

6.3. Theme 1: Characteristics of women with breast cancer who used CAM

In this first main theme, CAM providers described the characteristics of women with breast cancer who sought CAM therapies from them. Having advanced breast cancer symptoms was the first characteristic identified by the CAM providers. According to the CAM providers, financial constraints also influenced the women with breast cancer to seek early breast cancer treatment from them because of the women with breast cancer's inability to pay for medical cancer treatment. This resulted in the women with breast cancer using CAM therapies because they were more affordable and accessible than medical cancer treatment. The lack of knowledge and awareness toward medical treatments were also identified by the CAM providers as other characteristics of the women with breast cancer who used CAM for breast cancer in Indonesia. In addition, experiencing medical cancer treatment failure also encouraged many women with breast cancer to use CAM as an alternative medicine in the hope that it would cure their breast cancer. The sub-themes that emerged for this first main theme include: '*Having advanced breast cancer symptoms*', '*Financial constraints, lack of knowledge and awareness*,' and '*Medical treatment failure'*. These sub-themes are discussed in detail in the next sections.

6.3.1. Having advanced breast cancer symptoms

Almost all the CAM providers reported they had experienced caring for women with advanced breast cancer symptoms. Five of the participants mentioned the women with breast cancer came to them in a very poor health condition, due to the breast cancer having developed into advanced breast cancer symptoms. The CAM providers commonly encountered swollen, bleeding, fungated and decayed breast tumours. The CAM providers claimed that the advanced breast cancer symptoms occurred due to the tumour being untreated or the early treatment being unsuccessful. The following excerpts from some of the CAM providers describe the women with breast cancer's conditions when they sought treatment from the CAM providers.

> *I usually manage the breast tumour, which is seemed like an abscess. The breast was swollen and festered… Her [a woman] breast cancer was like an abscess on the breast tissue. It was festering so that I had to drain the pus out of the breast. I got four cups of blood and pus from her breast. (Jamila, participant 2, CAM provider, Batam, p.1 & 5)*

> *Most of women came with decaying and festering breast tumours. Have a look at this photograph [showing a photo to the interviewer] - this woman refused chemotherapy. She had used many alternative treatments before she came to see me. Now, after she has been using our herbal therapy, the breast is drying. (Nanik, participant 10, CAM provider, Bandung p. 4)*

The CAM providers' reports above exemplify what the women with breast cancer experienced with their advanced breast cancer symptoms as a result of failed treatment in the earlier stages of their conditions. The women with breast cancer sought CAM therapies from the CAM providers to shrink the breast tumour, reduce the breast inflammation and stop the breast from discharging blood, mucus and pus. This meant that the women with breast cancer delayed seeking any treatment until the breast cancer was at a very advanced stage with distressing symptoms.

The uncomfortable feelings felt by the CAM providers when first meeting the women with breast cancer and seeing the advanced breast cancer were described by the CAM providers. Some CAM providers stated they felt nauseated because of the unpleasant odour

from the decaying, necrotic breast tumours occurring in the advanced stages, and were also disgusted when having to remove maggots out of the necrotic breast tumour as stated in the following extracts:

> *At first, I felt scared to treat breast cancer. It was the first time I saw a decayed, festering breast. The smell was very unpleasant and stinky. I could smell it even from about 3 metres away from her. I felt like nauseated and like vomiting. Then later I got used to it. I don't feel disgusted about it anymore. That was my first experience in treating cancer in 2005. Removing maggots from breast wounds is now my daily duty…I don't feel uncomfortable or disgusted anymore. Because I am thinking, how if they are one of my family members or even my mother or my aunty or other relatives. I really enjoy it. Even most of the women's families felt disgusted and reluctant to clean the breast cancer. (Aris, participant 3, CAM provider Batam, p. 6 & 7)*

> *Some women had festering and decaying breast tumours. It was stinky, even from a far distance, I could smell the burst breast. By consuming my herbal potion, the breast was gradually dried and cured. (Kinanti, participant 8, CAM provider Bandung, p. 5)*

The CAM providers felt uncomfortable when taking care of the women with breast cancer with advanced breast cancer symptoms. Despite these challenges, the CAM providers found ways of overcoming their repulsion through the belief in their treatments and being empathetic. Managing advanced breast cancer symptoms was viewed to be challenging for the CAM providers. The CAM providers perceived the CAM therapies that they provided to be effective in relieving advanced breast cancer symptoms and would eventually heal the breast cancer.

Overall, the CAM providers commonly provided CAM therapy for women with breast cancer with advanced breast cancer symptoms. Based on the CAM providers' experiences, advanced breast cancer symptoms occurred due to the delay in seeking medical cancer treatment or from failed treatment. Medical cancer treatment was delayed because the women with breast cancer could not afford or were unaware of the importance of medical cancer treatment.

6.3.2. Financial constraints, lack of knowledge and awareness

Having financial constraints, a lack of knowledge and a lack of awareness were other common characteristics identified by the CAM providers of the women with breast cancer

who used CAM. According to the CAM providers, CAM therapies were favourable among those ‘unfortunate’ and ‘poor’ women with breast cancer who had advanced symptoms and who could not afford medical cancer treatment. The CAM providers identified that inability to pay for and access medical cancer treatment as reasons that compelled the women with breast cancer to use CAM therapies as an alternative medicine for their breast cancer. Three of the seven CAM providers in Batam reported most of their clients were women with breast cancer from a low socioeconomic status who could not afford medical cancer treatment. They came to the CAM providers and requested CAM therapies as described in the following excerpts:

> *In general, women who come to me are from low socio-economic level. (Aris, participant 3, CAM provider Batam, p. 6)*
>
> *Well, my clients were both woman from a high economic level and those who had a financial problem. But most of them who were more likely to use this therapy were woman who cannot afford medical treatment. (Riska, participant 5, CAM provider Batam, p .5)*
>
> *Most of the women who came for my treatment were from a middle-low social economic status. (Riko, participant 7, CAM provider, Batam, p .8)*

The participants’ statements above highlight that CAM therapies were most likely the first and the only breast cancer treatment option for women with breast cancer in the lower socioeconomic strata of society. This was particularly so for poor women with breast cancer who lived in remote areas who had limited access to medical treatment.

Apart from financial issues, according to the CAM providers, those women with breast cancer who had no financial constraints used CAM therapies because they lacked knowledge and awareness about breast cancer management and treatment. Many women with breast cancer and their family members did not understand how to conduct breast cancer wound care. Consequently, the women with breast cancer attended the CAM providers for breast wound care and treatment, where poor wound care by the women with breast cancer or their family caused breast tumour infections and necrosis as described in the following statement:

…But sometimes women or their family lacked knowledge of how to care for the breast cancer wound …most of the women's family would not do the breast wound care. They let the women suffer. Sometimes even if the family did a wound care, they covered the breast wound with a used cloth to stop the bleeding and festering. This could cause a new problem. The used cloth might be dirty and have a lot of bacteria so that maggots can occur… I have even had a patient from Kalimantan who was admitted to my clinic for six months. She was 55 years old. She had many breast lumps. Since she lived in a village, she didn't understand how to manage the breast cancer. Finally, she was brought to Jakarta to my clinic. (Aris, participant 3, CAM provider Batam, p. 6 & 7)

Four of the CAM providers in Batam revealed that most of their clients were women with breast cancer who lacked knowledge about medical cancer treatments and procedures such as surgery and chemotherapy. The CAM providers believed that lack of knowledge about medical cancer treatments caused the women with breast cancer to use CAM therapies as described in the following excerpts from CAM providers:

Most of my patients were women who had breast tumours. Some of them had a malignant breast tumour. Usually, if the tumours are benign, the women don't care about it. They were suggested to have surgery, but they preferred to use alternative medicine. (Jamila, participant 2, CAM provider, Batam, p. 5 & 6)

Most young women searched for information via the internet for how to do breast examination when they felt that they had a lump. They fear seeing doctors or having a mammogram. Therefore, they sought for alternative treatment as the first option before they go for a mammogram. But after having cupping therapy, the lump has gone. This included one of my teenager patients in another state. According to her doctor, she had a tumour approximately 6 centimetres. I treated her with cupping therapy. Alhamdulillah, the therapy worked significantly. The tumour size was gradually decreased to 5 centimetres, to 1 centimetre and finally it disappeared. (Aris, participant 3, CAM provider Batam, p.8 & 9)

As far as I know, the women who use germanium stone therapy don't use other treatment. They don't use doctor's therapy. Some of them go to hospital to check the development of the disease. (Riska, participant 5, CAM provider Batam, p. 5)

In 2014, there was a woman who has had cancer removal surgery. But within one year, a breast lump reoccurred again. The patient said that she was suggested to undergo chemotherapy. But she refused it. She required me to heal her. She said to me, 'Sinshe please heals me'. Two to three months later, she has recovered. (Riko, participant 7, CAM provider, Batam, p. 2)

The CAM providers' statements above described their confidence in ability to cure breast cancer using CAM therapies. According to CAM providers' experiences, CAM therapies were required by the women with breast cancer who lacked knowledge and preferred to use CAM as an alternative medicine instead of using medical cancer treatment. The CAM providers believed their therapies could cure the breast cancer and made claims to support

those beliefs. The CAM providers' statements demonstrated their lack of awareness about medical cancer treatment that led the women with breast cancer to the use of CAM. Medical treatment was problematic among poor women with breast cancer who lived in remote areas.

In summary, CAM therapies provided by CAM providers were commonly used by poor women with breast cancer who could not afford medical treatment, and those who were unfamiliar with the benefits of medical treatment. As such, there were opportunities for the CAM providers to administer their treatments as an alternative medicine for breast cancer management.

6.3.3. Medical treatment failure

The experiences of medical treatment failure were another characteristic of the women with breast cancer who used CAM therapies mentioned by the CAM providers. According to the CAM providers' reports, the women with breast cancer required CAM therapies because the medical cancer treatments they used, including surgery and chemotherapy, did not result in positive outcomes. Some of the CAM providers in remote areas stated they commonly treated women with breast cancer who had unsuccessful medical cancer treatment in Singapore. The experiences of unsuccessful medical treatment failure led the women with breast cancer to turn to CAM therapies as described in the following excerpts from CAM providers:

> *Generally, women seek my treatment after they have had chemotherapy…most women who come to me have been treated a by doctor. Some of them have had chemotherapy. Many of them immediately sought my treatment…Sometimes, when they found medical treatment didn't work, then they looked for traditional medicine. One of my clients spent much money for surgery, but the breast cancer did not get cured. (Rangga, participant 4, CAM provider, Batam, p. 6, 13 & 14)*

> *Germanium stone therapy is used as alternative and complementary therapy. Most women came to germanium stone therapy because they had already used many treatments but didn't get cured. So, when they saw and heard many patients obtained significant changes after using this therapy, the women came here to get cure as well (Riska, participant 5, CAM provider Batam, p. 5)*

> *I have treated many women with breast cancer with various stages. Stage 1, 2, 3, 4. But what I see, most of them come to me after they have failed with the other treatments used. I know it. Some women come to me after using medical treatment…For the rich women, they firstly sought treatment in Singapore or Malaysia. Later after the medical treatment has failed, then they came to me. (Riko, participant 7, CAM provider Batam, p. 3 & 8)*

The excerpts above indicated that the women with breast cancer sought CAM treatment because they were dissatisfied with medical cancer treatment where CAM therapies were sought as an alternative due to failed medical treatment. This last resort CAM therapy reinforced the CAM providers' beliefs in their CAM therapies, as well as their views about medical treatment failure.

In short, this first main theme represented the CAM providers' views on the general characteristics of the women with breast cancer who used CAM for breast cancer management in Indonesia. Many women with breast cancer came to the CAM providers with advanced breast cancer symptoms because of failed medical treatment, lack of awareness and knowledge, financial constraints or living in remote locations. Although some women with breast cancer had advanced breast cancer and fungating wounds, the CAM providers believed they could help them.

6.4. Theme 2: Providing non-evidence-based CAM

The second main theme of 'providing non-evidence-based CAM' described the types of CAM treatment that the CAM providers provided for breast cancer management. The non-evidence-based CAM refers to traditional and natural based CAM therapies that have not been proven scientifically to be safe or effective. In this study, the non-evidence-based therapies that were provided by CAM providers were herbal therapy, massage therapy, bloodletting therapy, energy therapy and spiritual therapy. These CAM therapies were also provided by CAM providers who had no qualifications or formal health education related or CAM therapy education as the CAM providers explained in the following excerpts:

I completed primary school, high school in an automotive area and a bachelor's degree in English language. Then now I am healing people. My work now is not linear to my education. (Aris, participant 3, CAM provider, Batam, p. 1)

I only completed year three at primary school. I learnt to heal from my personal experiences. I also learnt about CAM in Malaysia and Taiwan. But it was just a short workshop because I have already knew how to heal. (Riko, participant 7, CAM provider, Batam, p. 2)

I have no medical education background. I learnt herbal therapy in a very short time in Jakarta. But I already had experience. (Nanik, participant 10, CAM provider, Bandung, p. 2)

Insufficient health-related education backgrounds resulted in the CAM providers believing in unscientific therapies for breast cancer, relying instead on experience or a 'gift' that was given to them. One of the participants claimed breast cancer might be caused by black magic and another disagreed with a medical practitioner's diagnosis as shown in the following statements:

The black magic causes the stroke. Breast cancer can be like that too. It can be related to black magic. It needs to be clear. If it doesn't clear, it would be similar to a person who has used medical treatment but still cannot be cured (Aris, participant 3, CAM provider, Batam, p. 5)

I have treated many women with breast cancer. My previous patient lived nearby here. She had a damaged breast. Her doctor said it was breast cancer. But for me, it wasn't cancer because the lump was above her breast. It was only a benign tumour. But the doctor said it was cancer. (Rangga, participant 4, CAM provider Batam, p. 6)

Limited education levels and limited knowledge led the CAM providers to provide non-evidence-based CAM to the women with breast cancer. The therapies were delivered based on CAM providers' understanding, beliefs, traditional practices and experiences, which developed from having gifted healing abilities, their religion and spiritual beliefs, as well as their informal education and training. As such, this study classified the CAM therapies given to women with breast cancer by CAM providers into supernatural-based therapies and religious belief-based therapies. These CAM therapies were generally delivered with traditional methods and the cost depended on the women with breast cancer's ability to pay.

6.4.1. Supernatural-based therapy

Supernatural-based therapy refers to CAM treatment practiced by the CAM providers based on their knowledge, experience and beliefs in their healing ability. Three of the CAM providers explained that their knowledge and healing ability were inherited from their ancestors, who were traditional healers or shamans, as supernatural beings. These CAM providers believed they had possessed their healing ability since a young age. One of the CAM providers claimed the healing ability that she received from her grandfather was a very special gift. Unlike other CAM providers, this participant claimed she had a sixth sense which enabled her to forecast a person's lifespan. With this ability, she made decisions whether to heal or let her customers die. The following excerpts described how some CAM providers received knowledge and their healing abilities from their ancestors.

> *At first, I learnt healing from my father. Then from my grandfather and great grandfather. My ancestors inherited healing ability to me from the past to the next generation. It has been a long time that I have had this ability. Since I was in year 7 at primary school, I have begun healing people in my family, close friends and relatives. (Aris, participant 3, CAM provider, Batam, p. 1)*

> *Actually, my grandfather and ancestors were from China. Our ancestors are traditional healers. The healing ability was inherited from my grandfather to my uncle then to me. Then we migrated to other places. I asked guidance from an old person who has healing ability. (Rangga, participants 4, CAM provider, Batam, p. 9)*

> *I inherited my grandfather's knowledge …My grandfather was a traditional healer expert. He was a very famous shaman. He healed many people…My grandfather learnt to heal people from his grandfather as well. So, the healing knowledge and ability are inherited from the past generation then to me…This ability is not randomly passed on to others, as this gift is following by something special. The special thing is an ability to know which patients will die soon or not. I know it [the participant smile]. For example, when a patient came to me, I checked the patient's pulse. I predicted that the patient will die in 40 days. I wasn't keen to heal the patient anymore as it would be useless. I was given knowledge and ability. A person like me is not plain. I have something special such as a gift or sixth sense. I have been healing people since I was 15 years old. (Kinanti, participant 8, CAM provider Bandung, p.1, 2, & 7)*

Two of the CAM providers revealed they had received knowledge and healing abilities from their Gods. One of these participants claimed he prayed to God regularly requesting knowledge and the ability to create new herbal medicines. The CAM provider stated that this ability to cure people was given to him by God through his dreams. Another participant stated

she was gifted with her healing ability from God through a supernatural event, feeling something mystical coming to her during regular visits to the Islamic saint's cemetery. This mystical experience enabled this CAM provider to treat people using CAM therapies. The participants described this divine healing power in the following excerpts:

> *I have been practicing this therapy not that long, approximately 15 years. But since I was a teenager, I already had the ability to heal people. I regularly pray to gain knowledge and ability to make a new herbal medicine, and it comes through my dreams… In the past, my family didn't trust me. My friend asked me what knowledge I usde to heal people. They don't know that my knowledge and ability were from my dreams. When I seek medicine to treat diseases, I just pray to God. (Riko, p. participant 7, CAM provider Batam, p. 1, 9 & 11)*

> *In year 1995, I was published in a newspaper. It was written that I was gifted an ability to heal people from God… Alhamdulillah[14], since 1975, I have been regularly visiting the cemetery of Waliyullah.[15] But it's only a hobby. It wasn't for the purpose of acquiring the ability to heal, not at all. I was plain. Then at the end of year 1982, I have started feeling something uncanny on me…Well, I felt something awkward, I felt someone whispering at me. It was very bizarre. Then my husband said I was insane…I didn't learn how to treat people. The ability and knowledge were gifted from Allah[16] (Dinah, participant 9, CAM provider, Bandung, p.1 & 2)*

The CAM practices for breast cancer management in Indonesia were identified by the CAM providers as relating to a supernatural power either passed on to them by their ancestor, gained through experience or directly given to them by God. Some of the CAM therapies were provided by CAM providers, who stated that they had abilities to heal people at a very young age without CAM-related formal education, training or certification. This meant that the CAM providers provided unscientific CAM therapies where the safety and the efficacy were not proven. Furthermore, CAM therapies were also provided based on the CAM providers' religious and spiritual beliefs. None of the CAM providers considered the women with breast cancer's short-or long-term survival from the use of CAM.

[14] Alhamdulillah is an Arabic word that means praise be to God.
[15] Waliyullah is an Arabic word that means friends of God.
[16] Allah is God in the Islamic religion.

6.4.2. Religious and spiritual beliefs-based therapy

This subtheme identified that CAM treatments for breast cancer management were based on the CAM providers' religious and spiritual beliefs. The majority of the CAM providers were Muslim, thus, they practiced CAM treatments based on the Islamic religion. Cupping therapy was one of the most recommended CAM treatments in Islamic doctrines as mentioned by the participants. According to the CAM providers, this therapy was first practiced by the Prophet Muhammad as suggested by an angel. Based on this doctrine, the participants believed cupping therapy could cure cancer. In addition to the Prophet Muhammad's suggested therapy, CAM was also practiced based on the teachings of the first natural medicines inventor in the Islamic world. The following extracts represent several religious and spiritual beliefs-based therapies used by the CAM providers for breast cancer treatment.

> *Cupping therapy originally came from Prophet Muhammad Sunnah.[17] He found this therapy when he was taken by his enemy. An angel suggested Prophet Muhammad to do cupping and hijama.[18] Since then, Prophet Muhammad performed this therapy. Cupping therapy means to drain blood out of the body. (Jamila, participant 2, CAM provider, Batam, p.2)*

> *Since I am a Muslim, actually this treatment has already existed from Prophet Muhammad's time. But only a few Muslim people are able to practice this treatment…But for me, personally, battra therapy [19] is a treatment that refers to Sunnah Prophet Muhammad, named 'hijamah' or cupping…I believe cupping therapy can cure cancer because this therapy was suggested by Prophet Mohammad. (Aris, participant 3, CAM provider Batam, p. 1, 2 & 9)*

> *Our principle is 'Ibnusina[20], father of the doctors'. Thus, we use natural medicine, which is created by Ibnusina. (Nanik, participant 10, CAM provider Bandung, p. 5)*

One of the CAM providers stated she only prescribed herbal medicines permitted by Islamic law. The herbal medicines products must be labelled '*Halal*' by an Islamic organisation. Another CAM provider used a spiritual therapy approach, such as reciting holly verses from the Islamic sacred book to treat breast cancer. According to this CAM provider's view, spiritual therapy was very essential for soul and body healing as it cleansed the soul from

[17] Sunnah means something recommended by Prophet Muhammad's teachings.
[18] Hijama is Arabic word that means cupping.
[19] Battra therapy means traditional treatment.
[20] Ibnusina was known as the father of early modern medicines in Islam.

negativity and increased positive motivations to get a cure for the breast cancer. These Muslim CAM providers explained their religious and spiritual beliefs in the following examples:

> *I joined an Islamic herbal company because I prefer Halal products. I learnt about herbal therapy from a company that produces "Halal" herbal products. I give only "Halal" herbal products to my clients. (Jamila, participant 2, CAM provider Batam, p. 4)*

> *I use spiritual approaches such as 'ruqyah'[21] to heal women with breast cancer. 'Ruqyah' means reciting Quran[22] verses to a client. The "ruqyah" aims to increase positive motivation...The purpose of reciting those holly verses is also to cleanse the spiritual life and increase the faith…Spiritual condition must be the first concern. It is very essential. It is my duty as a provider to synchronise the soul and the body. If the soul is sick, it has to be treated first. In contrast, if the body is sick, the soul would not be treated. So, for breast cancer treatment, it uses both medical and ruqyah. The purpose of "ruqyah" is to get rid of pessimism and increase motivation as well as encouragement. (Aris, p.3, CAM provider Batam, 5 & 6)*

The CAM providers' explanations above indicated that the use of CAM for breast cancer management among women with breast cancer was significantly related to their personal religious and spiritual beliefs. Islamic-based CAM therapy was reported by CAM providers to be the most common CAM used for breast cancer management because the majority of both the CAM providers and the women with breast cancer were Muslim.

Three of the CAM providers mentioned that the effectiveness of CAM was dependent on the women with breast cancer's beliefs, the CAM providers' suggestions, and women with breast cancer's commitment to following instructions given by the CAM providers. The CAM providers stated they required the women with breast cancer to have a strong belief in their suggestions in order to achieve positive outcomes from the use of the recommended CAM therapies. The CAM therapies would not be given if the women with breast cancer did not believe in the treatment. One of the CAM providers emphasised that the cure came from believing their suggestions. This CAM provider perceived the suggestions given by them could create internal self-healing power. Thus, no matter what type of therapies were used

[21] Ruqiyah is an Arabic word that means spell, incantation.
[22] The Quran is the Islamic sacred book.

by the women with breast cancer, women with breast cancer would be cured if they believed in the CAM providers' suggestion. Some of the CAM providers stated that God used them to heal sick people including women with breast cancer. The quotations below demonstrate the importance of women with breast cancer believing in the CAM providers' suggestions.

> *Both provider and receiver must have trust in CAM. Believe in Allah and trust the provider. I have even refused a few women who didn't believe in my suggestions. I asked them 'Do you believe this treatment?' They answered, 'Not really sure'. I said, 'if you are not sure about this treatment, it is better not to use it, as the outcome may not be good'. If they are not sure about cupping therapy, then I have to make them really sure about it. I will tell them that it is not me, myself, who cures the cancer. I also suggest other therapies to require grace from Allah to cure patients through us. Only Allah can heal. The provider is only a medium. That's why I always ask my patients, 'Do you believe this therapy? 'If they said, '50% believe', they have to make it 100% believe to achieve the best treatment outcome. (Aris, participant 3, CAM provider, Batam, p.9)*

> *The effectiveness of the treatment depends on the patient and what treatment that is most suitable for them…I just give suggestions. Well, sometimes a patient got cured with only a glass of water. Yes, it was because of the suggestion… Actually, all diseases can be cured as long as patient comes with trust. Definitely cured. I believe it can be healed. (Aji, participant 6, CAM provider, Batam, p. 7 & 8)*

> *To use herbal therapy, the women must believe and obey my instructions. If they can't do it, don't use my treatment. Therefore, when a patient comes, I directly show the instructions and ask whether the patient agrees to obey it or not. If the patient is not able to commit, it is better to not use my therapy. If there is no instructions, wherever the treatment came from, it would not be successful. (Riko, participant 7, CAM provider, Batam, p.6 & 7)*

The excerpts above show that the CAM providers implicitly compelled the women with breast cancer to believe and commit to the use CAM therapies for breast cancer management. The CAM providers only gave hope and suggestions instead of appropriate scientifically proven breast cancer treatment to the women with breast cancer. They also convinced the women with breast cancer that their belief in God, as well as trust and obedience to their therapies would ensure the effectiveness of the CAM therapies and a cure. Most of the CAM therapies were provided by traditional methods as described in the following sub-theme.

6.4.3. Ancient traditional CAM practices

Ancient traditional CAM practices refers to therapies that were applied by using an ancient traditional approach. These included the use of a conventional baking oven to sterilise

cupping therapy instruments and use disposable needles once only. Another method that the CAM providers used to sterilise therapy equipment was vegetables like shallots. One of the CAM providers mentioned that he used shallots to sterilise needles prior to the needle being punctured into the women with breast cancer's skin. As mentioned by this participant, shallots had a stronger effect in killing germs than alcohol. Moreover, unlike medical waste disposal management, the CAM providers disposed of CAM therapy waste as general waste. For example, one of the CAM providers explained he collected blood waste from bloodletting procedures using used newspaper or a rubbish bin and then the blood waste was disposed of into a general waste bin. There was only one of the CAM providers with infection control practices aimed at preventing cross-infection from clients with a contagious disease or infection. This CAM provider required clients to purchase disposable cupping therapy cups. Some of the ancient traditional healing techniques implemented by the CAM providers are expressed in the following excerpts:

> *There is an oven [showing a conventional baking oven to the interviewer]. We have an oven to sterilise all the cupping instruments including the cups and needles. All are sterile. (Jamila, participant 2, CAM provider, Batam, p. 2)*
>
> *Shallot is used to sterilise and kill all germs on needles. Shallot can kill germs because it is hot. For example, I punctured the needle into the shallot before I puncture the patient's skin. Also, I cleanse the needle with a shallot before it is used on other patients. (Rangga, participant 4, CAM provider Batam, p. 10)*
>
> *Bloodletting procedures for breast cancer management are similar to other diseases. First of all, I determine which the best vein to be punctured is. It can be veins on the legs or hand. Then I just insert the needle into the selected vein and drain the blood out. The blood flows to a used newspaper [newspaper used to collect the blood] or it can be collected using a rubbish bin. (Aji, participant 6, CAM provider Batam, p. 2)*
>
> *I use alcohol, hydrogen peroxide to sterilise cupping instruments. For particular patients who have contagious diseases such as tuberculosis and hepatitis, I have to order cupping cups for them. They have to let me know whether they have tuberculosis or hepatitis so that I can make an order for the cupping cups. (Aris, participant 3, CAM provider, Batam, p. 2)*

The majority of the CAM providers did not apply standard precautions or infection control management in their CAM practices. Based on the interviewer's observations, none of the CAM treatment facilities were equipped with hand-washing stations. Standard infectious

precautions were not performed before conducting an invasive CAM procedure. As observed by the researcher, most of the CAM providers did not wash their hands or wearing gloves prior to performing bloodletting therapy. Also, an appropriate waste disposal was not provided. There was a lack of awareness about cross-infection control procedures by the CAM providers. The application of ancient traditional methods in the CAM providers' practices may place the women with breast cancer at health risk and compromise their safety.

Some of the CAM providers provided unregistered or illegal traditional CAM practices to the women with breast cancer. For example, one of the participants admitted that she supplied an herbal potion to a hospitalised women with breast cancer without the doctor's permission. The herbal potion was sprayed into the client's nose to be inhaled, as the patient was unable to drink the herbal portion as described in the following excerpt:

> *A doctor in that hospital didn't allow the patient to consume herbal therapy, so I put the herbal potion into a plastic spray bottle. When the doctor asked me, what I brought for the patient, I said that I didn't bring anything. Actually, I brought a herbal potion, which will be sprayed into the patient's nose so that the patient could inhale it. After I sprayed the herbal potion to the patient, the patient began to move, then I called the doctor. I was suspected of use my witchcraft to wake the patient…I supplied the herbal therapy to the patient secretly. I didn't speak to the doctor. When I sprayed my herbal therapy to the unconscious patient in hospital, I pretended that I am praying. In fact, I brought my herbal potion and sprayed it to the patient's nose. I sprayed the herbal therapy without the doctor's permission. (Kinanti, participant 8, CAM provider, Bandung, p. 9 & 10)*

Providing herbal therapy in hospital secretly meant the CAM provider was unaware of their client's safety. It was found that some CAM providers provided illegal CAM therapy and without the clients' consent against medical professional orders.

6.4.4. The cost of CAM therapies

The cost of CAM therapies for breast cancer management ranged from being cheap to expensive. Six of the CAM providers mentioned the average cost of most herbal therapies including herbal potions, herbal capsules and other herbal products were affordable for women with breast cancer. Other CAM therapies such cupping therapy, bloodletting,

acupressure and massage were charged according to the women with breast cancer's ability to pay. The CAM providers perceived that the cost of therapies they provided was less expensive than medical cancer treatment provided by qualified health professionals as described in the following excerpts:

> *Acupressure therapy isn't that expensive. (Lim, participant 1, CAM provider, Batam, p. 5)*
>
> *For cupping therapy treatment is only…It is very cheap. (Jamila, participant 2, CAM provider, Batam, p. 1)*
>
> *The cost of herbal treatment is average. Herbal therapy cost in this clinic is not expensive because the quality of the medicine is much better than others. Why my clients should concern about the price? (Nanik, participant 10, CAM provider, Bandung, p. 2 & 3)*

Some of the CAM therapies were paid for by the women with breast cancer according to their ability to pay. One of the CAM providers mentioned he charged a wealthy customer more than a poor customer. Some CAM providers gave CAM therapies for free if the customers were unable to pay. Examples of this are shown below.

> *The cost of bloodletting therapy depends on the patient's ability to pay. How much they able to pay. (Aji, participant 6, CAM provider, Batam, p. 4)*
>
> *When the patients come, I look at their financial ability. If they are rich people, the treatment price is a higher amount. But if they are poor people, I can give a lower price. If they really cannot afford it, I give them a free treatment. I often provide free treatment. (Riko, participant 2, CAM provider Batam, p. 2)*

The affordability of cheap CAM therapy such as germanium stone therapy was favoured generally among people in the area with various medical complaints, including women with breast cancer. A free trial of the germanium stone mattress attracted clients of CAM providers, by allowing them to try the mattress, and experience the potential benefits of it before they bought the product. The following excerpt highlights this situation:

> *Germanium stone therapy is a free therapy for all people who need healing. We give free treatment. It is free to let them try and feel the effect of the germanium stone mattress. …but for the promotional event, the price of the germanium stone mattress is on special (Riska, participant 5, CAM provider, Batam, p.1 & 6)*

In contrast, one of the CAM providers provided a costly herbal medicine that could only high-income customers could afforded, meaning those on a low income could not afford the CAM

therapy. This CAM provider reported her herbal medicine was commercialised by a healthcare worker in a hospital setting as mentioned in the following extract:

> *Well, a doctor bought herbal therapy from me with a reasonable price but then he injected it into patients and charged them almost 10 times more expensive than the price he purchased from me. Most of my patients are from the middle-high economic level (Kinanti, participant 8, CAM provider, Bandung, p. 2 & 3)*

Overall, the cost of most CAM therapies was reported to be less expensive than medical cancer treatment. The CAM providers attracted their customers, including women with breast cancer, by offering them affordable CAM therapies, specials on products and their ability to pay. Due to the standard cost of CAM therapies in Indonesia not being available, a free trial of CAM products and exemptions to get free CAM were provided to customers as a marketing tool for selling CAM therapy. The type of therapy provided was dependent on the financial means of the women with breast cancer and their income. Some CAM providers provided an altruistic service by providing basic therapy.

In summary, this second main theme and its sub-themes demonstrated that CAM therapies for breast cancer management in Indonesia were not provided based on evidence, competencies or qualifications. Instead, the CAM providers practiced CAM therapies based on their knowledge, skills, experiences, tradition and a self-proclaimed healing ability obtained from their ancestors through supernatural events. Accordingly, the CAM providers provided supernatural-based therapy, as well as religious and spiritual-based therapy determined by Islamic doctrine. These were favoured because the majority of CAM providers and the women with breast cancer were Muslim. The CAM therapies provided were often ancient and illegal, where infection control precaution and standards were not performed. The cost of CAM therapies was generally affordable and was often based on the customer's ability to pay. The CAM providers believed CAM therapies had potential benefits and could also provide a cure for breast cancer. Their beliefs of the advantages of CAM therapies are described in the next main theme.

6.5. Theme 3: CAM providers' beliefs in potential benefits of CAM

In this third main theme, the CAM providers explained their beliefs about the benefits of CAM therapies for breast cancer management. Most of the CAM providers believed that CAM, as traditional or alternative therapies, could cure breast cancer. According to their beliefs, CAM therapies were effective in stopping festering, ulcerating breast cancers, sped up breast wound healing, shrank breast tumours, and reduced side effects of medical treatment for cancer. The CAM providers believed that CAM therapies were safe and would not cause adverse effects. These beliefs were constructed by a way of thinking and belief that CAM was the first therapy used to treat many diseases in ancient times before medical treatment existed.

The participants provided CAM therapies for breast cancer management based on their beliefs in traditional treatment principles. They were confident that CAM therapies had advantages and could cure breast cancer. The detail of potential benefits of CAM therapies are presented in the following sub-themes of CAM potentially cures breast cancer, and CAM is safe.

6.5.1. CAM potentially cures breast cancer

The CAM providers believed CAM could accelerate breast cancer wound healing processes. As explained by the CAM providers, most of the women with breast cancer came to them with fungating breast cancer wounds that were malodorous, bleeding and discharging fluid from the nipple or the wound itself. The CAM providers managed these symptoms using animal- and plant-based supplements, germanium stone therapy, cupping therapy and bloodletting therapy. They believed these CAM therapies were effective in healing breast cancer wounds, as they removed toxins and cancer cells from the blood and stopped the breast from further festering. Examples of these beliefs are shown below:

> *I believe traditional medicine can cure cancer. Traditional medicine is an effective antibiotic. It cures festering breast cancer wounds. It also helps to produce new cells and*

kills cancer cells. Breast lumps can be disappeared by traditional medicine. (Rangga, participant 4, CAM provider Batam, p. 10)

Cupping therapy is to remove toxins and cancer cells from the blood. Naturally the body will produce fresh blood, which is good to improve the immune system… Sea cucumber extract is used to heal the breast cancer wound, shark cartilage is to kill cancer cells and spirulina can kill a virus. (Jamila, participant 1, CAM provider Batam, p. 3 & 5)

The bleeding and festering breast will be dried up with cupping therapy. Then, the breast cancer lump, which raised like a blooming flower, will be slowly withered after cupping therapy. The lump will come off by itself. Well, that is what my patients told me. (Aris, participant 3, CAM provider Batam, p. 7)

I also gave ointment and herbal potion to the woman. The herbal potion contains antibiotic [properties] to reduce the breast swollen and pus. It was included in the treatment for the tumour. In one month, the breast was gradually healed. The breast open wound had closed with ointment that was applied onto the breast…I believe that my herbal medicines can cure breast cancer. (Rangga, participant 4, CAM provider, Batam, p.6 & 9)

…before having germanium stone therapy, she needed to change her breast dressing and pad about 15 times a day. But after having germanium stone therapy, she changed the dressing only once a day. The breast wound is drying. (Riska, participant 5, CAM provider, Batam, p. 4)

The CAM providers mentioned that the herbal therapy given to the women with breast cancer potentially contained antibiotic properties. Also, cupping therapy and the heat from germanium therapy drained the pus off the breast cancer wound. According to the CAM providers' observations and the women with breast cancer's reports, the CAM therapies resulted in positive progress in healing and reducing the breast cancer process. These perceptions led the CAM providers to believe that CAM therapies significantly healed breast cancer.

The CAM providers also believed that CAM therapies could destroy cancer cells, resulting in cancer cells gradually decreasing in size then disappearing all together. The CAM providers' beliefs about these benefits were constructed by their observations of the women with breast cancer who they treated with CAM therapies as identified in the following excerpts:

This herbal potion can destroy cancer cells...It helps breast lump disappear. (Rangga, participant 4, CAM provider, Batam, p. 7)

There was a woman with a breast lump who came for therapy. Alhamdulillah,[23] the breast lump gradually shrunk by having a regular bloodletting therapy and consuming an herbal supplement. (Aji, participant 6, CAM provider, Batam, p.1)

The benefit of this herbal therapy is to kill cancer cells… Another benefit of herbal therapy is to increase the immune system. (Kinanti, participant 8, CAM Provider Batam, p. 4)

Well, this herbal therapy can alleviate pain and shrink breast tumours. I can see the significant effect by observing patients from the first to the second visit. For example, at the first time she came for this treatment, a woman had a swollen breast tumour. Then when she came for the second therapy, I saw the breast had flattened. My herbal therapy is not attacking the cancer cells, but it is destroying cancer cell roots. This is according to my belief, not the doctor's belief. If the cancer cells are directly destroyed instead of the roots, cancer cells can be spread. Cancer is like a tree. If only cutting of the tree, how about the root? (Dinah, participant 9, CAM provider, Bandung, p. 4)

The excerpts above indicated the CAM providers had contradictory beliefs to medical evidence regarding the control of cancer cells. The CAM providers believed CAM therapies could naturally destroy cancer cells without damaging the healthy cells. In contrast to this belief, they perceived medical cancer treatment to be harmful as it attacked both cancer cells and healthy cells. Unlike medical treatment, the CAM providers perceived that CAM therapies destroyed cancer cells from the roots stopping the cancer cells spreading to other organs.

One of the CAM providers believed CAM therapies could boost the immune system when weakened by the side effects of chemotherapy. In her understanding, many women with breast cancer died from a compromised immune system from the side effects of chemotherapy. This participant believed that CAM therapies should be utilised whilst undergoing chemotherapy as they could reduce the side effects of chemotherapy as mentioned in the following extract:

This herbal therapy can be utilised to reduce the side effects of chemotherapy. For example, while undergoing chemotherapy most patients experience nausea, hair loss, and the immune system reduces. Many women died at stage 3 breast cancer due to chemotherapy. It wasn't caused by the chemotherapy drug. The women died because the immune system wasn't strong enough. If the chemotherapy is used together with my herbal therapy, inshallah,[24] the patient will get cured. The herbal therapy reduces the side effects of chemotherapy. I gave a patient two bottles of herbal potion. After drinking the herbal potion, the patient didn't experience the side effects of chemotherapy. And, the

[23] Alhamdulillah is Arabic word means all praise to Allah (God).
[24] Inshallah is Arabic word means 'if God wills it'

herbal potion didn't interfere with the chemotherapy reaction. My herbal potion is only attacking aggressive cancer cells. (Kinanti, participant 8, CAM provider Bandung, p.6)

The participant was convinced that herbal therapy would not cause any negative impact on the chemotherapy treatment. According to the CAM provider, the combination of chemotherapy and herbal therapy resulted in short-term positive outcomes in breast cancer management.

Overall, the participants strongly believed that CAM therapies could support breast cancer wound healing, boost the immune system, destroy cancer cells, shrink breast tumours and reverse the fungating breast tumour and necrosis. Based on these potential benefits, the CAM providers were convinced that CAM therapies were effective and could cure breast cancer. Additionally, it was suggested by one CAM provider that CAM could be an adjunct to chemotherapy as it helped to relieve the adverse effects of chemotherapy. The CAM providers also believed the CAM therapies had no side effects and this belief is presented in the following sub-theme.

6.5.2. CAM is safe

All the CAM providers believed CAM therapies were safe and had no adverse effects, as they did not experience any adverse events with their clients based on their experience. According to the participants' belief, CAM therapies such as bloodletting therapy and germanium stone therapy provided more benefits than any side effects that may be produced. The long-term consumption of herbal medicine was also considered safe as the CAM providers had not seen negative reactions as demonstrated in the following excerpts:

The bloodletting therapy has no side effects. Instead, it has a good effect. (Aji, Participant 6, CAM provider, Batam, p. 5)

Germanium stone therapy is safe. As long as I have worked as a therapist, I have never found customers who are experiencing side effects of this therapy. No one reported about the side effects. (Riska, participant 5, CAM provider, Batam, p. 7)

My herbal therapy is safe. Even a pregnant woman can consume it. My herbal therapy is natural. It doesn't contain preservatives. (Riko, participant 7, CAM provider Batam, p. 4)

You can ask my patients who have consumed my herbal therapy. There was a woman who has used my herbal medicine for 10 years. I have many patients who use my therapy for more than 10 years. Not one of them complained of side effects of this herbal therapy (Dinah, participant 9, CAM Provider Bandung, p. 4)

The safety of CAM therapies was believed by the CAM providers based on their observations and reports from the CAM users including women with breast cancer. The CAM providers were unaware that their observations and the CAM users' reports were not sufficient evidence to prove the safety of CAM therapies.

In order to ensure the safety of herbal medicine consumption, two of the CAM providers suggested that their clients allow a one to two-hour interval between the consumption of the herbal therapy and the doctor's medication. These CAM providers believed herbal therapies were natural because they did not contain chemical substances or preservatives. The natural medicines did not interfere with medical treatments as mentioned by the participants in the following excerpts:

There is no side effect of the alternative treatment…Whatever the herbal therapy is, it can be consumed at least two hours after taking a doctor's medicine (Rangga, participant 4, CAM provider, Batam, p. 4)

I provide herbal therapy, which does not affect a doctor's treatment. They can be consumed together. But it needs at least a one-hour interval in the consumption of those therapies. One-hour interval. So, if patient use a doctor's medicine that is fine. But remember to make it a one-hour interval in between the treatments…It's herbal, natural and no risk. If chemical, it can affect kidneys. (Aji, participant 6, CAM provider Batam, p. 6)

One of the CAM providers revealed that the consumption of herbal therapies caused a burning sensation through all the body and this reaction indicated the herbal therapy worked well in killing cancer cells. This participant believed the burning sensation was not a negative reaction or side effect, but instead indicated the herbal therapy was effective as mentioned in the following extract:

My patients can drink the herbal therapy as much as they need like drinking mineral water. Due to the herbal liquid colour is very clear like mineral water, patients do not realised that they drink herbal liquid instead of mineral water. When the herbal therapy is consumed, the reaction is like a burning. It causes a feeling hot in the body. This reaction normally occurs after two days. The reaction indicates the herbal therapy is working to

kill the cancer cells. The dose should be increased to kill more cancer cells. The reaction feels like burning, but no side effects. It is safe (Kinanti, participant 8, CAM provider Bandung, p. 4)

As such, the CAM providers either believed their CAM therapies were totally safe and if there were any side effects this was part of the therapeutic benefit. The CAM providers believed CAM therapies were safe for breast cancer management, however, this belief was constructed by the participants' own experiences of providing CAM therapies.

In summary, this third main theme and its sub-themes represented the CAM providers' belief about the efficacy, curative nature and safety of CAM therapies. Based on their experiences, they strongly believed that CAM therapies provided potential benefits to cure the breast cancer itself, alleviate side effects, destroy cancer cells and boost the immune system. The CAM providers also believed that a strong immune system reduced the side effects of medical treatment and accelerated the breast cancer wound healing process. Additionally, the CAM providers viewed that CAM therapies were safe and would not interact with any chemotherapy or medical treatment. Based on these beliefs, the CAM providers suggested medical treatment should be integrated with CAM therapies.

6.6. Theme 4: Progressive and not so progressive attitudes toward CAM

The fourth main theme presents the CAM providers' expectations about CAM practices in Indonesia. Most of the CAM providers promoted CAM therapies to be used as a substitute for medical treatment rather than an adjunct therapy to support medical treatment. There were only a few CAM providers who stated that CAM therapies should and could be integrated with conventional medical treatment for breast cancer. Those who supported CAM as a primary breast cancer treatment showed they were critical toward conventional medicine, and suggested to the women with breast cancer not to access the prescribed medical treatment. The CAM providers expressed confidence in providing CAM therapies, although they had no education, regulations, standards or certification as a professional

CAM therapist. These attitudes are demonstrated below in the sub-themes of supporting CAM as adjunct therapy and alternative medicine and expecting CAM education development and practice acknowledgement.

6.6.1. Supporting CAM as an adjunct therapy and alternative medicine

Three of the 10 CAM providers suggested CAM therapies should be integrated with medical treatment as they could support medical treatment to cure breast cancer and relieve side effects of medical treatment. The lack of support for CAM therapy practices in Indonesia was raised by the CAM providers. According to their perceptions, CAM therapies were unacceptable and unrecognised by the healthcare system in this country. Some of the CAM providers believed medical treatment should be combined with CAM therapies as stated in the following excerpts:

> *Doctors in hospital should be tolerant to facilitating alternative therapies even it is illegal…When the medical treatment cannot manage the symptoms, why don't they transfer the patient to other expertise like alternative treatment? It would be good if cancer hospitals can provide non-medical treatment facilities. Both medical and alternative treatment should be integrated so that patients will feel more comfortable and confident to use those treatments. The non-medical treatment can accelerate the healing process. The government should not keep their ego of centralization healthcare system in which all diseases have to be cured by medical treatment. Do not being like that. It has to be balanced. Working together and supporting each other's treatment. (Aris, participant 3, CAM provider Batam, p. 10)*

> *…In China, many sciences came from traditional treatment. Medical doctors are learning together with traditional healers. But in Indonesia it has not happened…Well, I didn't understand why in Indonesia, traditional treatment and conventional medicine have not worked together…It is my expectation, if it can be possible to combine traditional medicine and medical treatment. I wish traditional therapy in Indonesia was officially recognised and rightful. (Rangga, participant 4, CAM provider Batam, p.2, 3 & 11)*

> *Herbal therapy should be combined with chemotherapy and radiotherapy. It's a must...My herbal therapy has to work together with chemotherapy. (Kinanti, participant 9, CAM provider Bandung, p. 4)*

The excerpts above indicated a need for acknowledgement and the regulation and legalisation of CAM practices. Some CAM providers had strong motivations to collaborate with healthcare professionals in treating breast cancer, whilst others were critical about medical cancer treatment, and what it could do for women with breast cancer.

Five of the CAM providers emphasised that CAM therapies should be used as an alternative or substitute treatment to replace medical cancer treatment. In their understanding, CAM therapies, including herbal therapy, bloodletting therapy, and germanium stone therapy, were effective ways to cure many diseases including breast cancer. The CAM providers suggested these natural treatments were an alternative treatment option if medical treatment was unsuccessful. Some of the CAM providers had critical attitudes toward medical cancer treatments and they encouraged women with breast cancer to avoid surgery or chemotherapy as mentioned in the following excerpts:

> *I am very supportive of herbal therapy as an alternative medicine…Alternative treatment is a real cure. Many people have a successful treatment with alternative medicine. They got cured. So far, I use 100% herbal medicine. Well I can say about 60% of patients got cured (Riko, participant 7, CAM provider Batam, p. 7 & 8)*

> *I agree that germanium therapy should be used as an alternative therapy. I have seen many customers who didn't get cured by using medical treatment. Instead, this germanium therapy that healed them. So, germanium stone therapy can be used as an alternative treatment. (Riska, participant 5, CAM provider, Batam, p. 6)*

> *In my opinion, alternative therapy is good. Women don't have to depend on medical treatment. We have to avoid side effects of chemical medicine. That's it. We go back to nature. (Jamila, participant 2, CAM provider Batam, p. 2)*

> *I believe in alternative treatment because it was existed before medical treatment was available. In the past, there was no doctor. The only healers were tabib and sinshe. All medicine was herbal. In this world, before doctors existed, all sick people used herbal therapy. (Riko, participant 7, CAM provider, Batam, p. 7)*

> *I have seen the reality. I don't mean to insult chemotherapy. But you can see, si chemotherapy always successful? Can chemotherapy can cure cancer? Can you tell me where the chemotherapy success is? In this CAM clinic, we have a medical team and a cancer expert to diagnose cancer. But we don't recommend surgery. We don't do biopsies and surgery for cancer treatment…I say to all my customers, 'don't ever use chemotherapy, no chemotherapy'. (Nanik, participant 9, CAM provider Bandung, p. 1 & 5)*

It was evident that the CAM providers supported the women with breast cancer to use alternative medicine as their primary breast cancer management. They discouraged and recommended women with breast cancer to not use medical cancer treatment as they wanted the women with breast cancer to use CAM therapies only. The CAM providers stated that they often saw end stages of breast cancer.

Some of the CAM providers were very confident and proud of their ability to heal sick people with medical conditions including women with breast cancer. The CAM providers claimed that the alternative medicines they provided were trusted by their customers from all socioeconomic levels. This reputation was recognised through word of mouth, advertising and media publications. One of the CAM providers stated her herbal therapy laboratory test results found a particular CAM therapy was effective in killing cancer, and that this result was concurred by a doctor. For example the CAM providers stated the following:

> *…women receive information about my treatment through word of mouth. For example, most of my patients are Chinese Islanders and local people. People can see that Chinese Islanders use my treatment even though they can afford treatment in Singapore and Malaysia. Chinese Islanders are rich people. If I am not qualified enough, why do they come to me? ... I am strongly expert in traditional medicine, as you can see in my brochure. (Rangga, participant 4, CAM provider, Batam, p. 10)*
>
> *…I have provided hundreds of free treatments, my name got famous - so that I received a reward from the government. (Riko, participant 7, CAM provider, Batam, p.8 & 9)*
>
> *I published via communication media including radio and television. I keep publishing my treatment until now. (Aris, participant 3, CAM provider, Batam, p. 1)*
>
> *Then I tested the herbal therapy in a laboratory. A doctor in that laboratory claimed my herbal therapy is the best. The herbal therapy is very effective in killing cancer cells. (Kinanti, participant 8, CAM provider, Bandung, p. 2)*
>
> *I strongly believe in bloodletting therapy because I have experienced it on myself. In a month, approximately 1000 people come to me for this therapy. I believe in this therapy by seeing the people's enthusiasm. Patients come and go then come back with bring more people for this therapy. If this therapy has no benefits, why do they come and bring more people? Why do they talk about this therapy to others? I have experienced the effectiveness of this therapy. If it is not effective, I don't think people would come for this therapy. (Aji, participant 6, CAM provider Batam, p. 7)*

The CAM providers qualified themselves as an alternative medicine expert based on their personal experiences and their popularity in the community. Many people including women with breast cancer believed in CAM therapy provided by the CAM providers, even though the CAM providers had no formal education, and CAM training, or were not certified as a professional CAM therapist.

Most of the CAM providers practiced CAM therapies as a livelihood. They traded imported health and wellbeing products. Marketing strategies allowed the CAM providers to earn

greater profits based on increased product sales. As one way to achieve increased profits from CAM practice, the CAM providers made CAM products as a requisite treatment for women with breast cancer. According to CAM providers, CAM therapies were offered to be commercialisation by the CAM providers in hospital settings. The CAM providers provided health and wellbeing options as an alternative medicine to cure many diseases including breast cancer as described in the following excerpts:

> *I sell many types of herbal supplements. All the best quality herbal products are available here. I have a superior product as well - the name is xxxx. This herbal product is from America and I have been to the product manufacturer in America…I provide the best products that potentially can cure cancer. I offer it to women who have breast cancer. If they like, they can buy it…Then I provide water therapy. Water therapy is a filtered water using alkaline water machine and it is prayed on. The alkaline water for therapy is must be bought from me because I have a special prayer for it…Politics is my hobby, and the bloodletting therapy's provider is my profession. For my hobby, I need to spend money. But my profession is to earn money. (Aji, participant 6, CAM provider Batam, p.1, 2, 5 & 6)*

> *I learnt about herbal therapy from the company that produces Halal herbal products. I received information about herbal therapy from my tutor. He was the one who created this herbal therapy. I didn't pay for the herbal therapy training course. He invited me. He provided accommodation, pocket money and free herbal therapy courses. (Jamila, participant 2, CAM provider Batam, p.4 & 6)*

> *I obtained the above information from the germanium therapy company centre, from Korea. I was trained by their people. I was taught how to give information and perform the therapy on customers. I have a certificate. It was a three-month training course…I was provided materials related to how to give a presentation to the customers, material for the presentation, and how to care for a sick person (Riska, participant 5, CAM provider, Batam, p. 2)*

> *My expectation for hospitals to accept non-medical therapy, which potentially can support the healing process. It can be commercial if the hospital wants it to be commercial. Can you imagine, one injection of my herbal therapy was sold for IDR 75.000.000 (AUD$7500) (Kinanti, participant 9, CAM provider, Bandung, p. 7)*

The excerpts above indicated that some of the CAM providers were more likely to view themselves as health and wellbeing product distributors and suppliers than a professional CAM therapist. The CAM products were provided based on marketing strategies rather than evidence-based, credible information. The manufacturers and the CAM providers targeted people with cancer including women with breast cancer by persuading or obligating them to purchase CAM products to treat breast cancer.

Deception in CAM practices particularly for breast cancer management was mentioned by one participant. According to his report, there were many corrupt CAM providers offering fraudulent CAM therapies for breast cancer management. According to this CAM provider, these CAM providers misled women with breast cancer with claims about their healing abilities, including a cure for the cancer, by transferring the disease into an animal as stated in the following excerpt:

> *There was a breast cancer woman who came to me. She said that she had spent about IDR 20.000.000 (AUD $2000) to buy an animal as required by a therapist for a ritual. With the ritual, the therapist transferred the breast cancer from the woman to the animal. In fact, the breast cancer could not be transferred to the animal; instead, it got worse. This was a deception. The illness was not cured, but money had been wasted. Poor her. That's why she came to me. (Aris, participant 3, CAM provider, Batam, p. 10)*

The CAM provider's experience above indicated that one of his customers who had breast cancer became a victim of a fraudulent CAM practice.

Overall, the 10 CAM providers who participated in this study supported CAM therapies as a substitute for medicine rather than as an adjunct therapy. Most of the CAM providers offered CAM as a primary breast cancer management for women with breast cancer and discouraged them from accessing medical treatment. Some of the CAM providers made their CAM practices profitable businesses by being influenced by manufacturers of herbal medicines and other CAM products. Some CAM providers commercialised fraudulent CAM therapies. Some of the CAM providers discussed the need for formal education to develop their knowledge and skills for providing CAM therapies, so that they could be officially acknowledged as a professional CAM therapist.

6.6.2. Expecting CAM education development and practice acknowledgement

The CAM providers expressed that formal education and training related to CAM therapies were not available in Indonesia. Unlike, medical health professionals, the CAM providers identified themselves as unofficially recognised because they had no certified qualifications. Consequently, the CAM providers wished to develop their knowledge and skills in CAM

therapies through formal education so that they would be eligible to be certified professional CAM therapist as mentioned in the following excerpts:

> *In Indonesia, there is no formal education or training for cupping therapy. There is only a short course, a two-month course…So I didn't take a long time to learn about this. Different to physicians and nurses who study for at least three years according to a curriculum. (Aris, participant 3, CAM provider Batam, p. 4)*

> *…traditional medicine in Indonesia has been accepted but the therapist has no certification. There was no CAM therapies school. I mean, by having certification from a formal education, I want traditional healers to be officially recognised by the government. Like medical doctors and professionals, they are recognised since they have academic certificates. It is not available in traditional medicine. If formal education for traditional treatment existed, therapist can learn and receive academic certificate then recognised by the government… Traditional treatment has no certification which recognised by the government. That's my intention. I want to have traditional treatment academic certification that is officially recognised by the government. Not only medical doctors can have a certificate but also traditional healers. (Rangga, participant 4, CAM provider Batam, p.11-12)*

Most of the CAM providers had strong intentions to develop their knowledge and skills in formal CAM therapy education. As described by the participants, certified qualifications would enable them to be recognised as a part of professional health workers. However, to the CAM providers' knowledge, formal education for CAM therapies in Indonesia was limited. According to the participants, there would be a high demand to expand the limited options to more formal CAM therapy education in Indonesia.

The CAM providers claimed that they encountered some challenges in obtaining research approval for CAM therapy trials. They also stated challenges in obtaining an official permit to practice CAM therapies. One of the participants reported failure to obtain research approval to trial an herbal therapy on hospitalised women with breast cancer. Finally, this participant personally approached a healthcare worker and obtained access to women with breast cancer to experiment with the herbal potion as described in the following extracts:

> *I wrote a proposal to trial my treatment and submitted it to a hospital. My proposal was refused because I proposed to combine medical treatment and herbal therapy. It was refused. Finally, I approached a doctor without a proposal. I was sick of it. But I kept begging the doctor so that the doctor accept my herbal therapy to be tested on cancer patients. I said to the doctor, 'Doctor, please try this herbal therapy. It's free, no need to pay. You can inject or administer it via intravenous infusion to cancer patients. It's fine'.*

Then may be the doctor thought about it. Finally, the doctor agreed to inject the herbal potion. Since that he shared his knowledge with me. (Kinanti, participant 7, CAM provider, Bandung, p.10)

Having an idea to conduct research investigating the efficacy and safety of CAM therapies on patients indicated the participant possessed a progressive attitude toward scientific research on CAM therapies. However, the CAM provider had very little understanding of research processes and appeared to have no knowledge of ethical responsibilities toward research participants.

Another participant felt constrained by government regulations and policies for getting official CAM practice permits, standards and regulations. A clinic that provided both conventional and CAM was closed due to failure to obtain permission by the government health department. This participant identified unclear regulations and policies regarding the implementation of CAM practices in Indonesia as mentioned in the following extract:

CAM therapies have potential benefits. But to practice CAM, I was being constrained by the health department. CAM practice regulation in Indonesia is very complicated. This is the problem why this CAM clinic has not been fully re-opened again. I want my clinic to become the first CAM clinic in Indonesia. Recently there is a new council regulation PPRI 103[25] that allows complementary therapy practice. I want this policy that can be implemented in Indonesia. However, health department staff claimed that the regulation has not available. But I really want that the integration of CAM and conventional medicine implemented here [in the clinic] …Literally, CAM therapies should be provided by medical professionals. It cannot be called CAM therapy if it is not provided by a medical health care worker. Therefore, the Indonesia's health department disallowed us from providing CAM therapy. To them, our treatment is categorised as alternative medicine. But my expectation, this clinic should be accepted because many people want to use this therapy. (Nanik, participant 10, CAM provider Bandung, p.1 & 2)

The participant's statement above indicated that the integration of conventional medicine and CAM therapies had not been well implemented in Indonesia. The CAM providers were unfamiliar with CAM practice regulations and policies. This led to misperceptions about both complementary and alternative medicine practices. The CAM providers did not understand

[25] PPRI 103, which stands for Peraturan Pemerintah Republic Indonesia means Government policy and Rules of the Republic of Indonesia number 103

that certification in CAM therapy education and training would be required to obtain a regulated CAM practice permit.

Overall, a lack of formal education and familiarity with regulations and policies in relation to CAM therapies limited the CAM providers from gaining certification to practice CAM, as well as conducting research in their practice or a clinical setting. The CAM providers wished to have formal education that would allow them to be competent and professional CAM therapists.

This final main theme presented the CAM providers attitudes and expectations toward CAM therapies practice for breast cancer management. The CAM providers were supportive and confident about the use of CAM as an alternative to medicine rather than using it as adjunct therapy.

This fourth main theme also uncovered corruption and deception in CAM therapy practice, as the CAM providers promoted and commercialised herbal food supplements and promoted other health equipment products as a cure for cancer. Most CAM therapies were provided as one profitable business in healthcare. Some of the CAM providers acknowledged the importance of formal CAM education, as the knowledge and skills in CAM would allow them to obtain a legal licence to practice CAM and conduct research on CAM therapies. Accordingly, these CAM providers were enthusiastic to develop their knowledge, skills and learn more about CAM practice regulations, standards, and policies.

6.7. Similar and divergent views of women with breast cancer and CAM providers

The thematic analysis of this study identified similarities and disparities in the views of women with breast cancer and CAM providers about the use of CAM for breast cancer management in Indonesia. In terms of convergent views, both groups of women with breast cancer and CAM providers considering CAM as potential alternative medicine for

breast cancer management believed in non-evidence based CAM and espoused the potential benefits of CAM. Divergent views were identified with different perceptions regarding CAM being a promising cure or not being a cure at all. The convergent and divergent views are discussed in the following section.

The first common view that emerged through the findings was that CAM was a potential alternative medicine for breast cancer management. Based on women with breast cancer experience and CAM providers understanding, CAM was used for breast cancer management due to women with breast cancer's inability to access and pay for medical cancer treatment, a lack of knowledge and awareness, fear or disappointment with medical treatment and finally, family influences. Compared to medical cancer treatment, CAM was perceived to be more accessible and affordable. Hence, the women with breast cancer and CAM providers viewed CAM as a suitable alternative medicine for breast cancer management when medical cancer treatment was not available.

Believing in non-evidence-based CAM was the second similar view expressed by women with breast cancer and CAM providers. Women with breast cancer used CAM based on the unfounded beliefs, religious beliefs and personal experience of other people. Similarly, most of the CAM providers provided ancient traditional CAM therapies based on their supernatural gifted, religious and spiritual beliefs. These similar beliefs highlight that both participant groups were not unaware of, but also had inadequate knowledge of, the efficacy and safety of non-evidenced based CAM. Believing in non-evidence-based CAM led to the use of inappropriate treatment resulting in negative outcomes and also harmful side effects.

Another convergent view was the belief in the potential benefits of CAM. Both participants groups were confident that CAM provides potential health benefits such as reducing pain, increasing physical strength, boosting the immune system, and preventing the growth of

cancer cells. Being safe and less expensive were other potential benefits of CAM viewed by women with breast cancer and CAM providers. The views regarding potential benefits of CAM evolved through women with breast cancer's personal experiences, and CAM providers' observations on women with breast cancer responses toward CAM. However, personal experience would not be adequate to prove potential benefits of CAM as each individual responds differently to CAM. Despite some women with breast cancer and CAM providers' experiences of the potential benefits of CAM, there were also potential adverse effects of CAM experienced. Several negative experiences that occurred from using CAM brought some women with breast cancer to acknowledge the futility of this therapy resulting in divergent views, as explained below.

Contradictory views on the use of CAM as an alternative medicine for breast cancer management were revealed by some women with breast cancer who acknowledged the potential toxicity of CAM, experienced its unpleasant taste of herbal medicine, and the futility, as well as doubted CAM safety and legality. These women with breast cancer expressed strong aversion to the use of CAM that was offered by unprofessional CAM providers as an alternative medicines to cure breast cancer. According to these women with breast cancer's experiences, CAM could not cure breast cancer because CAM provided only short-term therapeutic effects to relieve breast cancer symptoms. The women with breast cancer viewed the use of CAM as being futile as it delayed medical cancer treatment, resulting in breast cancer developing into advance stages, and some to an incurable terminal stage.

Furthermore, doubt on legality of CAM practice was revealed by women with breast cancer who experienced the use of fraudulent CAM. The women with breast cancer felt they were being deceived and exploited by unprofessional CAM providers who offered CAM to be used as an alternative medicine, and who discouraged them to use medical

cancer treatment while using CAM. The women with breast cancer viewed that these behaviours would not only inflict financial loss but also cause physical and emotional harm. Thus, it was suggested by the women with breast cancer that government surveillance on fraudulent CAM practices in Indonesia should be enhanced. Some of the women with breast cancer views emphasised that CAM should not be used as an alternative medicine for breast cancer, and the use of CAM as a complementary therapy should be administered by professional CAM providers.

In contrast to women with breast cancer's view above, the majority of CAM providers in this study perceived CAM as a promising cure for breast cancer. The CAM providers strongly believed that CAM could cure breast cancer without medical cancer treatment, although there was no scientific evidence to date proving its efficacy and safety. The CAM providers in this study proposed CAM should be officially integrated into the healthcare system because the healing process cannot be separated from religious and cultural belief supports where these are provided in CAM. In addition, the CAM providers viewed CAM to be a great business opportunity in healthcare services, as this therapy is highly sought after by people with cancer including the poorer women with breast cancer in this study and those who refused medical cancer treatment. Accordingly, the CAM providers argued that their position should be acknowledged as being included with the other professional healthcare CAM providers such as doctor, nurses and other health practitioners. The CAM providers particularly those in rural and remote regions expected CAM practice registration and licencing processes to be more accessible and available in the future.

The similar and divergent views of women with breast cancer and CAM providers provide essential insights and understandings about the reality of CAM use for breast cancer in Indonesia. The convergent views showed evidence that there is an urgent need to

enhance women with breast cancer's awareness and to increase CAM providers' knowledge about the appropriate breast cancer treatment. The views of women with breast cancer and CAM providers regarding CAM were evident that CAM practices in Indonesia need to be improved. Prospect strategies are offered in the next section which examines the implications of this study.

6.8. Chapter summary

The findings in this chapter described and interpreted the CAM providers' perceptions, attitudes, knowledge and expectations toward CAM therapies for breast cancer management in a remote and a metropolitan city in Indonesia. The CAM providers identified that having advanced breast cancer symptoms, poverty, lack of knowledge and unsuccessful medical treatment were the specific characteristics of women with breast cancer who used CAM for breast cancer management. None of the CAM providers were certified as a competent CAM therapist as they had no formal education or training in CAM therapies. Most of the CAM therapies provided by the CAM providers were administered using ancient traditional methods based on their natural healing ability, religious and spiritual beliefs. The cost of CAM therapies was perceived to be more affordable than medical cancer treatment. It was also reported by the CAM providers that they believed CAM therapies to be effective, safe and could cure breast cancer. The CAM providers used these beliefs to deceive women with breast cancer to use CAM as an alternative to conventional medicine, rather than to use CAM as a complementary therapy. Corruption was identified by the CAM providers in CAM practices that generated additional money but were harmful to the women with breast cancer. Finally, the CAM providers identified the need for formal education in relation to CAM therapies, as they wished to be accepted and acknowledged as a competent professional CAM therapist. Eventually, it was hoped by CAM providers that the integration of CAM therapies and medical treatment could be officially implemented in Indonesia.

In Chapter Five, the women with breast cancer's experiences were presented and the findings of CAM providers in this current chapter have been discussed. The women with breast cancer's experiences and the CAM providers' perceptions as well as their attitudes toward the use of CAM therapies for breast cancer management indicated similar and different meanings for the two cohorts. Both the women with breast cancer and CAM providers' views and experiences had positive and negative impacts on the breast cancer management in a remote area and a metropolitan city in Indonesia. The following chapter (Chapter Seven) will discuss the findings of this study, as well as important points to consider in the use of CAM for breast cancer management in Indonesia. This discussion chapter will be followed by the final chapter, Chapter Eight, which will conclude the thesis by discussing the implications from this study for the healthcare system, nursing practice, CAM education and further research, policy makers, CAM providers and women with breast cancer in Indonesia specifically in Batam and Bandung.

CHAPTER SEVEN: DISCUSSION OF THE FINDINGS

7.1. Introduction

The previous two chapters of findings presented the descriptions of the women with breast cancer‘s experiences and the views of the CAM providers regarding the phenomena of CAM use for breast cancer management. This current chapter provides a detailed discussion of these findings. The findings highlighted in Chapter Five revealed four main themes of women with breast cancer experiences in the use of CAM. These included ‘Access, affordability and support for medical treatment’, ‘Believing in CAM therapies’, ‘Feeling the potential benefits of CAM’, and ‘Acknowledging the negative aspects of CAM’. Chapter Six presented the four main themes that emerged from the CAM providers’ views and understandings of the use of CAM for breast cancer management. The main themes were ‘Characteristics of women with breast cancer who used CAM’, ‘Providing non-evidence-based CAM’, ‘CAM providers’ beliefs of potential benefits of CAM’, ‘Progressive and not so progressive attitude towards CAM’. Additionally, the women with breast cancer and CAM providers’ convergent and divergent views about the use of CAM were presented in Chapter Six.

The emerging themes have been interpreted using a hermeneutic phenomenological approach in order to gain meaning and a deeper understanding of the phenomena related to the use of CAM for breast cancer management. In this chapter, the themes are discussed and evaluated using existing academic peer-reviewed literature. The following discussions of the findings, which will be explained in detail, have been guided by a specifically developed framework that has integrated van Manen’s life existential concepts and the CAM Healthcare Model. Justification for the use of this integrated framework is explained below.

7.2. Framework

Integration of the five lived existential concepts of van Manen (van Manen, 2016), and the CAM Healthcare Model (modified by Fouladbakhsh and Stommel (Fouladbakhsh & Stommel, 2007)) was utilised as the framework to structure the discussion of the findings. The CAM Healthcare Model is a modification of a previous model, Anderson's Behavioural Model of Health Service Use (Fouladbakhsh & Stommel, 2007). The Behavioural Model for Health Service Use has been utilised over the past three decades, as a framework to guide research examining factors that predict utilisation of and access to health services (Babitsch, Gohl, & von Lengerke, 2012; Fouladbakhsh & Stommel, 2007). For example, Graham, Hasking, Brooker, Clarke, and Meadows (2017) claimed that the use of Anderson's Behavioural Model of Health Service Use successfully depicted mental health services use among Australians with depression. A qualitative study conducted by Condelius and Andersson (2015) also applied Anderson's behavioural model of health service use in exploring factors related to care access among older people in the last phase of their life in Sweden. They stated that the utilisation of this behavioural model in the qualitative study guided older people to talk about the satisfaction or dissatisfaction with access of care (Condelius & Andersson, 2015).

The Behavioural Model of Health Service Use could also potentially be used in CAM healthcare studies (Fouladbakhsh & Stommel, 2007; Hendrickson, Zollinger, & McCleary, 2006). Hendrickson et al. (2006) used this model in their study as a framework to assess the social and health determinant factors of CAM use among adults in Kansas. Faith, Thorburn, and Tippens (2013) claimed that the Behavioural Model of Health Service Use was a useful framework for identifying factors that were associated with CAM use disclosure based on data from the 2001 Health Care Quality Survey in the United States. Similarly, Upchurch and Rainisch (2015) stated that the application of the model provided a comprehensive picture of CAM use for both wellness and treatment based on data from the

2007 National Health Interview Survey in the United States. In addition, Lo-Fo-Wong, Ranchor, de Haes, Sprangers, and Henselmans (2012) used the CAM healthcare model as a guide to examine stability of CAM use among Dutch women with breast cancer. They claimed that the CAM Healthcare Model provided specific functions to identify stability of CAM use, prevalence of CAM use, reasons for use, and psychological predictors of use between provided-directed and self-directed use of CAM (Lo-Fo-Wong et al., 2012).

The application of the CAM Healthcare Model in the previous studies indicated that this model could potentially be used as a framework in discussing women with breast cancer's lived experiences, and CAM providers' views about the use of CAM for breast cancer management in Indonesia. In addition, van Manen's five life existential concepts: relationality (lived self-other), corporeality (lived body), spatiality (lived space), temporality (lived time), and materiality (lived things), assisted in the exploration of the meaning aspects of participants' lifeworld of the particular phenomena under study as explained in Chapter Three (van Manen, 2016). Reflections of the five life existential concepts underpin the discussion of each empirical indicator described in the CAM Healthcare Model regarding the use of CAM.

There were four justifications for the use of the integrated CAM Healthcare model and van Manen's concepts as a framework to discuss the findings of this study. Firstly, the CAM Healthcare Model provided a guide for the researcher to understand CAM health behaviour including factors associated with the use of CAM (CAM providers, practices, and products), patterns and purposes of use, as well as related outcomes. Secondly, in this study context, the application of the CAM Healthcare Model assisted in identifying determinant factors that influenced the utilisation of CAM and CAM provider services for breast cancer management. Thirdly, the use of this framework also assisted in the description of potential empirical indicators specific to the use of CAM, based on women with breast cancer's lived

experiences and CAM providers' views. Finally, the CAM Healthcare Model provided a suitable structure so that a general behaviour of CAM used for breast cancer management underpinned by women with breast cancer's lived experiences and CAM providers' views could be reflected through the five existential concepts.

The CAM Healthcare Model describes the use of CAM as a function of five broad determinants: i) predisposing factors, ii) enabling factors, iii) need for care factors, iv) health service use, and v) outcomes of care (Fouladbakhsh & Stommel, 2007). In this study context, the predisposing factors discussed the demographics (gender, marital status and age) and social structure of CAM use (knowledge and culture practice). The enabling factors described how resources, access, availability of CAM and conventional services and geographic location relate to the use of CAM (Fouladbakhsh & Stommel, 2007). Based on women with breast cancer's lived experiences and CAM providers' views, (7.4.1) poverty, and (7.4.2) lack of access and availability of medical treatment were identified as the enabling factors to the use of CAM for breast cancer management.

The need for care factors explains health status or illness conditions as triggers to the use of CAM. These are included to relieve breast cancer symptoms, reduce the side effects of chemotherapy and prevent recurrent breast cancer. The health service use concept describes how CAM is received and used, as well as the purposes and the manner of CAM use. This concept discusses the need for professional CAM providers and standardised CAM products, as well as self-directed CAM practices that are commonly used by women with breast cancer. In terms of purposes and manners of use, this concept explains how CAM was used as a primary treatment instead of an adjunctive therapy to support medical cancer treatment. The last factor, outcomes of care, elucidates the efficacy and safety of using CAM that were experienced by women with breast cancer in this study. Additionally, the CAM providers' views on CAM are reinforced in this discussion. Figure 6 (p. 212) below

shows the framework that has been used to guide discussions of the women with breast cancer's lived experiences and CAM providers views in the use of CAM for breast cancer management in Indonesia.

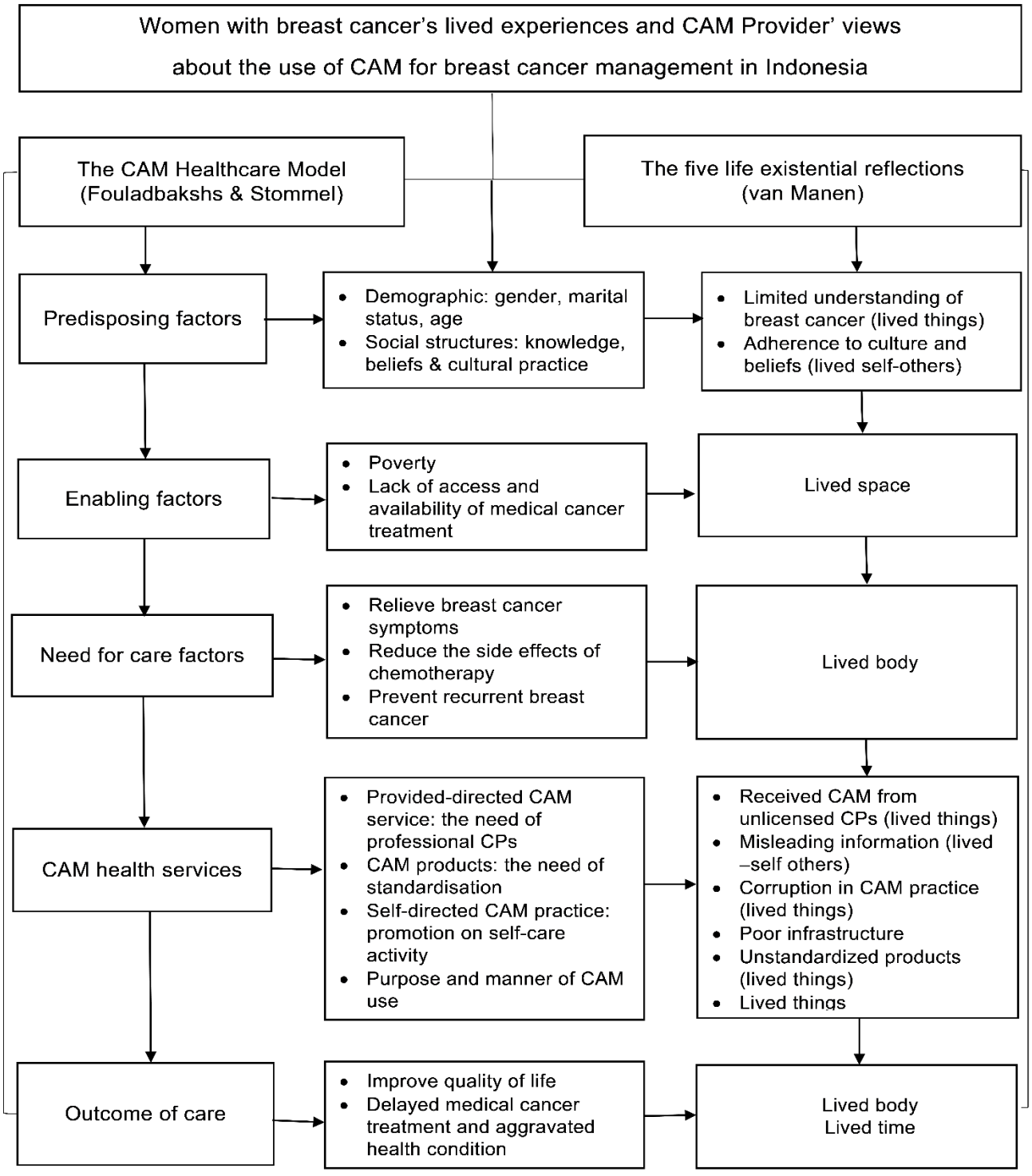


Figure 6: The integration of van Manen's life existential concepts and the CAM Healthcare model developed by Fouladbakshs and Stommel (2007).

7.3. Predisposing factors

According to Fouladbakhsh and Stommel (2007), predisposing factors describing an individual's tendency to use CAM incorporates several categories including demographics and social structure (Fouladbakhsh & Stommel, 2007). In this study, demographic factors include gender, age and marital status of the women with breast cancer. Social structure demonstrated education levels, cultural practice, CAM knowledge, belief and values as factors in the use of CAM. Beliefs and values factors indicate how believing in health and illness, as well as healthcare treatment and satisfaction are related to the use of CAM. The predisposing factors will be discussed in detail in the following sections.

7.3.1. Demographics – Gender, marital status and age

The women with breast cancer's gender and marital status were considered as predisposing factors for the use of CAM, because most of the married women with breast cancer who participated in this study used CAM based on their husbands' decisions. The ages of the women with breast cancer varied from 23 to 66 years old (see Table 6, p. 112 for the demographic data of women with breast cancer). The age of women with breast cancer in this study was similar to participants' ages in previous qualitative studies in other Asian countries including Malaysia (Muhamad et al., 2012), and in studies from Thailand (Sirisupluxana et al., 2009). The demographic data of those studies showed that the use of CAM for breast cancer management was used by women with breast cancer from different age groups. The correlation between age and CAM usage has been investigated in quantitative studies. A number of cross-sectional studies in Asian countries identified that the use of CAM for breast cancer management was not significantly associated with age (Chui et al., 2014; Kang et al., 2012; Knight et al., 2015). Both findings of this study and of previous studies indicate that CAM was favoured among women with breast cancer at all age levels.

However, in this study the lived body (*corporeality*) concept reflected that an intention to use CAM was related to age. For example, the oldest participant in this study reported that she refused chemotherapy due to her age being 66 years, where she assumed that her body at this age would not be able to cope with the debilitating effects of chemotherapy. She also mentioned that she witnessed a friend who suffered then died of the side effects of chemotherapy at an older age. This negative experience discouraged the participant from choosing CAM instead of chemotherapy; hence, she chose CAM instead as she expressed that she would like to enjoy her end of life with CAM rather than suffering from the side effects of chemotherapy.

In contrast, a quantitative study that was conducted by Wong et al. (2014) in Singapore found that women with breast cancer at a younger age were more likely to use CAM than those at an older age. Wong et al. (2014) stated this was because younger women with breast cancer perceived CAM to be a natural remedy that provides a holistic cure; hence, they used it immediately after their breast cancer diagnosis. Elderly women with breast cancer considered CAM as an alternative medicine due to assuming their bodies at an older age might be more likely to have debilitating side effects from chemotherapy. However, the literature suggests that medical cancer treatment, including chemotherapy significantly improved overall survival rates in women with breast cancer at all ages including the elderly (Berthelot et al., 2019; Jeon et al., 2019; Johnson, Agbisit, Delfino, Robinson, & Desai, 2019; Mok, Yoo, & Chae, 2019; Nakayama, Shimizu, Iino, Watanuki, & Sawaki, 2020; Sawaki et al., 2019).

Overall, the elderly participants in this study were unfamiliar with the benefits of medical cancer treatment, and unaware that their body would respond differently to breast cancer treatments including CAM. Thus, counselling by professional healthcare personnel may help

elderly women with breast cancer in making informed decisions about breast cancer treatment.

7.3.2. Social structure – Knowledge, beliefs and cultural practices

Social structure, as a predisposing factor, describes the contribution of education levels and knowledge, beliefs, and cultural practice that impact on the use of CAM (Fouladbakhsh & Stommel, 2007). The demographic data of the women with breast cancer in this study indicated that CAM was used by women with breast cancer with lower and higher education levels. This means the use of CAM was not associated with education levels. This finding is supported by a number of studies in Asian countries that found there was no significant correlation between CAM usage and education levels (Kang et al., 2012; Knight et al., 2015; Wanchai et al., 2012, 2016; Wong et al., 2014).

A more recent survey in Indonesia revealed that the use of CAM was strongly associated with women with breast cancer's education levels (Azhar et al., 2016). That study found the women with breast cancer with lower education levels were more likely to use CAM than those with higher education levels (Azhar et al., 2016). Azhar et al. (2016) stated this was because women with breast cancer with a lower education expected a cure from using CAM; in contrast, those with higher education levels were more aware of CAMs potential interactions when integrated with medical treatment. That study considered knowledge, as opposed to education level, as one of the main predisposing factors for the use of CAM instead of education levels, although did acknowledge there might be some impact from education levels. In this study, social structure factors were dominantly related to knowledge about breast cancer and CAM, as well as cultural practices. These factors were demonstrated by limited understanding of breast cancer and CAM, and adherence to cultural practices and beliefs.

7.3.2.1. Limited understanding of breast cancer (Lived things)

Limited understanding of breast cancer was identified as one of the main predisposing factors for the CAM use. This factor was reflected by the lived things (*materiality*) concept, in which this concept asked how things were experienced in relation to the phenomena (van Manen, 2016). In this study, women with breast cancer were asked how breast cancer and its treatment was experienced in regard to the use of CAM. The lived things *(materiality)* reflected CAM as an option to cure breast cancer due to fear of medical cancer treatment, where the fear was the result of limited understanding of breast cancer. According to 'the lived things' concept, women with breast cancer experienced surgery and chemotherapy as frightening breast cancer treatments. For example, women with breast cancer believed surgery could stimulate breast cancer cells growth, and the side effects of chemotherapy could cause premature death. These unfounded beliefs were conceived by women with breast cancer from other people's lived experiences, resulting in the refusal of medical treatments and a preference to use CAM as their treatment option.

The use of CAM by women with breast cancer due to being afraid of medical cancer treatments was also revealed by CAM providers in this study. The majority of CAM providers claimed CAM was highly sought after by women with breast cancer who feared both surgery and chemotherapy. It was evident that the combination of fear and lack of knowledge led the women with breast cancer to use CAM. Similarly, a qualitative study conducted by Nies, Ali, Abdullah, Islahudin, and Shah (2018) also found that Malaysian women with breast cancer in their study sought alternative medicine for breast cancer treatment due to fear of death caused by the side effects of chemotherapy. Fear of medical cancer treatments might occur due to the lack of knowledge about the effectiveness and safety of medical treatments (Nies et al., 2018; Wagner, Lüdders, Hoellen, Rody, & Banz-Jansen, 2019), as well as a lack of understanding of the importance of medical cancer treatments (Martei, Vanderpuye, & Jones, 2018; Nies et al., 2018; Sanuade et al., 2018; Shaverdian et al., 2018). Fears due

to limited understanding of medical cancer treatment led women with breast cancer in those studies to use CAM and delayed them from substantive medical breast cancer treatment. The behaviour of delaying medical cancer treatment has the potential to negatively impact on women with breast cancer's quality of life.

According to Liu et al. (2018) inadequate knowledge of breast cancer leads to poor awareness levels of the importance of early breast cancer assessment procedures. Similarly, the lived things (*materiality*) concept applied to this study indicates that CAM was used by women with breast cancer due to their inability to identify early breast cancer symptoms, and their fear of a medical breast medical examination. For example, the women with breast cancer and CAM providers in this study perceived that breast cancer symptoms such as a lump, changes in breast skin colour, and nipple discharge as common diseases that could be treated by using CAM. Therefore, the women with breast cancer sought CAM from CAM providers instead of sourcing further medical breast medical examinations and treatments. Some of the women with breast cancer even postponed and avoided the mammogram screening procedures due to being too afraid to know the results.

Muhanna and Floyd (2019) reported that a mammogram is one of the breast cancer screening procedures that women with breast cancer are afraid of, as they fear the diagnosis of breast cancer. According to Singh, Malila, Pitkäniemi, and Anttila (2019), a mammogram should not be delayed because most women who attended a mammogram screening with symptoms had a higher risk of developing breast cancer and risk of dying from breast cancer than those without symptoms.

Furthermore, Wagner et al. (2019) suggested that psycho-oncological support should be provided for women with breast cancer to overcome anxiety and fear of oncological treatments. Also, breast health education programs and accurate information from healthcare professionals are essential for women with breast cancer in order to increase

their understanding of medical cancer treatments (Nies et al., 2018). Breast cancer educational programs have been provided in Indonesia, but they are less available in rural and remote regions as reported by women with breast cancer in this study. Inadequate knowledge may also be impacted by low health literacy levels, which are not considered in the provided breast cancer materials. However, there were no recent studies found to examine women with breast cancer's health literacy in Indonesia. Higher levels of health literacy about breast cancer not only positively enhanced women with breast cancer's knowledge and their confidence, but also alleviated their fears of medical cancer treatments. Additionally, counselling by suitably trained personnel should be easily available for women with breast cancer who are fearful of medical cancer treatment.

There were no previous studies exploring CAM providers' knowledge about the use of CAM for breast cancer management. Therefore, the findings of this study contribute new knowledge that CAM providers had limited understanding about breast cancer. Inadequate knowledge about breast cancer may lead CAM providers to provide inaccurate information for women with breast cancer who seek CAM therapies from them. Thus, CAM providers need to have better knowledge about breast cancer so that they can support women with breast cancer to use both medical breast cancer treatment and CAM.

7.3.2.2 Adherence to culture and beliefs (Lived self-others)

This study's findings indicated that CAM use was based on the women with breast cancer's husband's advice, family's support and other people's recommendations including CAM providers and religious leaders. The lived self-others (*relationality*) concept was applied to understand how relationships with others were experienced by women with breast cancer in relation to the use of CAM. This concept reflected that relationships with God, family members, friends, CAM providers and acquaintances had a strong influence on CAM use. The meaningful relationships were captured by considering culture and beliefs in making decisions for breast cancer treatment (Haque et al., 2018; Liem, 2019). The lived self-others

concept provides several examples of adherence to culture and beliefs in regard to the use of CAM as experienced by women with breast cancer below.

Firstly, many women with breast cancer reported that they used CAM due to being disallowed to seek medical cancer treatment by their husband. According to women with breast cancer, their husband played a vital role in making decisions about their treatment and they were obligated to obey that decision. The obligation to obey stems from Islamic law and patriarchal traditions, which have been adopted by Indonesian women, where their husband is the most powerful decision-maker in the family (Pahria, 2017; Rinaldo, 2019). Consequently, the women with breast cancer must obey their husbands' decision regarding breast cancer treatment that their husband selected including CAM. Similarly, Akhtar et al. (2018) identified there were more than 25% of 200 Bangladeshi women with breast cancer who took CAM as an alternative medicine based on their husband's advice. The majority of women with breast cancer in Indonesia and Bangladesh were Muslim where the Islamic religion obligates a wife to obey and adhere to her husband's advice and decisions.

Secondly, some women with breast cancer expressed that they took CAM to show respect to parents and friends for their efforts for providing material supports on the use of CAM. As reported by the women with breast cancer, they were given and recommended use of CAM as a main treatment for breast cancer by their parents and friends. These women with breast cancer felt guilty and were reluctant to refuse the CAM that had been given to them. Using CAM to respect family and friends indicated that the use of CAM was also an obligation to family and friends who had provided support. However, according to Latte-Naor, Sidlow, Sun, Li, and Mao (2018), the use of CAM to cure breast cancer is an unrealistic expectation that is often offered by family and friends to women with breast cancer. Using CAM without medical cancer treatment could lead to progression of the disease, risk of cancer reoccurrence and premature death (Akhtar et al., 2018).

Similarly, a qualitative study conducted by Muhamad et al. (2012) found that Malaysian women with breast cancer sought and used alternative medicine to cure breast cancer based on their spouses' and parents' decision. Another quantitative study in Malaysia found family members and friends were the primary support system and information sources (Shaharudin et al., 2011). In the Malay culture, family and friends are encouraged to provide moral and material support especially during times of illness (Shaharudin et al., 2011). This tradition is also supported by Islamic teaching, which obligates family members and Muslim followers to support sick people (Shaharudin et al., 2011). Accordingly, in a cultural context, family and friend's' involvement impacts on the use of CAM among Malay and Muslim women with breast cancer in the cultural context (Mujar et al., 2017). Malaysian women with breast cancer in the previous studies and Indonesian women with breast cancer in this current study were ethnic Malay and Muslim, where they believed that adherence to culture and beliefs are necessary. Thus, the women with breast cancer's family members, and husbands in particular, may also need to develop their knowledge and awareness of the importance of medical breast cancer treatment. Family members' involvement with a greater depth of specific knowledge of breast cancer could positively support women with breast cancer to use appropriate breast cancer management.

The lived-self others *(relationality)* concept also reflected that faith in God and relationships with spiritual leaders contributed to the use of CAM in this study. For example, the Muslim women with breast cancer preferred to use CAM for breast cancer rather than medical cancer treatment. They claimed that a powerful source of healing and cure were in Allah's hands only, and believed that they would be cured from breast cancer no matter what treatments they used due to a strong faith in Allah. Muslim women generally fully submit their life to God's will and, therefore, they would accept their destiny to die of breast cancer (Ahaddour, Van Den Branden, & Broeckaert, 2019).

In addition, encouragement to use CAM instead of medical treatment was also identified through the CAM providers' views. For instance, the Muslim CAM providers stated that medical cancer treatment is the second option to be considered if Islamic healing systems could not successfully cure breast cancer. They encouraged women with breast cancer to expect the miracle of cure from Allah by using only the Islamic healing system-based CAM which they provided. This unrealistic expectation led to the refusal of medical cancer treatment, and the selection of CAM treatments based on the Islamic spiritual healing system to cure breast cancer. However, Ahmad et al. (2018) argued that the Islamic-spiritual healing system cannot be used to replace medical treatment, but it may be considered as a part of an holistic healing approach. The literature suggests that Muslim CAM providers and spiritual leaders need to increase their knowledge regarding contemporary religious healing development, and awareness of the modern healthcare systems based on the Islam perspective (Qureshi & Padela, 2016; Szombathy, 2018).

Recommendations for use of CAM given by other religious leaders were mentioned by the non-Muslim women with breast cancer in this study. For instance, a Buddhist participant had a religious leader suggest she avoid surgery and chemotherapy, and instead to seek CAM from a Chinese traditional healer. A Christian woman also reported that her pastor and leaders at her church recommended she consume herbal products. Spiritual leaders and CAM providers misled women with breast cancer on the use of CAM for breast cancer as a cure instead of using medical cancer treatments. CAM providers and spiritual leaders in Indonesia need to be provided with comprehensive specific education that encompasses CAM and the integration with medical treatment.

Overall, the life existential concepts reflect that demographics (age) and social structure (knowledge and cultural practice) are predisposing factors to the use of CAM for breast cancer management. *The lived body* (*corporeality*) concept describes CAM as an alternative

medicine option for women with breast cancer at an older age, because the body may not be able to cope with the side effects of chemotherapy. The lived things *(materiality)* reflects misconceptions regarding medical cancer treatment causing fears, which led to the use of CAM for breast cancer. These misconceptions may occur due to limited understanding and low health literacy about breast cancer and its treatment.

It is evident from this study that knowledge can be a predisposing factor for the use of CAM for breast cancer management. This new knowledge contributes to the overall body of knowledge in this area of CAM practice and education. In addition, the lived self-others *(relationality)* concept demonstrated the use of CAM as an obedience and adherence to their husband's decision, appreciation to family and friends for their support, and faith in God as well as religious beliefs. Therefore, breast cancer education should be provided to family members, CAM providers, as well as spiritual leaders. Their support for the use of both medical cancer treatment and CAM as an adjunctive therapy could contribute to increased survival rates and quality of life for women with breast cancer.

7.4. Enabling factors

Enabling factors refers to potential variables that allowed women with breast cancer to use CAM for breast cancer management. Fouladbakhsh and Stommel (2007) viewed enabling factors for the use of CAM as resources, access, availability of medical treatment or CAM services and geographic location. The CAM healthcare model describes CAM usage as potentially related to resources including income, employment, health insurance, and provider's connection to women with breast cancer. The availability of CAM providers and products, CAM literature and self-help information, CAM referral network and conventional services also contribute to the use of CAM. Another important enabling factor is geographic location of the CAM user's residence. Living in urban, suburban and rural regions are also associated with the use/non-use of CAM (Fouladbakhsh & Stommel, 2007). The theme of

access, affordability and support for medical cancer treatment identified poverty, lack of access and availability of medical cancer treatment in this study being identified as the enabling factors that were related to the use/non-use of CAM for breast cancer in the Indonesian setting. These enabling factors are reflected by women with breast cancer through the lived space *(spatiality)* concept as explained below.

7.4.1. Poverty (Lived space)

The concept of *lived space (spatiality)* was used to ask how space was experienced by women with breast cancer in regard to the use of CAM. This concept reflected that poverty created a space that made medical cancer treatment unachievable. For example, most women with breast cancer were unemployed due to their breast cancer and had become financially dependent on their husband's low income. The poor women with breast cancer claimed that average family income was less than 2.000.000.00 rupiah per month. This was approximately equal to AUD $200.00 during the data collection period in 2017. The family income was only enough to cover their family's living expenses at a very low standard. This financial constraint led to the inability to pay for medical cancer treatment costs and health insurance. Consequently, the poor women with breast cancer sought CAM to cure their breast cancer, as they perceived CAM to be less expensive compared to medical cancer treatment.

The use of CAM due to the inability to pay for their medical cancer treatment was also revealed by CAM providers. Most of the CAM providers claimed that CAM therapies were commonly used by poor women with breast cancer who could not afford medical cancer treatment. This outcome was because the CAM providers allowed women with breast cancer to pay for the CAM according to their ability. Some CAM providers provided free-of-charge CAM therapy to the poor women with breast cancer. For instance, the CAM providers provided free CAM service such as holy water prayer therapy, massage, energy therapy,

and home-processed herbal potions as these CAM did not require costly advanced healing materials or instruments. Similarly, a previous quantitative study in Indonesia, which was conducted by Azhar et al. (2016), also discovered that the use of CAM was higher among women with breast cancer with lower-middle income, because the women with breast cancer could not afford to pay for the cost of medical cancer treatment. This concept is supported by Mulyanto et al. (2019) who stated that personal income affects the utilisation of medical treatment in Indonesia. In Bangladesh, the women with breast cancer with poor economic status also used CAM to treat breast cancer as it required less money and cost almost nothing (Akhtar et al., 2018). The level of poverty had compelled women with breast cancer living in Indonesia in this study to use CAM for breast cancer management.

Indonesia is categorised as a low-middle income country, where more than 28 million Indonesian people are still living below the national poverty line (UNDP, 2019). Many poor Indonesians including women with breast cancer do not have access to basic social services such as healthcare and education (UNDP, 2019). The high costs of breast cancer medical treatment often cause a financial burden to women with breast cancer particularly in lower-income countries and lower-middle-income countries (Bellanger, Zeinomar, Tehranifar, & Terry, 2018; Han et al., 2019). Pinto, Masaki, and Harimurti (2016) claimed that approximately seven million households in Indonesia face poverty or are even drawn below the national poverty line due to high out-of-pocket healthcare service spending. Martei et al. (2018) also emphasised that the out-of-pocket money costs of medical cancer treatment and other related expenses cause a financial burden to women with breast cancer. Breast cancer leads to a long-lasting direct and indirect financial burden for women with breast cancer (Dean et al., 2019; Han et al., 2019). This financial burden affects women with breast cancer's decisions when selecting CAM for breast cancer treatment particularly among those experiencing financial hardship (Irwin et al., 2014). Therefore, CAM therapies are seen to be more attractive than medical cancer treatment by impoverished women with breast

cancer in Indonesia specifically women with breast cancer in this current study. The CAM providers in this study also viewed that the lack of access to medical cancer treatment is an opportunity to offer CAM as an alternative medicine to substitute medical cancer treatment.

In contrast, the use of CAM in other Asian countries, including Malaysia and Thailand, was less frequent among women with breast cancer with lower-middle income due to their inability to pay for out-of-pocket expenses of the CAM service (which are not included in government healthcare support) (Chui et al., 2015, 2018; Knight et al., 2015; Saibul et al., 2012; Wanchai et al., 2016; Zulkipli et al., 2018). Some of women with breast cancer in Thailand had to discontinue the CAM use due to economic factors (Wanchai et al., 2016). In more high income Asian countries, CAM was commonly used by wealthier women with breast cancer to complement their medical cancer treatment (Huang et al., 2015; Lee et al., 2014; Lin & Chiu, 2011; Wang & Chung, 2012; Wong et al., 2014). Huang et al. (2015) and Lin and Chiu (2011) revealed that the use of CAM as a complementary therapy was prevalent among Taiwanese women with breast cancer who had sufficient family income. These wealthier women with breast cancer had private health insurance that covered the costs of CAM services. These women with breast cancer could afford the out-of-pocket monetary cost of CAM services if some of the CAM services were not covered by their health insurance (Huang et al., 2015; Lin & Chiu, 2011).

Both poor and wealthy women with breast cancer in Asian countries have an interest in using CAM as a part of breast cancer management. The wealthy women with breast cancer in other Asian countries had no issue with accessing medical cancer treatment. They were able to utilise CAM as they had sufficient income to cover the out-of-pocket expenses of a CAM service that was provided by professional CAM providers. In contrast, the poor women with breast cancer in this current study used CAM due to their inability to pay for medical

cancer treatment. These women sought cheaper or free CAM therapy from unqualified CAM providers in order to decrease the financial burden.

The reflection of *lived space (spatiality)* on women with breast cancer's lived experiences and CAM providers' views generates new knowledge that poverty that led to the inability to pay for medical cancer treatment is an enabling factor for the use of CAM for breast cancer management in this study in Indonesia. The reflection of lived space in poverty indicated that women with breast cancer with financial hardships needed financial assistance, a monetary allowance, or medical funding resources, in order to access appropriate medical cancer treatment. Government or private finance organisations may offer medical treatment grants or medical loans to assist the women to pay for medical cancer treatment costs.

7.4.2. Lack of access and availability of medical cancer treatment (Lived space)

This study findings indicated that lack of access and availability of medical cancer treatment was one of the most common reasons for women with breast cancer in remote and rural regions to use CAM. For instance, the women with breast cancer who resided in the remote region of Batam city had to access medical cancer treatment in other more developed cities or overseas, due to the fact there were no medical cancer facilities available in their region when they were first diagnosed with breast cancer. There were only two wealthy women with breast cancer in this remote region who could access medical cancer treatment overseas. These women spent approximately IDR300, 000,000 rupiah or equal to AUD$30,000 for treatment costs, travel expenses, accommodation and meals to access medical cancer treatment in Malaysia and Singapore.

The other eight poor women with breast cancer reported that they could not pay for medical treatment costs and other related treatment expenses including travel cost, accommodation and meals. According to the Republic of Indonesia Health system review 2017, the majority of hospitals are located in Java and Bali where over 50% of the Indonesian population

resides (Mahendradhata et al., 2017). Consequently, those who live out of these regions or in the rural and remote areas, and need specific medical services such as cancer treatment may have to travel to Java or Bali due to such treatment not being available in public hospitals, as experienced by women with breast cancer in this study. According to Paramita, Yamazaki, Setiawati, and Koyama (2018), inequality of healthcare resources distribution in Indonesia limits access to the healthcare system. Pengpid and Peltzer (2018) also claimed that inadequate access to the healthcare system was associated with the use of traditional medicine in Indonesia.

Family companionship is vital for women with breast cancer to assist with activities of daily living during hospitalisation; however, this also requires additional expenses. Consequently, these women with breast cancer sought CAM as a breast cancer treatment from traditional healers or unprofessional CAM providers. Similarly, women with breast cancer in this study who lived in the rural regions of West Java also experienced additional financial burden when seeking medical cancer treatment, which were generally provided in hospitals in metropolitan cities. These women with breast cancer preferred to use CAM as it was perceived to be more accessible and affordable for them. The lived space *(spatiality)* concept reflected that women with breast cancer experienced space as obstacles to access medical cancer treatment. This obstacle was because the distance to access medical cancer treatment required travel costs, accommodation, meals and family companionship expenses. The poor women with breast cancer in rural and remote regions were not only burdened by the cost of medical cancer treatment but also additional related treatment expenses. Hence, the poor women with breast cancer in rural and remote regions were reluctant to use medical cancer treatment and preferred to use CAM. The lived space *(spatiality)* of CAM providers lived experiences also reflects that the availability of CAM providers in rural and remote regions is an option for women with breast cancer in this study to use CAM instead of seeking medical cancer treatment.

Huraerah (2019) stated that rural communities were less likely to visit healthcare facilities than those in urban areas. Transportation costs were expensive and travel time consuming (Huraerah, 2019). The use of CAM due to lack of access and availability of medical cancer treatment indicated that oncological care in rural and remote regions needs to be expanded. The availability of medical cancer treatment in rural and remote regions could reduce travel costs and accommodation expenses for those seeking medical treatment. The *lived space* (spatiality) concept signifies geographic location as an enabling factor to the use of CAM as described in the CAM Healthcare Model.

In summary, the lived space *(spatiality)* reflects poverty and a lack of access and availability of medical treatments, as well as family companionship as enabling factors to the use of CAM for breast cancer management in Indonesia. Using CAM without medical cancer treatment may not be effective in successfully treating breast cancer, however, integrating CAM with medical cancer treatment may improve survival rates and quality of life. Additional healthcare support such as travel-cost allowance, free temporary accommodation and meals could assist poor women with breast cancer in rural and remote regions in accessing medical cancer treatment, as well as in relieving their financial burden (Klungrit, Thanasilp, & Jitpanya, 2019). Low cost medical breast cancer treatment is highly in demand by poor women with breast cancer with limited financial resources in lower-middle countries including Indonesia (Elias et al., 2018; Huraerah, 2019; Irwin et al., 2014; Kurtovic-Kozaric et al., 2018; Torre, Islami, Siegel, Ward, & Jemal, 2017). Additionally, poverty and a lack of access and availability of medical treatments allow unprofessional CAM providers to offer CAM as an alternative medicine for breast cancer treatment.

7.5. Need for care factors (illness experience, perceived need for CAM)

The CAM Healthcare Model suggested that the potential indicators for the use of CAM can be identified by examining health status and illness experiences including diagnosis,

symptom and treatment, as well as perceived need for CAM (Fouladbakhsh & Stommel, 2007). In this study context, the need for care factors were identified using the lived body *(corporeality) concept*. This concept guides reflection of how the body is experienced in relation to the illness, the symptoms and the treatments the women with breast cancer required for CAM for breast cancer management. Relief of breast cancer symptoms, reduction of side effects from chemotherapy and prevention of breast cancer relapse were identified as the need for care factors for the use of CAM among women with breast cancer in this study.

7.5.1. Relieve breast cancer symptoms (Lived body)

The concept of the lived body (*corporeality*) on women with breast cancer's lived experiences and CAM providers views describes that women with breast cancer experienced breast cancer symptoms including a lump, a change in breast shape and size, nipple discharge, pain, swollen breast and ulcerating cancer wounds. According to the women with breast cancer experiences and CAM providers' views, CAM was needed by women with breast cancer to relieve breast cancer symptoms. For example, grated herbs from a traditional healer was applied onto breast tumours to relieve breast pain and inflammation. Herbal remedies were consumed by the women with breast cancer as a natural analgesic to relieve breast cancer pain. These remedies were also consumed to shrink the breast lump and reduce the amount of purulent discharge from an ulcerating breast cancer in a natural way. In addition to herbal remedies, women with breast cancer reported the need for massage therapy, prayer therapy and mediation to relieve breast cancer symptoms.

However, a number of previous studies in other Asian countries found that CAM was needed to reduce symptoms related to breast cancer treatment rather than to relieve breast cancer symptoms (Gül et al., 2014; Huang et al., 2015; Hwang et al., 2015; Naja et al., 2015;

Sirisupluxana et al., 2009). The need of CAM to relieve breast cancer symptoms indicates women with breast cancer were expecting potential benefits from CAM rather than understanding that relieving breast cancer symptoms would not successfully treat their breast cancer but instead the breast cancer would develop into advanced stages. Although some CAM therapies might provide temporary therapeutic effects to relieve breast cancer symptoms, these would not successfully treat breast cancer (Akhtar et al., 2018; Sanuade et al., 2018). Therefore, women with breast cancer and CAM providers should have available targeted education so that they are more aware that they need not only CAM therapy, but also medical cancer treatment. Other factors of CAM that require further exploration are strategies or treatments to reduce the side effects of chemotherapy.

7.5.2. Reduce the side effects of chemotherapy (Lived body)

Chemotherapy is one of the mainstream medical breast cancer treatments, which has been proven effective in increasing survival rates for breast cancer patients (Joshi, 2019). The side effects of chemotherapy are considered to be manageable (Oun, Moussa, & Wheate, 2018). However, it is undoubtable that the side effects of chemotherapy negatively impact on women with breast cancer's physical and emotional wellbeing (Cancer Australia, 2019). Additionally, side effects of chemotherapy reduce quality of life for women with breast cancer during chemotherapy (Dano et al., 2019).

The lived body *(corporeality)* reflects that most of the women with breast cancer in this study experienced side effects of chemotherapy including fatigue, pain, insomnia, nausea, vomiting, decreased appetite as well as weakened immune systems. None of the women with breast cancer reported psychological distress related to chemotherapy. According to the women with breast cancer's experiences, they needed CAM to reduce those negative effects so that they could complete the prescribed chemotherapy cycles. For example, the women with breast cancer consumed natural products to increase their physical endurance

whilst undergoing chemotherapy. One participant reported that chemotherapy supressed her leucocyte level, where she was then not allowed to complete the cycles. She said that she consumed dog and snake meat to increase her leucocyte level. Other women with breast cancer took herbal medicine to help them sleep well and increase their appetite.

The need for CAM to reduce the side effects of chemotherapy was also identified in previous studies. A survey in another city in Indonesia, which was conducted by Almasdy et al. (2018), found that 85% (55 of 85) of women with breast cancer used CAM to reduce the side effects of chemotherapy. In other Asian countries including Saudi Arabia, Turkey, Malaysia and Taiwan, women with breast cancer used herbal therapy, dietary and nutrition supplements, as well as relaxation techniques to reduce the side effects of chemotherapy (Alsharif & Mazanec, 2019; Can et al., 2012; Chui et al., 2018; Huang et al., 2015).

The side effects of chemotherapy need to be managed, as they could lead to secondary diseases, and cause serious health conditions resulting in decreased quality-of-life and survival rates (Joshi, 2019). Worsened health conditions and poor quality-of-life may impact on women with breast cancer's ability to complete chemotherapy cycles, as experienced by women with breast cancer and viewed by CAM providers in this study. Reducing the side effects of chemotherapy by using CAM shown to be useful and not harmful could improve women with breast cancer's general wellbeing (Hack, Hackl, et al., 2018; Porter et al., 2017). The use of appropriate CAM seems to be an essential component of breast cancer management, particularly for women with breast cancer's specific health conditions affected by the side effects of chemotherapy. Therefore, the use of CAM might be considered to be included as a part of breast cancer management. Private health insurance companies or the national health insurance system could consider covering appropriate CAM therapy services that provided by professional CAM providers, particularly for impoverished women with

breast cancer with specific health conditions. Another important need of care factor for the use of CAM is to include education related to the prevention of recurrent breast cancer.

7.5.3. Prevent recurrent breast cancer (Lived body)

The lived body *(corporeality)* reflects that the traumatic experience of having breast cancer and its treatments led to proactive behaviour to prevent breast cancer relapse. For example, some of the women with breast cancer claimed that they were regularly consuming mangosteen peel and soursop extract, coffee tree parasite plant, ginger therapy and black cumin capsules after completing chemotherapy and radiotherapy. The women with breast cancer perceived they needed CAM to prevent recurrent breast cancer. Gansler, Strollo, Fallon, and Leach (2019) also noted that the use of biologically based CAM to reduce the risk of cancer recurrence was prevalent among cancer survivors in the United States including women with breast cancer. However, they argued that the use of biologically based CAM for reducing recurrence risk was an unrealistic expectation, because long-term use of biologically based CAM could increase the risk for developing other forms of cancer or other serious health conditions. Additionally, these authors emphasised that the costs of CAM could cause significant additional expenses due to most CAM services not being covered by health insurance (Gansler et al., 2019).

Instead of biologically based methods, relaxation techniques such as meditation and massage could reduce fear and anxiety for patients who feared cancer recurrence (Gansler et al., 2019). In addition, practicing healthy lifestyles and health behaviours, as well as prayer therapy could help with coping skills for potential future breast cancer diagnoses (Monira, Christa, Hannah, & Kimberly, 2019). Accordingly, the use of biologically based CAM to prevent recurrent breast cancer may be unnecessary.

Overall, the lived body *(corporeality)* was used to identify how the body is experienced by women with breast cancer in regard to the use of CAM for breast cancer management. This

life existential concept reflects that CAM was needed by women with breast cancer to alleviate breast cancer symptoms and minimise the side effects of chemotherapy. They also perceived that CAM was needed to prevent breast cancer relapse. This means that accurate information about CAM is needed by women with breast cancer throughout their illness experience including before seeking medical treatment, while undergoing chemotherapy and after completing medical treatment. The need for CAM for breast cancer management is associated with health service use factors such as how CAM is used, as well as purpose and manner of CAM use. These factors are discussed in the following section.

7.6. CAM health service use

The concept of health service use in the CAM Healthcare Model describes how CAM is used and the purposes and manners of using CAM (Fouladbakhsh & Stommel, 2007). In the context of this study, health service use specifically portrays the types of CAM that women with breast cancer used for breast cancer management, as well as their purposes and manners of use toward CAM. The health service use is discussed based on women with breast cancer's experiences and CAM providers' views which are represented in the study findings (Chapter Five and Chapter Six). The CAM Healthcare Model classifies CAM service use as CAM providers-directed services, CAM products and self-directed practices.

The purpose of using the health service includes health promotion, illness treatment and symptom management. In terms of manners of use, it can be complementary therapy if it is combined with medical treatment, or it is considered as an alternative medicine when used to substitute medical treatment (Fouladbakhsh & Stommel, 2007; NCCIH, 2019). The health service use in this study is reflected by women with breast cancer through the lived self-others *(relationality)* and the lived things *(materiality)* concepts. These life existential concepts indicate that the use of CAM needs professional CAM providers, CAM products standardisation, and promotion in self-care activities. The study findings also indicated that

CAM was generally used as a primary treatment to treat breast cancer. The meanings of CAM use are discussed in the following sections below.

7.6.1. Provider-directed CAM service: The need for professional CAM providers

Provider-directed CAM service refers to the use of CAM that requires practitioners' direct service or supervision to provide care or therapy. This includes acupuncture, massage therapy, naturopathic treatment, folk medicine treatment, shamanic healing, spiritual healing, energy therapy, hypnosis and chiropractic services (Fouladbakhsh & Stommel, 2007). In other words, provider-directed CAM services are therapies that are directly administered by CAM providers to women with breast cancer as receivers.

7.6.1.1. Received CAM from unlicensed CAM providers (Lived things)

The lived things *(materiality)* concept was applied to understand how the provider-directed CAM service was experienced by women with breast cancer for their breast cancer management. This concept reflects that most provider-directed CAM services used by women with breast cancer were obtained from unlicensed CAM providers. Unlicensed CAM providers refers to CAM providers who had no legal permit to provide CAM practice. It is regulated by the Indonesian healthcare system that CAM services must be provided by healthcare workers who have a minimum diploma degree in health education, and are certified and registered as a competent practitioner in specific CAM skills and knowledge (Ministry of Health Republic of Indonesia, 2014). There were no previous studies in Asian countries that discussed CAM being provided by unprofessional CAM providers.

None of the CAM providers in this study attained formal education related to health and CAM practices or were certified as competent CAM practitioners. As explained by the CAM providers in this study, their CAM service was delivered based on their gifted healing ability given by their ancestors via supernatural methods and religious beliefs. For instance, herbal therapy, massage therapy, cupping therapy, bloodletting therapy and spiritual healing rituals

were commonly provided by unregistered or unlicensed CAM providers such as traditional healers, shamans and spiritual leaders. The women with breast cancer used these provider-directed CAM services from CAM providers who were unprofessional, unqualified, unlicensed and unregistered.

In contrast, previous studies showed women with breast cancer in other Asian countries generally received a variety of provider-directed CAM services from professional CAM providers. In Malaysia, women with breast cancer bought nutrition supplements and vitamins from healthcare CAM providers including nurses and medical assistants (Knight et al., 2015; Saibul et al., 2012; Shaharudin et al., 2011). Taiwanese women with breast cancer mostly obtained Chinese medicine and acupuncture provided by licensed practitioners at hospitals or clinical settings (Lin & Chiu, 2011).

Moreover, women with breast cancer in Australia, European countries and United States used mind and body therapies such as acupuncture, yoga, massage, and energy therapy in addition to biologically based products which are provided by suitably trained and qualified practitioners (Eckerd Lambe, 2013; Fox et al., 2013; Link et al., 2013; Lo-Fo-Wong et al., 2012; Neuhouser et al., 2016; Salamonsen, Kruse, & Eriksen, 2012; Tautz et al., 2012; Vidal, Carvalho, & Bispo, 2013). These were different to the types of CAM used by provider-directed CAM therapies in this study. In Indonesia, professional provider-directed CAM, such as acupuncture, are only provided in clinical settings in major centres at a cost, hence, women with breast cancer in this study infrequently used this type of therapy (Almasdy et al., 2018; Wijanto, Tamtomo, & Joebagyo, 2019). Most women with breast cancer in this study perceived the cost of CAM provided by professional practitioners to be more costly than that offered by unlicensed traditional healers. Therefore, this study provides new knowledge regarding CAM services in rural and remote in Indonesia. This new knowledge that CAM therapies provided by unprofessional traditional healers were more attractive to

poor women with breast cancer even though the quality, efficacy and safety had not been scientifically proven contributes to the body of knowledge in this under-researched area of healthcare.

7.6.1.2. Misleading information (Lived self-others)

The lived self-others *(relationality)* concept reflects that influences from CAM providers contributed to the use of CAM, as previously discussed in predisposing factors (p. 213). The study findings revealed that the majority of unlicensed CAM providers offered religious belief-based CAM to be used as the main treatment for breast cancer. For example, the unlicensed Muslim CAM providers recommended Islamic healing practices such as reciting prayers, verses from the Holy Quran, and Islamic ritual or '*ruqya'* to be used by Muslim women with breast cancer. The Muslim CAM providers viewed physical sickness such as breast cancer to be caused by spiritual disorders including uncontrolled negative energy, evil spirits and witchcraft. Consequently, the spiritual disorders must firstly be healed by Islamic spiritual leaders with supernatural powers from Allah, in order to heal the physical sickness (Haque et al., 2018).

However, Szombathy (2018) argued that spiritual healing rituals are controversial in contemporary Islamic fundamentalism, as spiritual healing rituals are considered as a local tradition of an Islamic ethnic group instead of a part of real Islam doctrines. Accordingly, Islamic spiritual healing rituals may not generally be obligated in Islamic religious practice. Offering Islam spiritual healing to cure breast cancer without medical cancer treatment leads vulnerable women with breast cancer to use inappropriate breast cancer treatment. Therefore, the Muslim CAM providers need to understand that spiritual healing practices may provide comfort but do not cure breast cancer as experienced by the women with breast cancer in this study. Spiritual healing practices could be integrated with medical treatment where they are part of Allah's plans in providing healing to cure illness (Ragsdale et al., 2018). Thus, the CAM providers should encourage women with breast cancer to seek

medical treatment as the main treatment and offer Islamic spiritual healing practices as CAM as a secondary therapy. The integration of spiritual healing practices and medical treatment could result in better outcomes for breast cancer management for these women with breast cancer.

In addition, the study findings found that the unprofessional CAM providers commonly advertised and promoted fraudulent CAM as a treatment to cure cancer via social media, magazines, television, radio and the internet. They delivered deceptive information such as stating that CAM was the cheapest and safest medicine to cure cancer naturally. These behaviours are against CAM service provision laws and regulations in Indonesia, which state that CAM therapy should not be promoted as a treatment to cure cancer (Hill et al., 2019; Ministry of Health Republic Indonesia, 2017). This means that the unprofessional CAM providers had misled women with breast cancer to use fraudulent CAM. It is evident that the women with breast cancer with lower education and knowledge levels were often found to be the common victims of receiving misleading information about the use of CAM. According to Bianchini, Truccolo, Bidoli, Group, and Mazzocut (2019) misleading information negatively impacts on treatment decision-making attitudes in cancer patients including women with breast cancer. Misleading information that was delivered by unauthorised CAM providers led the women with breast cancer in this study to use inappropriate CAM as a cancer treatment. The use of inappropriate CAM due to misleading information physically and financially disadvantaged women with breast cancer.

7.6.1.3. Corruption in CAM practice (Lived things)

The findings of this current study also revealed corruption in CAM practices. For example, one CAM provider reported that she conducted an experiment to test her herbal therapy on a woman with breast cancer in hospital without ethical clearance from the hospital. According to this CAM provider, a doctor informally accepted and illegally commercialised the herbal therapy. These behaviours were deemed to violate the Medical Code of Conduct

and scientific research procedures that have been regulated by the Indonesian Ministry of Health (Ministry of Health Republic Indonesia, 2014, 2017). This CAM provider was not eligible to conduct high-risk scientific research because she had no formal education regarding health or qualified research skills. Formal CAM education and training are needed in order to develop CAM providers' knowledge and skills particularly for those who are interested in conducting ethically approved research about CAM.

Corruption in CAM practice occurred due to insufficient surveillance within the healthcare system. According to CAM providers' views, as indicated by this study's findings, providing CAM therapy is a highly profitable business and a good source of income for those who have no formal education and are unable to find employment or a better career. For instance, some of the CAM providers were members of multilevel marketing companies that distributed food supplement products. The CAM providers often sold the products as medicine instead of adjunctive therapy as was intended by the companies. Another example was falsification of CAM practice registration and licencing as reported by women with breast cancer. Many women with breast cancer experienced services from unprofessional, unregistered CAM providers. According to women with breast cancer in this study, many CAM providers displayed fake registration and licence certificates in their practice facilities, who were providing fraudulent CAM treatments to cure cancer. According to Erry et al. (2014) and Peltzer and Pengpid (2019), many CAM providers in Indonesia were providing CAM without a licence or registration to practice CAM. This corruption within CAM practices physically, emotionally and financially disadvantaged women with breast cancer who were interested in using CAM.

7.6.1.4. Poor infrastructure

The study findings showed that the majority of CAM providers provided CAM services at their private residence that had poor infrastructure. However, the Indonesian government legislation Act number 103 of the year 2014 on CAM services regulated that a CAM facility

should not be provided in the CAM providers private residence (Hill et al., 2019; Ministry of Health Republic Indonesia, 2014, 2017) . The Act also required that CAM facilities must have an administration desk, consultation room, specific therapy room, lounge and toilets (Moustakas, 1994). Electricity, water installation, air circulation, and a fire extinguisher must be provided, and the facilities must be well organised and maintained (Rhee et al., 2019).

However, the CAM facility standards were not implemented by most of the CAM providers in this study. The CAM providers performed CAM services using ancient healing methods with limited infection control or standard precautions. For example, as observed by this researcher, handwashing procedures were not performed before or after contact with the customer who received bloodletting therapy, the bloodletting waste and needle disposal were treated as general domestic waste, and cupping therapy cups were reused without proper sterilisation techniques. The CAM providers were exposed to potentially infectious blood, tissues, secretions, other body fluids and contaminated equipment as their infection control management was inadequate or non-existent. This behaviour indicated a lack of understanding and awareness regarding infection control management and hygiene procedures when providing CAM services. According to Kuhar et al. (2019), inadequate infection control management in healthcare settings such as a CAM facility practice, may lead to contagious disease transmission between CAM providers and CAM receivers including women with breast cancer.

A high level of interest to develop knowledge and skills related to CAM for breast cancer management was expressed by the unprofessional CAM providers although they lacked knowledge regarding the required standards for practice. The CAM providers in this study expressed that religious-based beliefs and traditional therapies were becoming out-dated. This CAM providers view meant that there was an urgent need for certified CAM education and training programs to be made available for CAM providers in Indonesia. According to

Khalil et al. (2019), education and training courses related to infection control precautions should be a compulsory course requirement prior to obtaining a CAM practice licence. A greater level of understanding, knowledge and official accredited training would help CAM providers to become registered professional CAM providers and enable them to provide high quality and safe CAM services, particularly for women with breast cancer.

7.6.2. CAM products: The need of standardisation (Lived things)

The lived things *(materiality)* concept was utilised to identify CAM herbal products that were used by women with breast cancer and provided by CAM providers for breast cancer management. A variety of CAM herbal products were used by women with breast cancer that include therapies that they obtained from CAM providers, directly self-purchased (over-the-counter), and home-processed herbal remedies. For example, Chinese herbal medicine was mentioned by women with breast cancer as the most common herbal product received from CAM providers. According to CAM providers, particular Chinese herbal medicines must be imported because they are not available in Indonesia. In addition, other imported animal and plant-based products used by women with breast cancer and offered by CAM providers in this study were ginger and ginseng teas, honey, propolis, deer's placenta capsule, green tea, spirulina, sea cucumber jelly and shark cartilage capsule. This finding is in line with previous studies which described the consumption of those animal and plants-based products that were also favoured among women with breast cancer in other Asian countries including China, Malaysia, Korea, Lebanon, Taiwan and Turkey (Chen et al., 2008; Chui et al., 2014; Gül et al., 2014; Kang et al., 2012; Naja et al., 2015; Saibul et al., 2012; Shaharudin et al., 2011; Yildirim, 2010). According to the World Health Organization (2019a), the imported herbal products are potentially better quality and safer, as they are more likely to be produced based on scientific evidence and International industrial standards for herbal products. However, the use of imported herbal products in this study was less frequent due

to the price being more expensive than local-manufactured products, and traditional home-processed remedies.

The concept of *materiality* demonstrated that poor women with breast cancer mainly used traditional home-processed herbal products to treat their breast cancer. For instance, women with breast cancer explained that they boiled and extracted fresh soursop leaves with the amount of leaves based on their date of birth or their own feelings. Afterwards, they consumed the potion as a regular tea to cure their breast cancer. This indicates that the soursop leaf potion was consumed without a specific measured dosage or in a definite timeframe. However, Chan, McLachlan, Hanrahan, and Harnett (2020) noted in their literature review that a safe oral dose to consume soursop leaf extract was up to 540 mg/day for up to 30 days. Excessive soursop leaf consumption has potential neurotoxic effects (Chan et al., 2020). Therefore, women with breast cancer need to be aware of safe dosage levels recommended for consumption of soursop leaf-based CAM products.

The use of soursop leaf-based products were also prevalent among Indonesian women with breast cancer in other studies as well as in Malaysia (Almasdy et al., 2018; Christina, Abigail, Cuthbertson, & Whitehead, 2019; Deliana et al., 2019; Nies et al., 2018). The prevalence of this CAM therapy could be due to this tropical plant being commonly available in Southeast Asian countries, such as Indonesia and Malaysia. Soursop therapy is not as common in other Asian countries because each country produces CAM products based on their local medicinal plants (Gül et al., 2014; Gulluoglu et al., 2008; Kalender et al., 2014).

In addition, the lived things *(materiality) concept also* reflects exploitation in the use of CAM products. Some of the women with breast cancer were concerned about the legality of CAM products as they felt they were being deceived by unprofessional CAM providers who directed them to use fraudulent CAM products. For example, germanium stone mattress therapy, holy water, which was prayed on by a traditional healer or spiritual leader, wearing

of an anti-cancer vest and snake venom-based products were offered to them by CAM providers as breast cancer treatments instead of complementary therapy. The women with breast cancer reported financial loss, declined health conditions and disappointment from purchasing and using those products. The use of fraudulent CAM products provided by unprofessional CAM providers had caused physical and psychological harm to women with breast cancer. Therefore, it is essential that women with breast cancer consult and disclose the use of CAM to healthcare professionals. Healthcare professionals are able to provide the best possible care and treatment to women with breast cancer who use CAM as they would be more aware that some CAMs may interact with medical cancer treatment, and negatively impact on women with breast cancer health outcomes. According to Bianchini et al. (2019), Hack, et al. (2018) and Harnett and Morgan-Daniel (2018), suitably trained health professionals would be the most reliable source to obtain accurate and relevant information on CAM product usage.

Fraudulent CAM products may exist due to lack of CAM providers' familiarity with the rules of CAM practices as well as inadequate surveillance on the implementation of standards of care and regulations in providing CAM products (Raposo, 2019). Therefore, surveillance of CAM practices should be enhanced. It is essential for CAM providers to be familiar with the standards of care, guidelines and regulations in order to protect women with breast cancer and themselves from any malpractice event (Erry et al., 2014; Pahria, 2017; Ramadoss & Koumaravelou, 2019). Further research is encouraged to evaluate standardisation of CAM products that are commercialised for breast cancer management in Indonesia. Another type of CAM service used by women with breast cancer was self-directed CAM practice.

7.6.3. Self-directed practice: Promotion on self-care activity

Self-directed CAM practice refers to CAM approaches that are often used independently instead of under the supervision of a CAM provider. These approaches include meditation,

home yoga practice, music therapy, dance therapy, prayer and spiritual therapy (Fouladbakhsh & Stommel, 2007). The most popular self-directed CAM practice in this study was prayer-based spiritual and religious belief, followed by meditation. The women with breast cancer in this study believed that prayer was a way to request guidance for CAM use. This finding is similar to previous studies that found that prayer was commonly included as a part of CAM for breast cancer during chemotherapy among Muslim women with breast cancer in Iran, Lebanon, Malaysia Saudi Arabia and Turkey (Alsharif & Mazanec, 2019; Can et al., 2012; Chui et al., 2014; Gül et al., 2014; Gulluoglu et al., 2008; Jafari et al., 2013; Kalender et al., 2014; Knight et al., 2015; Muhamad et al., 2012; Naja et al., 2015; Saibul et al., 2012; Shaharudin et al., 2011). However, Chui et al. (2014) argued that prayer should not be considered as a therapy because it is a universal human activity to request help or to express thankfulness to God or an object of worship. Additionally, all Muslim women with breast cancer are obligated to pray five times daily regardless of whether they are sick or healthy (Chui et al., 2014).

In addition to prayer therapy, Muslim women with breast cancer in this study regularly practiced the Islamic meditation *'dhikr'* to overcome breast cancer symptoms and control their emotions. *Dhikr* means remembering Allah and the holy verses from the Quran (Sulistyawati & Probosuseno, 2019). This Islamic meditation has proven to have positive effects in reducing anxiety in Muslim patients with cancer (Sulistyawati & Probosuseno, 2019). This finding was supported by previous studies in Malaysia and Thailand which found meditation was used by Buddhist women with breast cancer as a spiritual therapy to reduce anxiety and depression due to breast cancer (Huang et al., 2015; Saibul et al., 2012; Sirisupluxana et al., 2009; Wanchai et al., 2012). Self-directed CAM practices such as prayer and meditation are perceived to be inexpensive and safe compared to provider-directed CAM services and CAM products. These CAM might be considered to be preferable to CAM

options for breast cancer management. The purpose and manner in the use of CAM services, CAM products and self-directed CAM practice are discussed in the section below.

7.6.4. Purpose and manner of CAM service use (Lived things)

The National Centre for Complementary Integrative Health in the United States (NCCIH, 2019) states that CAM should be used as complementary therapy or alternative medicine. CAM therapies are considered as complementary therapy if they are used together with conventional medicine, alternative medicine or if they are used to replace conventional medicine (National Cancer Institute, 2019; NCCIH, 2019). The current study found that all the women with breast cancer firstly sought and used CAM with the aim of curing their breast cancer and chose this option due to their lack of knowledge, limited access to medical cancer treatment, financial constraints, culture and religious beliefs. Seeking medical treatment was commonly considered as a second opinion after realising that CAM could not permanently cure their breast cancer. Similar findings were reported in a quantitative study conducted by Azhar et al. (2016) in Indonesia, who found that women with breast cancer on low incomes and who had low education levels used CAM as their main treatment due to financial constraints, as well as fear of both surgery and chemotherapy. That study supports this study's findings that CAM is used as a primary treatment for breast cancer instead of a complementary therapy.

The lived things *(materiality)* concept indicates that the purpose of using CAM as a primary treatment to cure breast cancer was then transformed into complementary therapy or alternative medicine. For instance, 13 women with breast cancer in this study claimed that they continued using CAM as an adjunctive therapy to support their medical cancer treatment. Similarly, a previous quantitative study conducted by Almasdy et al. (2018) in West Sumatera Indonesia found women with breast cancer used CAM as a complementary therapy, as they believed CAM could support their breast cancer healing process. The use

of CAM as complementary therapy to support medical cancer treatment was also prevalent among women with breast cancer in China, Korea, Malaysia, Palestine, Singapore, Taiwan, Thailand and Turkey (Can et al., 2012; Chen et al., 2008; Chui et al., 2018; Gül et al., 2014; Gulluoglu et al., 2008; Jaradat et al., 2016; Kang et al., 2012; Knight et al., 2015; Lee et al., 2014; Mujar et al., 2017; Saibul et al., 2012; Shaharudin et al., 2011; Wang & Chung, 2012; Yildirim, 2010; Zulkipli et al., 2018). It can be seen that CAM is used as complementary therapy when medical cancer treatment is provided for and accessible to women with breast cancer. Another purpose of using CAM among women with breast cancer in this study was that CAM was considered an alternative medicine to cure breast cancer.

The findings found that five women with breast cancer used CAM to replace surgery and chemotherapy due to financial constraints and fear of the side effects of those treatments. For example, some women with breast cancer consumed a snake venom-based remedy, Chinese herbal medicine, energy therapy, and Islamic meditation to substitute chemotherapy and radiotherapy. Nevertheless, women with breast cancer who used alternative medicine reported they had a regular medical breast assessment to evaluate outcomes from using the alternative medicines. The women with breast cancer claimed that they had a greater level of confidence using alternative medicine as they received more hope and encouragement from CAM providers than from their oncologists. This behaviour indicates the need for greater psychological support from oncologists to enhance women with breast cancer's confidence when undergoing medical cancer treatment. Further research is required to evaluate in depth the implications of psychological support for women with breast cancer undergoing medical treatment in Indonesia.

This study also identified progressive and negative attitudes toward the use of CAM for breast cancer management. The women with breast cancer who used CAM as complementary therapy or alternative medicine proposed that CAM should be integrated

with medical cancer treatment and be provided in healthcare settings. The integration of CAM in healthcare settings has been regulated by the Ministry of Health of Indonesia since 2007 (Mahendradhata et al., 2017). However, the implementation of the regulations is very limited due to inadequate professional CAM providers to provide scientific evidence-based CAM (Erry et al., 2014; Wijanto et al., 2019).

In contrast, two of the women with breast cancer discontinued the use of CAM as they experienced disappointment after using fraudulent CAM therapy. They argued that CAM should not be integrated with medical treatment as their experience was that medical treatment was the most effective treatment to cure their breast cancer. Furthermore, this study revealed that the use of CAM was generally concealed from health professionals due to fear of being disallowed to use CAM. This indicates that there was a lack of transparency in the use of CAM between the women with breast cancer and their doctors or nurses. Also, women with breast cancer reported that they were never asked by their doctors or nurses whether they used CAM therapy or not. This indicated that CAM usage may not have been included in the nursing assessment and care in the clinical setting. These findings are similar to previous studies from Asian countries where women with breast cancer did not disclose the use of complementary therapy to their healthcare CAM providers (Azhar et al., 2016; Gulluoglu et al., 2008; Hwang et al., 2015; Kang et al., 2012; Shaharudin et al., 2011; Wanchai et al., 2012; Wong et al., 2014; Yildirim, 2010; Zulkipli et al., 2018). Lack of transparency and non-disclosure on the use of CAM could have a negative impact on breast cancer healing processes. CAM therapies could interact with chemotherapy which in turn could impact on breast cancer healing processes, or reduce the effectiveness of the chemotherapy (Akbulut, Yagmur, Gumus, Babur, & Can, 2014; Andersen et al., 2015; Smith & Shejwalkar, 2020; Sweet, Dowd, Zhou, Standish, & Andersen, 2016).

Overall, the lived things *(materiality) and the lived self-others (relationality*) concept discussed how women with breast cancer experienced the use of provider-directed CAM services, CAM products and self-directed practice for breast cancer management. The findings highlight the need for professional CAM therapists to provide high quality and safe CAM therapies. Standardisation of CAM products is also required to assist in controlling the commercialisation of fraudulent CAM products. The use of CAM services and CAM products were more popular than self-directed CAM practices although quality and safety have been shown to be doubtful. The use of CAM by the poor women with breast cancer as a primary treatment seems to be unavoidable because CAM is perceived as the only potential inexpensive treatment available while waiting for access to medical treatment. Consequently, there was a need to have specific guidelines and standards of care to ensure quality, safety and efficacy of CAM for breast cancer management in Indonesia.

7.7. Outcome of care

The CAM Healthcare Model describes outcomes of care as improved quality of life. Improved quality of life can be measured by potential empirical indicators including decreased symptom reports, decreased functional limitations, increased sense of wellbeing and satisfaction, diagnostic verification of condition improvements, as well as increased perception of control over health (Fouladbakhsh & Stommel, 2007). In general, the improved quality of life related to the use of CAM, particularly in a quantitative study, is commonly measured using specific quality of life scales such as the QLQ-C30 or QLQ-BR23 questionaries which have been developed by the European Organisation for Research and Treatment of Cancer (EORTC) (Albabtain et al., 2018; Fouladbakhsh & Stommel, 2007; Gül et al., 2014; Hack, Hackl, et al., 2018). The outcomes of care in this phenomenological study were assessed using the lived body *(corporeality)* concept*,* as suggested by van Manen (2014), theoretical underpinnings as this provided guidance on how the body experienced the outcomes of CAM usage for breast cancer management. The lived body *(corporeality)*

concept reflects the outcomes of care as improved quality of life even though there was delayed medical cancer treatment.

7.7.1. Improve quality of life (Lived body)

The majority of women with breast cancer in this phenomenological study experienced several potential beneficial outcomes from using CAM for breast cancer management. For example, the consumption of herbal products such as soursop leaves and mangosteen rind was found to reduce pain and breast inflammation, shrink breast lumps, dry purulent breast tumours, as well as accelerated breast wound healing. This finding is similar to a study in Malaysia that found consuming soursop decreased breast tumours in size from 9 cm to 7 cm without the use of chemotherapy (Nies et al., 2018). It has been reported that soursop leaf extract and mangosteen rind can potentially shrink breast tumours because they contain antioxidant, antitumor and anti-inflammatory properties that could inhibit breast cancer cell proliferation and trigger the apoptotic pathway (Aizat, Jamil, Ahmad-Hashim, & Noor, 2019; Chan et al., 2020; Chaverri, Rodriguez, Ibarra, & Perez-Rojas, 2019; Smith & Shejwalkar, 2020; Vemu, Nauman, Veenstra, & Johnson, 2019; Yajid, Ab Rahman, Wong, & Zain, 2018). A number of studies have reported the potential benefits of soursop leaf and mangosteen rind extract, and suggested these plants can be used for cancer management (Daddiouaissa et al., 2019; Kim et al., 2018; Pertiwi, Arisanty, & Linosefa, 2020; Vemu et al., 2019; Wathoni et al., 2019; Widiyastuti, Sholikhah, & Haryanti, 2019; Zeweil, Sadek, Taha, El-Sayed, & Menshawy, 2019).

In addition to herbal products, women with breast cancer experienced that consuming snake meat soup and snake venom-based remedies could shrink their breast tumour and kill cancer cells. Several quantitative studies have reported that snake venom contains antitumor, anti-cancerous and anti-metastatic effects which could inhibit breast cancer cell progression (Bezerra et al., 2019; de Vasconcelos Azevedo et al., 2019; Montealegre-

Sánchez et al., 2019; Samant, Ghag-Sawant, Thatavarthy, Shah, & Chowdhary, 2019). However, these beneficial outcomes are mostly based on quantitative studies evidence and the results of in-vitro experiments on breast cancer cell. Further evidence from rigorous human studies such as large random controlled trials are required to assess the effectiveness and outcomes of these methods of treatment.

Other beneficial outcomes experienced by women with breast cancer who used CAM were increased physical strength and improved immune systems. Most women with breast cancer felt physically stronger after consuming soursop leaf extract, herbal medicine, honey, and special food such as snake and dog meat soup during chemotherapy treatment. Similarly, feeling energised and having increased physical strength after consuming plant-or animal-based CAM products were also reported by Malaysian women with breast cancer who used CAM when undergoing chemotherapy (Nies et al., 2018). The findings of the current study are also consistent with previous studies that found the use of CAM significantly improved quality of life among women with breast cancer undergoing chemotherapy (Albabtain et al., 2018; Biswal et al., 2013; Gül et al., 2014; Hack, Hackl, et al., 2018; Kim et al., 2015; Klafke et al., 2019; Rossi et al., 2018). According to Tiezzi et al. (2016), CAM could improve certain physical functions that might be impaired by chemotherapy; thus, it is widely used to manage symptoms of chemotherapy.

The beneficial outcomes of prayer therapy, meditation and energy therapy, which were experienced by women with breast cancer were reduced emotional distress and a strengthened relationship with their God. For instance, women with breast cancer experienced that prayer therapy and meditation increased their prayer intensity which brought them closer to their God. The integration of CAM and medical cancer treatment could optimise breast cancer healing processes as experienced by women with breast cancer in this study. This finding is in line with a previous study in Malaysia that revealed

prayer therapy could evoke a relaxation response during chemotherapy among Muslim women with breast cancer, and strengthen their faith in positive outcomes from the healing process (Chui et al., 2014). According to Pedersen, Christensen, Jensen, and Zachariae (2013), having a strong belief in God and a higher spiritual power can have a positive influence on breast cancer treatment. Furthermore, according to Alsharif and Mazanec (2019), reading the Quran, praying and drinking holy water could significantly relieve stress and sickness for Muslim women with breast cancer who undergo surgery and chemotherapy. Meditation has also been shown to be effective in increasing quality of life of women with breast cancer undergoing radiotherapy (Jafari et al., 2013). Prayer therapy, meditation and energy have potential therapeutic effects in reducing stress and anxiety resulting in the improved immune systems of women with breast cancer (Abrahão et al., 2019; Kim et al., 2013; Voiß, Höxtermann, Dobos, & Cramer, 2019)..

The increased physical strength, perceived improve immune system, relieved pain, and reduced emotional distress were experienced by women with breast cancer as beneficial outcomes of using some types of CAM that improved their quality of life. Based on these positive outcomes, this study suggests CAM such as scientifically proven supplements, massage, touch therapy, reflexology, acupuncture, yoga, and prayer therapy should be offered as an adjunctive therapy to support physical and psychological wellbeing during breast cancer treatment.

However, the futility of CAM was also revealed by some of the women with breast cancer in this study who did not experience any significant positive outcomes from using CAM. This finding is in line with several studies that found there was no significant correlation between the use of CAM and quality of life (Chui et al., 2015; Kang et al., 2012; Naja et al., 2015). The negative outcomes of CAM were also experienced by some of the women with breast cancer in this current study as discussed below.

7.7.2. Delayed medical cancer treatment and aggravated health condition (Lived time)

The lived body *(corporeality) concept* reflects negative outcomes of CAM as aggravating the women with breast cancer's health condition. For example, women with breast cancer experienced that the use of CAM caused their breast tumour to increase in size, rupture and ulcerate. The women with breast cancer experienced that using CAM for a long period of time increased their CA (cancer antigen) level and allowed the breast cancer to spread into other organs such as the liver, colon, and bones resulting in these cancers being incurable.

The lived time (*temporality)* concept also reflects the use of CAM as an inappropriate treatment as its use delayed appropriate medical cancer treatment. This finding is similar to findings of previous studies in Bangladesh, Indonesia and Korea where the use of CAM delayed medical cancer treatment resulting in negative outcomes including increased cancer stage development and worse health conditions (Akhtar et al., 2018; Deliana et al., 2019; Sanghun, Kicheul, & Songha, 2018).

The lived body *(corporeality)* concept also revealed that some of the women with breast cancer experienced adverse events from using CAM. For example, nausea, stomach burning pain, and soreness were experienced after consuming soursop leaf extract. The consumption of Chinese herbal medicine could cause liver and kidney damage as experienced by some of the women with breast cancer. According to Smith and Shejwalkar (2020), adverse events may occur because soursop contains neurotoxic acetogenin compounds. This supports the concept that CAM is not always as safe as is perceived by the majority of women with breast cancer who participated in this study. Other authors have stated that the use of CAM has been associated with disease progression, increased risk of death and decreased survival rates for women with breast cancer (Mujar et al., 2017; Sanuade et al., 2018). This means that the use of CAM without medical cancer treatment has a negative impact on breast cancer management.

There were no adverse events of CAM use reported by women with breast cancer in previous studies but the potential negative side effects of CAM use were of concern for some authors (Kang et al., 2012). Andersen et al. (2015) identified potential risks of excessive bleeding due to the use of herbs among women with breast cancer prior to surgery. These authors claimed that some herbs could contain antiplatelet activity, which potentially could prolong bleeding time, and thus recommended that they should not be taken prior to breast surgery (Andersen et al., 2015). In addition, biologically active compounds in some herbs can potentially interact with medical treatment including chemotherapy drugs (Sweet et al., 2016; Yeung et al., 2018). Furthermore, it has been reported that herbal medicine may lessen the effectiveness of chemotherapy resulting in unsuccessful outcomes of breast cancer treatment (Smith, Clavarino, Long, & Steadman, 2014).

Overall, the lived body *(corporeality) and* the lived time *(temporality)* concepts were applied to guide the assessment of women with breast cancer's experiences regarding outcomes of CAM use for breast cancer management. These concepts reflect the experiences of potential therapeutic effects and adverse events from using CAM. These outcomes indicated that CAM could not cure breast cancer but could improve quality of life. Accordingly, some CAM that are known to be safe should be offered as an adjunctive therapy to improve quality of life rather than alternative medicine to cure breast cancer. It is essential for women with breast cancer to be aware of outcomes of care from using CAM, as this could help them in making decisions regarding the most appropriate breast cancer treatment and the most appropriate CAM that could be used as an adjunctive therapy. More studies are required to investigate specific outcomes from the use of CAM as alternative medicine for breast cancer management.

7.8. Chapter summary

This discussion chapter presents phenomenological interpretations of women with breast cancer's experiences and CAM providers' perceptions that are described in the previous findings chapters (Chapter Five and Chapter Six). The discussion was structured using an integration framework of van Manen's life existential concepts and the CAM Healthcare Model. Based on this framework, the women with breast cancer's experiences and CAM providers' views highlighted predisposing factors, enabling factors, need of care factors, health service use and outcomes of care on CAM use for breast cancer management. Lack of understanding and awareness about breast cancer medical treatment, and adherence to cultural practice were the main predisposing factors regarding the use of CAM. Poverty and limited access and availability of medical cancer treatments were discussed as enabling factors on the use of CAM. The need for care factors explained that CAM was used to relieve breast cancer symptoms, and reduced the side effects of chemotherapy. It was identified that health service use needs to have registered and licensed CAM practitioners in order to provide high quality and safe CAM, as well as to assist in the prevention of corruption within CAM practices. The need for standardisation was also discussed, as most of the women with breast cancer consumed unstandardized traditional home-processed products which were self-provided or obtained from unprofessional CAM providers. The most favourable self-directed CAM practices were prayer and meditation, which were part of religious belief rituals. The main purpose of CAM usage was as a primary treatment to cure breast cancer instead of as an adjunctive therapy. In terms of outcomes of care, the women with breast cancer experienced potential therapeutic effects from using CAM, but some of women experienced negative side effects. The use of CAM as a primary treatment or as an alternative medicine could delay medical cancer treatment and impact on women with breast cancer's quality of life. Ultimately, suitable CAM should be used as an adjunctive therapy to support medical cancer treatment.

The following chapter will conclude this thesis by presenting an overview of this phenomenological research. Additionally, limitations and strengths of the study and the implications based on findings of this study are presented in Chapter Eight, the final chapter of this thesis.

CHAPTER EIGHT: IMPLICATIONS AND CONCLUSION

8.1. Introduction

The main research question was ‘‘*what are the experiences of women with breast cancer, and their use of CAM, and CAM providers’ views of breast cancer management in Indonesia?’* A hermeneutic phenomenological approach was used to answer the research question. This approach allowed exploration, description and interpretation of the phenomenon of CAM use for breast cancer management among Indonesian women with breast cancer that is provided by CAM providers. In addition, this hermeneutic phenomenological research approach provided a way to understand and uncover meaning of women with breast cancer’s lived experiences, and CAM providers’ views on the use of CAM for breast cancer management in Indonesia. The findings of the study were discussed in the previous chapter. Implications from the research findings for healthcare practice, nursing education, policy makers, and future research is presented in this chapter followed by the limitations and strengths of the study. Lastly, the explanation of new knowledge and conclusion of this research project ends this thesis.

8.2. Implications of the study

The study findings revealed factors and outcomes of CAM use for breast cancer management in Indonesia, based on women with breast cancer’s experiences and CAM providers’ perceptions. The discussion of the findings generated important implications for the healthcare system, nursing practice, CAM education and research, policy makers, CAM providers and women with breast cancer in Kepulauan Riau and West Java, Indonesia. The implications could positively impact on the use of CAM as a part of breast cancer management for women with breast cancer in rural and remote regions who have limitations

in accessing medical cancer treatment. These implications will be discussed in the next section of this chapter.

8.2.1. Implications for the healthcare system

The study findings identified that lack of access and availability of medical cancer treatment as factors that impacted on the use of CAM for breast cancer management. Financial burdens due to travel costs, accommodation, meals and other expenses related to access to medical treatment provided in capital cities were experienced by women with breast cancer living in poverty particularly in rural and remote regions. This financial hardship resulted in CAM being the only available breast cancer treatment option. Another common factor to the use of CAM was fear of medical cancer treatment due to a lack of knowledge and awareness. Many of the women with breast cancer refused surgery and chemotherapy; instead, they opted for CAM based on unreliable information from social media. It was evident from the women with breast cancer's experiences in this study that the use of CAM did not cure their breast cancer, despite some potential benefits that provided temporary therapeutic effects. Therefore, this study suggested that both medical cancer treatment and safe CAM provided by professional CAM providers be more accessible and available for women with breast cancer in Batam and Bandung.

This phenomenological study's findings have implications for the healthcare system for this study's settings including: expansion of the chemotherapy care system in remote and rural regions, increase the integration of appropriate CAM into medical cancer treatment in clinical settings, the development of clinical guidelines for CAM use, providing reliable information related to breast cancer treatment and CAM. Further details of these implications are presented in the following section.

Women with breast cancer in remote and rural regions experienced distance as a barrier to access to medical cancer treatment in hospitals in metropolitan cities. This barrier indicated

that there is a need to expand cancer care facilities and oncological resources in remote and rural regions such as Batam city. A tele-chemotherapy service may be one of the potential strategies that could be introduced to extend cancer care in rural and remote regions. This model of care allows general nurses in rural and remote regions to administer prescribed chemotherapy, targeted agents and immunotherapy under the direct supervision of oncologists or chemotherapy proficient-nurses at cancer care primary sites via a video conferencing platform (Sabesan et al., 2018). This new chemotherapy model has been successfully implemented in rural sites in North Queensland, Australia, and it could be applicable to the Indonesian healthcare system, where high travel and accommodation expenses affect the majority of the rural and remote population in this archipelago country.

There is no subsidised travel or accommodation available to assist those with financial hardship. The availability of tele-chemotherapy has the potential to reduce travel and accommodation expenses. Specifically, this system of care could help rural and remote women with breast cancer in receiving appropriate medical breast cancer treatment, and using recommended CAM as adjunctive therapy. Using both medical treatment and appropriate CAM could increase survival rates of breast cancer particularly among poor women with breast cancer in rural and remote regions.

The integration of medical cancer treatment and appropriate CAM in clinical settings needs to be increased. The integration of medical cancer treatment and CAM is regulated by the Ministry of Health of the Republic of Indonesia, regulation no. 37, year 2017 (Ministry of Health Republic Indonesia, 2017). This regulation explains that CAM should be provided by professional practitioners in healthcare settings including community health centres and hospitals. According to the Indonesia Health Profile 2018, approximately 4.000 of 9.731 community health centres in Indonesia have integrated traditional therapies with medical

treatments (Ministry of Health Republic of Indonesia, 2019). However, data regarding the integration of medical cancer treatment in hospital settings is absent. The absence of the data indicated that the integration of medical cancer treatment in hospital settings was not available. There is a need to increase the integration of medical cancer treatment and CAM in healthcare settings, as this would prevent women with breast cancer from using fraudulent CAM offered by unprofessional CAM providers. Providing suitable CAM in community health centres may also increase the use of evidence-based CAM as a temporary treatment prior to accessing to medical cancer treatment, particularly for women with breast cancer in rural and remote regions.

The healthcare system in Batam and Bandung should also consider developing clinical practice guidelines and protocols for CAM use in clinical settings. Clinical practice guidelines could inform clinicians, including doctors and nurses about existing evidence of the safety and efficacy of CAM that could be integrated with medical breast cancer treatment, or cancer palliative care (Greenlee et al., 2014; Lam et al., 2019; Okubo et al., 2019; Schad et al., 2018; Ung, Harnett, & Hu, 2019). Clinical practice guidelines could provide lists of CAM interventions and recommendations based on their level of evidence of effectiveness and safety. For example, the clinical practice guidelines may recommend massage therapy, meditation, music therapy and acupuncture be used as CAM to reduce pain, anxiety and depression. Clinical practice guidelines for CAM use for breast cancer management could assist with ensuring that the efficacy and safety of CAM is known by CAM providers.

Furthermore, fear of medical cancer treatment was reflected by women with breast cancer as a predisposing factor for the use of CAM where their fear had delayed them seeking medical cancer treatment. The majority of women with breast cancer expressed fear of immediate death if they had surgery or chemotherapy. This fear occurred due to the women

with breast cancer being more familiar with the side effects of medical cancer treatment rather than its effectiveness. Therefore, women with breast cancer should be provided with psycho-oncological support to reduce their fear of medical cancer treatment. Wagner et al. (2019) suggested that psycho-oncology can assist in overcoming anxiety and fear of oncological treatments. Akyuz et al. (2019) also stated that women with breast cancer may need psychological support prior to undergoing medical cancer treatment. Thus, psycho-oncological care should be included in breast cancer treatment plans in the Indonesian settings such as Batam and Bandung. Further research is recommended to investigate the need and availability of psycho-oncological support for women with breast cancer undergoing medical treatment in Indonesia.

Another implication for the healthcare system is the contribution from professional healthcare CAM providers to provide accurate information related to breast cancer treatment and CAM use for women with breast cancer. Most women with breast cancer in this study obtained information about breast cancer treatment and CAM use from mass media and online sources including social media, personal blogs, Google, YouTube and health and cancer treatment related websites. The internet was found to be an essential tool for people with cancer including women with breast cancer seeking information about cancer treatment and CAM prior to their decision-making process. However, most information related to CAM in the mass media and online sources was found to be deceptive, inaccurate, commercial, poor in quality, and commonly provided by non-healthcare professionals. Mass media generally shared confused messages about CAM, and led the public, including cancer patients, to use fraudulent CAM that was harmful. Therefore, there is a need for greater involvement of healthcare professionals who are experts and knowledgeable about CAM and breast cancer treatments to provide specific information as this could help women with

breast cancer avoid obtaining misleading information about breast cancer treatment. Further research is needed to evaluate the quality of online CAM information and its sources.

8.3.2. Implications for nursing practice

The findings of this study indicated that there is a high demand for CAM services for breast cancer management. The Indonesian Ministry of Health regulates that CAM should be provided by healthcare professionals such as nurses (Ministry of Health Republic Indonesia, 2017, 2019). However, most nurses in Indonesia have not been permitted to practice CAM, due to them not having the required licence or Certificate of Competencies to practice CAM (Erry et al., 2014). The opportunity to provide CAM was identified by unprofessional CAM providers who offered fraudulent CAM. Thus, this study recommends that nurses need to enhance their knowledge and skills in the fields of CAM, so that they can obtain the required licence and Certificate of Competencies and be eligible to provide scientifically based CAM. The strong interest for the use of CAM by the cancer population, such as women with breast cancer, highlights prospective career opportunities for nurses such as CAM practitioners, holistic nursing and educator roles.

In addition, nurses have a vital role in providing care, support, and recommendations for related CAM (Hart, 2019). The women with breast cancer in this study claimed that they concealed CAM use from healthcare CAM providers including nurses. Nurses were not identified as information sources for the use of CAM for breast cancer. However, it is important that nurses are informed about all treatments being used by women with breast cancer including other therapies independent of medical cancer treatment. To be able to provide the best quality patient care, nurses should encourage women with breast cancer to disclose their use of CAM as some CAM therapies may interact with medical cancer treatment and may cause harmful effects as experienced by women with breast cancer in this study. Information, recommendations and support given by nurses may assist women

with breast cancer in making decisions regarding the use of appropriate CAM. Thus, nurses should initiate discussions related to CAM with women with breast cancer while providing care in clinical practice settings. In addition, the use of CAM should be assessed and well documented by nurses as this assessment could inform potential CAM therapy use that could be included in nursing care plans. For example, nurses could include meditation, music therapy or massage as pain relief management in their nursing care plans. Oncology massage, healing touch therapy, aromatherapy, and acupuncture could also be offered as nursing care to reduce the side effects of chemotherapy. Therefore, it is recommended that nurses include CAM topics for continuing education programs offered in clinical settings.

8.3.3. Implications for CAM education and research

This phenomenological study found that the unprofessional CAM providers would like more formal education and training to be available in Indonesia. As regulated by the Ministry of Health of Indonesia, CAM providers require Certification of Competencies in CAM, in order to apply for a licence and registration to practice CAM (Mahendradhata et al., 2017). However, professional organisations who provide CAM education programs, training, and competencies assessments are lacking (Erry et al., 2014). The lack of CAM education and training programs indicated that there are opportunities for national and international CAM education CAM providers to provide more CAM certification programs in Indonesia. This study recommends that CAM education includes specific core courses related to CAM such as infection control management, knowledge of law and regulations, ethics, as well as safety management in CAM practice. This information could be provided as online learning modules from accredited CAM education facilities. A strong interest by unprofessional CAM providers in this study in conducting scientific research related to CAM was also identified. Thus, CAM courses could introduce research methods to CAM providers as this could give them insight into what is required to conduct research at a professional level, and allow them to explore how they could be involved in research projects.

In a recent Indonesia health profile report, it was documented that there was only one nursing college in Indonesia that provides CAM courses specifically about Jamu (Indonesian herbal therapy) and acupuncture (Ministry of Health Republic of Indonesia, 2019). This shortage of CAM providers in CAM nursing education highlights the need for more formal CAM education opportunities so that more nurses are trained with appropriate knowledge and skills. Therefore, this study recommends that a CAM curriculum should be introduced to nursing students and that they be trained to identify high quality CAM recommendations from reliable information sources. Nursing students at advanced levels, such as at the Master's degree and doctorate levels should be encouraged to conduct scientific research in CAM fields. Further rigorous scientific research related to CAM use in human studies are required to investigate safety, efficacy and beneficial outcomes of CAM particularly for breast cancer management.

In addition, the findings of this phenomenological study and from other previous studies, indicate that there are a number of Indonesian indigenous plants that potentially could be used to produce less expensive chemotherapy treatments and CAM. However, rigorous scientifically based research on these Indonesian herbal medicines needs to be conducted to identify the efficacy of such treatments. The findings of scientific research should be regularly disseminated to CAM providers through seminars, conferences and publications, as this could provide new and current knowledge to CAM providers. Complementary and alternative medicine education programs and research have the potential to increase the number of future professional CAM providers in Indonesia.

It is also recommended that an official CAM information centre website to be established in Indonesia in the Bahasa language. This website may be funded and maintained by the Indonesian government, or reputable national or international organisations that specifically focuses on CAM. This website could be used by Indonesian CAM experts to provide current

evidence-based CAM information and align with international CAM providers, as well as be a reliable information source for those who are interested in using and administering CAM. The use of evidence-based CAM provided by professional CAM providers could positively impact on women with breast cancer treatment outcomes. Therefore, some potential strategies are required to enhance significant outcome from using CAM and to improve CAM practices in Indonesia.

8.3.3. Implications for policy makers

This phenomenological study identified implications for policy makers in Indonesia. Firstly, policy makers should consider that policies recommend increased supervision and law reinforcement regarding CAM practice in Indonesia especially in Batam and Bandung. Regulations and standards for CAM practice have been established by the Indonesian Ministry of Health to ensure quality CAM services and protect consumers from malpractice. Prior to practicing CAM, CAM providers must have a license and be registered (Mahendradhata et al., 2017). However, the findings of this study revealed most CAM providers illegally practiced CAM without any licence or registration. This illegal CAM practice may be because the bureaucracy for CAM registration is complicated and the concept of traditional treatment and complementary therapies remains unclear and needs to be reviewed. Therefore, it is recommended that policy makers act more decisively toward violations of CAM practice regulations to decrease fraudulent CAM. In addition, it is important that authorities undertake surveillance and apply law enforcement to CAM practices, in order to maintain safety and to protect women with breast cancer from corruption in CAM practice.

Secondly, policy makers need to recommend to the government that financial assistance and subsidised travel, and accommodation for the women with breast cancer living in poverty in rural and remote regions are provided. As experienced by women with breast

cancer in this study, the high cost of medical cancer treatment, travel and accommodation expenses compelled those in rural and remote regions to use CAM as a primary treatment. Therefore, there is a need for financial assistance, monetary allowance or medical funding resources to be made available to support women with breast cancer with financial hardship so that they can access appropriate medical cancer treatment. Options for financial support includes government funding or private finance organisations to provide medical treatment grants, or low repayment loans for impoverished women with breast cancer to assist them with medical cancer treatment payments. Free transportation for impoverished women with breast cancer from rural and remote regions to cancer care centres needs to be provided. Concession fares on public transportation and lodging for temporary accommodation during treatments should be made available for impoverished women with breast cancer, as these measures could assist in reducing the financial burden associated with breast cancer treatment. The availability of financial support could encourage women with breast cancer to access medical cancer treatment and use more suitable CAM as complementary therapy.

Finally, the third implication for policy makers is that policies need to be developed on the approach and engagement process for religious organisation leaders to facilitate breast cancer education programs and campaigns. The findings of this study demonstrated that religious and spiritual leaders had a strong influence on the use of CAM for breast cancer management. Most of these religious leaders recommended women with breast cancer use CAM as their main treatment based on knowledge originated from the religious leaders' religion. It is important to inform religious and spiritual leaders that appropriate safe CAM use should be integrated with medical treatment. Policies need to guide religious and spiritual leaders to participate as a team with healthcare CAM providers to encourage women with breast cancer to use both medical cancer treatment and suitable CAM. Additionally, religious organisations can potentially be information sources about breast

cancer management. Policies also need to guide religious and spiritual leaders who consider facilitating breast health education programs in their religious communities (Gyedu et al., 2018). Therefore, policy makers need to provide policies that support religious and spiritual leaders to facilitate religious activities related to breast cancer education programs such as regular free seminars and campaigns. This support for breast cancer education could increase women with breast cancer's knowledge and awareness of the importance of medical treatment to increase survival rates of breast cancer. The religious and spiritual leader's participation could positively impact on maintaining women with breast cancer's health and wellbeing.

8.3.4. Implications for CAM providers

The need for professional CAM therapists who provide high quality and safe CAM therapy was highlighted by women with breast cancer in this study. The women with breast cancer expected to receive CAM services that were provided by qualified and licenced CAM providers. Therefore, it is recommended that all unprofessional CAM providers increase their knowledge and skills and become professional CAM practitioners. It is essential for CAM providers to develop their knowledge regarding evidence-based CAM therapies, infection control management, and safety procedures. Additionally, it is recommended that Muslim CAM providers and spiritual leaders be required to increase their knowledge of contemporary religious healing developments, and awareness of modern healthcare systems based on the Islamic perspective (Qureshi, Khalil, & Alsanad, 2018; Qureshi & Padela, 2016; Szombathy, 2018). Professional CAM providers could offer suitable CAM as an adjunctive therapy and encourage women with breast cancer to use medical cancer treatment as a main treatment for breast cancer. It is crucial for CAM providers to implement standard precautions in their practices to prevent the risk of cross-infection, particularly in women with breast cancer who may have compromised immune systems due to chemotherapy. Further research is required to evaluate CAM providers understanding,

knowledge and competencies in implementing infection control precaution standards in their practice.

Furthermore, it is recommended that all CAM providers must implement the required regulations and standards of care in CAM services. The regulations and the standards of care are developed in order to provide safe, professional and ethical CAM care for the public (Ng, 2020). CAM providers should develop standard operational procedures for each CAM therapy and for all service activities in their practice. The standard operational procedures could then guide CAM providers in conducting CAM procedures in a safe and professional manner.

Provision of standardised CAM products that have been registered by the Indonesian National Agency of Drug and Food Control (BPOM) is also recommended for consideration by CAM providers. The standardised CAM products have met the requirements of good manufacturing practices that ensure scientific quality, efficacy and safety of the CAM products (Hack, Antoniadis, et al., 2018; Mahendradhata et al., 2017; World Health Organization, 2019a). Therefore, CAM providers need to be aware of standardisation and registration of CAM products so that they provide high quality and safe CAM products for their customers including women with breast cancer. In addition, CAM providers need to understand and be aware that CAM products must not be advertised in print media, electronic media and testimonies as regulated by the Indonesian Ministry of Health (Ministry of Health Republic Indonesia, 2017). According to Mahendradhata et al. (2017), any activity that goes against the regulations could be punished by administrative sanction, revocation of licence to practice CAM or court activity. Therefore, CAM providers should not provide deceptive information or fraudulent CAM in order to maintain their CAM practice. Additionally, CAM providers should not offer only affordable CAM services but also need to consider the quality, safety and effectiveness of CAM.

8.3.5. Implications for women with breast cancer

This phenomenological study identified several implications for women with breast cancer. Firstly, women with breast cancer who are interested in using CAM need to seek advice from suitably qualified and experienced healthcare professionals such as oncologists and CAM specialist nurses. Health professionals can be reliable sources to obtain accurate and relevant information on CAM usage. Additionally, it is recommended that women with breast cancer obtain online information about CAM from breast cancer or official CAM websites such as the National Centre for Complementary and Integrative Health website, rather than rely on less credible sources such as personal testimony or word of mouth from others. Print material that is generally provided at official breast cancer and CAM organisations or in cancer care facilities could be used as resources for assisting in decision making on the most suitable breast cancer treatment. Women with breast cancer should be encouraged to share more positive experiences than negative experiences regarding the use of medical cancer treatment. Sharing negative experiences with other women with breast cancer could mislead them and result in the use of inappropriate treatments. Alternatively, encouragement and support for the use of medical cancer treatment could positively impact on other women with breast cancer's treatments and outcomes. It is important for women with breast cancer to understand that there may not be any positive outcomes from receiving CAM from unprofessional CAM providers for breast cancer treatment. Therefore, it is recommended that women with breast cancer obtain information about CAM from reliable sources such as healthcare professionals and qualified CAM practitioners.

Secondly, it is essential that women with breast cancer disclose their CAM use to their oncologists and/or nurses. Women with breast cancer need to understand that healthcare professionals would respect their preference to use CAM, because patients have their own rights to receive information regarding medical procedures and treatments, as well as obtaining second opinions or adjunctive treatments such as CAM (Mahendradhata et al.,

2017). Discussion with suitably qualified health professionals may be considered to discuss the use of CAM as a prevention to breast cancer recurrence. Thus, this study recommends that women with breast cancer should not be afraid or reluctant to discuss CAM with their healthcare professionals including doctors and nurses. Disclosing CAM use to healthcare professionals could prevent women with breast cancer from potential negative drug interactions and/or toxicity effects that might occur from using specific animal-based or plant-based CAM products.

It is vital that women with breast cancer attend breast cancer education programs and campaigns provided by qualified healthcare professionals at hospitals, cancer care facilities, and primary health centres or in community health-related events. These health educational activities have been proven to be effective in raising women with breast cancer's knowledge and awareness of appropriate breast cancer management (Almutairi et al., 2019; Alsaraireh & Darawad, 2019; Mardela et al., 2017). A greater understanding about breast cancer and higher level of awareness about CAM could prevent women with breast cancer from fraudulent CAM therapies that are offered by unprofessional CAM providers.

Finally, it is recommended that women with breast cancer use medical cancer treatment as the primary method of breast cancer management and to complement that treatment with CAM that has been proven to be effective and safe. The literature reviewed in this study presented that self-directed CAM practices such as prayer, meditation, music therapy, home-yoga practice and aromatherapy are potentially effective and safe to be used in breast cancer management. These CAM therapies can be inexpensive and safe compared to provider-directed CAM services and do not require guidance from CAM providers. The use of self-directed CAM may not require extra expenses therefore allowing women with breast cancer to prioritise their limited spending on medical treatment costs. Therefore, self-directed CAM is considered the preferable option for adjunct breast cancer management. In

addition, it is important for women with breast cancer to become more prudent in selecting appropriate CAM for reducing the risk of breast cancer recurrence.

8.4. Limitations and strengths of the study

This phenomenological study had a number of limitations and strengths. The limitations and the strengths were mainly related to the lived experience gathering process, transcript validation, and data analysis as discussed below.

The first limitation was that the samples of lived experience in the use of CAM were collected from a small group of participants, recruited from two of 34 provinces in Indonesia. The women with breast cancer's experiences in this study would not be adequate to reflect the entirety of women with breast cancer's experiences in Indonesia, as each province in this country has a variety of similar and differing cultural contexts and religious beliefs. The two provinces in this study were located in the West Indonesian region where the majority of the population are Muslim. Hence, most of the participating women with breast cancer and CAM providers in this study were Muslim. Their experiences and views about CAM use may be different to those of non-Muslim women with breast cancer and CAM providers.

The second limitation of note was that women with breast cancer in this study were recruited from cancer support organisations in remote (Batam) and the urban regions (Bandung), as this study was seeking to understand women with breast cancer's experiences who lived in those different regions. However, the majority of members of the cancer support in the urban region (Bandung) were women with breast cancer from rural West Java regions, who were undergoing cancer treatment in a public hospital in Bandung. The women with breast cancer from rural and remote regions generally had similar experiences and views about the use of CAM for breast cancer management. There was limited reflection on the use of CAM from wealthy and well-educated women with breast cancer who live in metropolitan cities, or women with breast cancer who were undergoing medical cancer treatment in a private

hospital. Those women with breast cancer may have had different experiences in the use of CAM as they may have had more access to medical cancer treatment.

The third limitation of this study was unverified interview transcriptions. The researcher offered each of the participants to review the interview transcripts, to check the credibility and accuracy. However, none of the participants were willing to read their interview transcripts due to personal reasons.

The final identified limitation of this phenomenological study was the interview transcripts translation process between Bahasa and English, which might have had some impact on the data interpretation. The interview transcripts were translated by the principal researcher who is fluent in both Bahasa and English in order to prevent potential loss of meaning of the data due to the translation process. The transcript translation process was also considered as a part of analysis process. The accuracy of some of the translated transcriptions were verified by professional translators (Indonesian and native speaker) who were fluent in English and Bahasa, and the researcher's supervisors who are English native speakers only. However, the translation process in this cross-language phenomenological study could have altered the original use or structure of the translated words. As a consequence, loss of meaning could potentially have occurred in the translation process and affected the interpretation.

Although these limitations are noted, this phenomenological study has many strengths and contributions of new knowledge regarding the use of CAM for breast cancer management. First of all, this study is the first known phenomenological research project that has used van Manen's life existential concepts to reflect women with breast cancer's lived experiences and CAM providers views in the use of CAM for breast cancer management in Indonesia. Additionally, this study applied the CAM Healthcare Model as a framework to guide the discussion of the findings, thus adding strength and clarity.

There was a quick response to the recruitment due to the participants having a high level of interest in this study. Both groups of women with breast cancer and CAM providers were very enthusiastic to share their experiences and views about the use of CAM for breast cancer management in Indonesia. Some women with breast cancer offered the researcher to observe how they processed and consumed their herbal remedies. Similarly, the majority of CAM providers invited the researcher to inspect their CAM facilities and directly observe their activities in providing CAM therapies. This allowed rich data to be collected in the field notes and assisted in conceptualising the concepts more clearly that were discussed during the interviews.

Thirdly, the participants provided rich in-depth information relevant to the phenomenological study questions, and data saturation was reached. Long hours were involved in transcribing each lengthy conversation verbatim where the 31 transcriptions then were then translated into the English language, which also involved a long period of time of being immersed in the data. These persistent efforts produced a rich, strong, deep phenomenological text of women with breast cancer's lived experiences and CAM providers' views in the use of CAM for breast cancer management.

The interviews were conducted in Bahasa, Indonesia's national language. However, some of the participants used a couple of words from their first languages (Bataknesse, Chinese, Javanese and Sundanese) or specific terms in Islam originating from the Arabic language, where in the researcher did not understand and was not familiar with those words. The researcher sought rich explanations and descriptions of the words from the women with breast cancer, until the meaning was understood.

Finally, this study provided an avenue for women with breast cancer and CAM providers to voice their experiences and views on the use of CAM for breast cancer management in Indonesia. The women with breast cancer's experiences and CAM providers' views provide

deep insight, understanding and evidence of the need to improve breast cancer management and CAM practice in Indonesia, specifically in Batam and Bandung.

8.5. New knowledge from this study

This phenomenological research study contributes new knowledge that addresses knowledge gaps regarding the use of CAM for breast cancer management in Indonesia, specifically in Batam and Bandung. New knowledge included that CAM was experienced by women with breast cancer and viewed by CAM providers as an affordable and effective natural breast cancer treatment. Thus, CAM was used by women with breast cancer and offered by CAM providers as the main therapy for breast cancer treatment based on socioeconomic status, culture and religious beliefs. Further new knowledge identified from this study is women with breast cancer and CAM providers had a lack of knowledge about medical cancer treatment; hence, many women with breast cancer used inappropriate or fraudulent CAM that was provided illegally by uncertified or unlicensed CAM providers. This phenomenological research study uncovered that soursop leaf and mangosteen skin extract were the most popular herbal therapy used by women with breast cancer. Other preferable CAMs in Indonesia were prayer or spiritual therapy, traditional massage and bloodletting or cupping therapy. The use of CAM for breast cancer management having both potential therapeutic effects and negatives effects is new knowledge. The outcomes from using CAM based on women with breast cancer's experiences as presented in this study indicated that some CAM could improve quality of life. However, some fraudulent CAM obtained from unprofessional CAM providers could cause harmful effects, delay medical cancer treatment, and increase breast cancer treatment costs. New knowledge also discovered in this study is that CAM assessment in clinical settings, particularly in Indonesia, has not been performed by CAM healthcare providers including nurses. Finally, unreliable sources of information about CAM for breast cancer mislead women with breast cancer into using inappropriate CAM. Reliable information about CAM for breast cancer management should

be provided by suitably trained healthcare professionals and CAM providers. The new knowledge from this study makes a substantial contribution to the development of CAM assessment and guidelines to implement the use of CAM in clinical settings. Ultimately, the new knowledge from this study may contribute to improving CAM practices, oncology nursing and holistic nursing practice, education and research in Indonesia.

8.5. Conclusion

This phenomenological study aimed to understand women with breast cancer lived experiences and CAM providers' perspectives within the use of CAM for breast cancer management in Indonesia. This researcher had personal experiences as a nurse in Indonesia often encountering women with breast cancer who used CAM therapies, which led her to question *'What are the experiences of women with breast cancer, and their use of CAM, and CAM providers' views of breast cancer management in Indonesia?'* In addition, this researcher had a strong desire to understand the meaning of the women with breast cancer's lived experiences from using CAM therapies and CAM providers' views, after she witnessed her patient and relatives who had cancer eventually die due to the use of inappropriate cancer treatment including CAM. Previous relevant literature was reviewed to obtain insights regarding the use of CAM for breast cancer management in Asian countries, specifically in Indonesia. However, there were few studies exploring women with breast cancer's lived experience in the use of CAM for breast cancer.

A hermeneutic phenomenological approach was used as the methodology and methods in this study. van Manen's hermeneutic phenomenology in particular, provided a method to reflect the basic structure of the lived experience of human existence. This approach allowed the researcher to describe and interpret the women with breast cancer's lived experiences and CAM providers' views regarding the use of CAM for breast cancer management.

Twenty-one women with breast cancer from two different provinces in Indonesia shared their lived experiences of using CAM for breast cancer management. Ten CAM providers also expressed their views on CAM use in Indonesia. The phenomena of CAM use for breast cancer as experienced by the women with breast cancer and viewed by CAM providers were described through several main themes and sub-themes which were generated by a manual thematic analysis process.

The women with breast cancer's experiences reflected that CAM was mainly used as a primary treatment to treat breast cancer due to a lack of knowledge and awareness, poverty and limited access to medical cancer treatment. Family, particularly husbands, parents, friends, spiritual leaders, and CAM providers were reported by women with breast cancer as the most influential proponents for the use of CAM. It was evident that women with breast cancer used a variety of CAM to relieve breast cancer symptoms, reduce the side effect of chemotherapy, and to prevent breast cancer relapse. This study identified the type of CAM that was commonly used by women with breast cancer and provided by CAM providers. Potential benefits and disadvantages of CAM were also uncovered through the women with breast cancer experiences in this study. Moreover, this study provides evidence that women with breast cancer used animal-or plant-based remedies, spiritual and religious belief-based CAM and fraudulent CAM products from unprofessional CAM providers. The use of such CAM was found to delay women with breast cancer seeking medical cancer treatment, resulting in aggravated health conditions and emotional and financial harm.

The findings of this study indicate that the use of CAM among women with breast cancer in Indonesia is different to women with breast cancer in other Asian region countries. The majority of women with breast cancer in this study used CAM as a primary breast cancer treatment; in contrast, most women with breast cancer in other Asian countries used CAM as a complementary therapy. There is an urgent need to increase women with breast

cancer's knowledge and awareness about the importance of appropriate medical cancer treatment to reduce the number of women with breast cancer dying prematurely due to inappropriate treatments. Both women with breast cancer and CAM providers need to be educated that using only CAM therapy does not successfully treat breast cancer. It is also vital that women with breast cancer are encouraged by and familiar with scientific evidence regarding CAM and medical cancer treatments. This study has presented implications for the healthcare systems, nursing practice, CAM education and research in Indonesia regarding CAM providers and women with breast cancer. The recommendations offered from this study could contribute to better outcomes related to breast cancer treatment, including CAM, which are used by women with breast cancer, and hence, increase survival rates and improve quality of life of women with breast cancer in Indonesia.

In summary, it is evident from the women with breast cancer's lived experiences and CAM providers' views in this thesis that CAM as a primary treatment was ineffective in curing breast cancer. Nevertheless, some CAM has potential therapeutic effects that may benefit women with breast cancer and improve their quality of life while undergoing medical breast cancer treatment. As such, suitably safe CAM should be used as an adjunctive therapy instead of an alternative medicine to cure/treat breast cancer. The potential benefits of CAM experienced by women with breast cancer indicated that CAM could possibly be used as a pre-medical cancer treatment for those who cannot have direct access to medical cancer treatment. It is essential that the use of CAM as an adjunctive therapy to manage the side effects of chemotherapy be supervised by healthcare professionals. It is recommended that CAM should not be used as a main therapy to cure/treat breast cancer. Complementary and alternative medicine should be considered as an adjunctive therapy, or as an option for palliative care particularly for women with breast cancer who are at the terminal stage of the disease, have untreatable breast cancer or who refuse medical cancer treatment.

APPENDICES

Appendix 1: Summary of the selected articles

No	Authors/ Countries	Aim of the Study	Method, Samples and Level of evidence (LoE)	Major Findings				Strengths/ Weaknesses:	Significance to the Issue
				Demographics Data	Type of CAM Used/Intervention	Sources of Information	Reasons to Use CAM/Outcome		
1	Akhtar K, Akhtar, K Rahman M. (2018). Use of alternative medicine is delaying health-seeking behaviour by Bangladeshi breast cancer patients. *European Journal of Breast Health, 14*(3), 166. Bangladesh	To find perception of the use alternative medicine by Bangladeshi breast cancer patients	Quantitative Cross-sectional study Structured questionnaire 200 breast cancer patients LoE: IV	Age: was 42±9 Illiterate: 45% (90) Housewife: 83% (166) Family income: around 9000 taka (just over $100)	Homeopathy	Neighbours, husbands, relatives, friends, mass media, family members, herbal health workers, hospital health workers.	Solve the economic problem, challenged by agents of the alternative medicine, perceived alternative medicine to be helpful.	<u>Strength:</u> Reasonable sample size	Illiteracy, poor economic status, cultural context, availability and accessibility of alternative medicine diverted the patients to seek help from orthodox to alternative medicine. Orthodox treatment leads to delayed presentation by the breast cancer patients
2	Akyuz, M. D., Oran, N. T., Yucel, U., Eksioglu, A., & Kocak, Y. C. (2019). The relationship between hopelessness level and CAM use in patients with breast cancer.	To determining the relationship between hopelessness level and use of complementary and alternative medicine (CAM) methods in women with breast cancer.	Quantitative Descriptive and cross-sectional study 336 women with breast cancer LoE: IV	Age: 51 and 60 years of age. Married (4.5%)	Herbal medicine Religious practices Imagery technique	Media, friends or people around, people with similar illnesses, health workers, Other people.	Psychological comfort, strengthening of immunity system, coping with helplessness, strengthening of the body, increasing the effectiveness of the treatment.	<u>Strength:</u> Reasonable sample size	CAM was due to hopelessness Women with breast cancer need psychological support There was no significant statistical difference between the groups

	Journal of Cancer Research and Therapeutics, 15(5), 1155. Turkey								in terms of age, educational level, marital status, employment status, family type, monthly income, social security, family history of cancer, and presence of a chronic illness.
3	Albabtain, H., Alwhaibi, M., Alburaikan, K., & Asiri, Y. (2018). Quality of life and CAM use among women with breast cancer. *Saudi Pharmaceutical Journal, 26*(3), 416-421. Saudi Arabia	To examine the prevalence of CAM use and its' relation to the patients' quality of life among women with breast cancer at a tertiary hospital in Saudi Arabia.	Quantitative A cross-sectional study 95 women with breast cancer at a tertiary hospital in Saudi Arabia. LoE: IV	Age: 40-59 years Married: 76% Unemployed: 84% Low income (i.e., income level below 5000 Saudi Riyals):57% women with breast cancer were undergoing cancer treatment:89%	Spiritual therapy Honey Olive oil herbal therapy	Family and friends (54.7%) Media (20%)	Improve physical & psychological well-being (38.9%) Strengthen the immune system (36.8%) and directly eliminate cancer (29.5%). Improve physical & psychological well-being (58.9%) Increase immunity (22.1%).	<u>Weakness:</u> Small sample size	The majority of CAM users did not experience side effects Satisfied with their CAM use and 45.3% reported CAM to be effective. Higher proportions (46.3%) of CAM users did not discuss their use of CAM with their physicians.
4	Almasdy, D., Eptiyeni, E., Khamri, D., & Kurniasih, N. (2018). Use of CAM among breast cancer patients in a public hospital in Padang, Indonesia. *Journal of Young*	To investigate the use of CAM in breast cancer patients in a public hospital in Padang, Indonesia	Quantitative cross-sectional study A total of 85 breast cancer patients were included in the study. LoE: IV	Not identified	Herbal medicine Herbal remedies treatment with tea Vitamins and minerals Spiritual therapy, homeopathy and relaxation techniques	Family or friends (70.91%) Advertising through TV, radio, newspaper, internet, book, (29.09%). Only 5.45% patients had consulted the CAM therapies	To support health To calm the body and mind	<u>Weakness:</u> Small sample size	It is recommended that health workers, especially clinical pharmacists, explore information about CAM use by patients and may provide information on appropriate CAM use The use of acupuncture and

	Pharmacists, 10(2), S145. Padang, Indonesia					that they used to health personnel			acupressure was less popular
5	Alsharif, F. H., & Mazanec, S. R. (2019). The use of CAM among women with breast cancer in Saudi Arabia, *Applied Nursing Research*, *48*(2019), 75-80. Saudi Arabia	To explore the frequency of use of CAM among women with breast cancer in Saudi Arabia.	Quantitative A descriptive cross-sectional study design Participants: 85 Saudi women with breast cancer undergoing cancer treatment LoE: IV	Age: 48 years Married (76.5%) Resided in an urban area (83.5%) Unemployed (62%), No income (49.4%).	Honey, olive oil, antioxidants Fennel flower seeds, and ginger. Reading the Holy Quran, and praying. ZamZam water and listening to music	Not identified	Relieve physical symptoms and side effects, relieve psychological stress, and dissatisfaction with the medical treatment, and gain over control of disease.	<u>Weaknesses:</u> Participants were recruited from only one institution Small sample size	The use of CAM among Saudi women with breast cancer is highly prevalent, with a predominance of interventions of religious background.
6	Azhar Y, Achmad D, Lukman K, Hilmanto D, Aryandono T. (2016). Predictors of complementary and alternative medicine. *Asian Pacific Journal of Cancer Prevention, 17*, 2115-2118. Bandung, Indonesia	To assess CAM use and their associated factors with breast cancer patients	Quantitative Cross-sectional Structured questionnaire 330 women suffering from Breast Cancer (BC) LoE: IV	Age (mean): 46 years (59%) Education level: High School (59%) Income: Less than $200.00 /month (90%) Ca Stage: Not identified	Not identified	Patients less trust to physician Lack of communication between physician and patients regarding the use of CAM	Insufficient income, lower level of education, afraid of conventional therapy, prefer to use CAM as main therapy, less trust to doctors	<u>Strength:</u> First survey regarding the use of CAM conducted in Indonesia <u>Weaknesses:</u> Small number of participants Cannot be generalised due to study conducted only in West Java province Source of information about CAM has not been explored Some references were missing	CAM use as a main treatment instead of complementary CAM used was higher among patients with low income CAM mostly used by lower education level women In lower-middle income country, patients with lower income and education are usually afraid of seeking conventional treatment and prefer

									to use CAM as main therapy.
7	Biswal BM, Sulaiman SA, Ismail HC, Zakaria H & Musa KI. (2012). Effect of Whitaniasomnifera (Ashwagandha) on the development of chemotherapy-induced fatigue and quality of life in breast cancer patients. *Integrative Cancer Therapies, 12*(4), 312-322. Malaysia	To investigate the efficacy of *WithaniaSomnifera* (WS) for the treatment for chemotherapy-induced fatigue and preservation of QoL among breast cancer patients	Quantitative Prospective open-label non-randomized comparative clinical trial 100 women with breast cancer Study (n=50) Control (n=50) LoE: III-1	Age study group (mean): 51 years Age control group (mean):51 Education level: Not Identified Income: Not identified Cancer stage: Stage 1(n=2) Stage 2(n=19) Stage 3(n=21) Stage 4 (n=8)	Chemotherapies (intravenously repeated every three weeks) Standard antiemetic (Ondastron 8mg or Granisetron 3 mg) Materials: Chemotherapy Whithania Somnifera extract packed in veggie capsule Study group: 4 caps of WS (2 mg) three times daily (6 cycle throughout the course of chemotherapy)	Not identified	WS was effective to reduce cancer-related fatigue Fatigue score in control group was higher than in study group (P<001PFS, P<. 003 SCFS-6) EORTC QLQ-C30 was statically significant in 7 out of 18 symptoms in the intervention group compared with the study group (P<001) The 24-month overall survival both group: study (72%) Control (56%)	Strengths: The first clinical trial in the use of WS on breast cancer patients Weaknesses: Small sample size Unclear sampling technique Numerous confounding controls (stages of cancer, anaemia, tumour volume, physical activity) Information about the setting was unclear	There is evident that herb such as WS may be potentially safe and could be used to improve QoL and amelioration of fatigue
8	Can G, Demir M, Aydiner A. (2012). Complementary and alternative therapies used by Turkish breast cancer patients undergoing chemotherapy. *Breast Care, 7*, 471-475	To determine the prevalence and determining factors for use of CAM by breast cancer patients undergoing chemotherapy	Quantitative Descriptive study A face-to face interview surveys 96 breast cancer women LoE: IV	Age (mean): 50 years Education level: Primary school graduates (60.4%) Income: Had a medium income (90.6%) Ca stage: Metastatic diseases (45.8%)	Herbal supplement Prayer	Not identified	Not identified	Weaknesses: Limitation of the study was not documented Unclear sampling technique	Some CAM practices are not suitable for women

	Turkey								
9	Chen Z, Gu K, Zheng Y, Zheng W, Lu W, & Shu XO. (2008). The use of CAM among Chinese women with breast cancer. *The Journal of Alternative and Complementary Medicine, 15*(8), 1049-1055. China	To estimate the prevalence and perceived benefits of CAM and Chinese Herbal Medicine and relevant demographic and clinical factors	Quantitative Cross-sectional cohort study Structured questionnaire 5046 women with breast cancer LoE: IV	Age (mean): 53.3 year Education level: At least high school (53.6%) Income: More than 12.000 yuan/year (1 yuan equal to $0.12 US at the recruitment period) Ca Stage: 0-II (85.6%	Ganoderma lucidum (lingzhi) capsules and sporophyte Vitamins Ginseng or ginseng products	Not Identified	Cancer treatment and boosting of the immune system,	<u>Strengths:</u> Large sample size, High response rate Patients with an earlier clinical stage or who had undergone radiotherapy used less CHM	CHM use was associated with younger age, higher income
10	Chen et al. (2013). Qigong improves quality of life in women undergoing radiotherapy for breast cancer: Results of a randomized controlled trial. *Cancer, 119*(9), 1690-1698. China	To examine the efficacy of a qigong intervention on QOL in women with breast cancer during and after treatment	Quantitative RCT 100 women with breast cancer Intervention: 45 minute qigong class 5 time a week for 5-6 weeks during radiotherapy LoE: II	Not available	Not available	Not identified	Qigong may reduce depressive symptoms in women with breast cancer undergoing RT.	<u>Weaknesses:</u> No active control intervention Conducted in a single site in China	Qigong may be recommended for women with breast cancer
11	Chui, P. L., Abdullah, K. L., Wong, L. P., & Taib, N. A. (2018). Complementary and alternative medicine use and symptom burden	To assess CAM use and examine the symptom burden of CAM and non-CAM users among patients with breast cancer who	Quantitative Cross-sectional survey 546 women with breast cancer	Women with breast cancer used CAM 386 (70.7%)	Prayer for health Massage Meditation Vitamin and mineral supplements Cactus juice Cleansing detoxifying diet	Not identified	Immune boosters Perceived this treatment as helpful	<u>Weaknesses:</u> The cross-sectional design that we used can only determine the strengths of the associations and cannot determine the	Complementary and alternative medicine use is common among Malaysian patients who are undergoing chemotherapy for breast cancer

	in women undergoing chemotherapy for breast cancer in Malaysia. *Cancer Nursing, 41*(3), 189-199. Malaysia	are undergoing chemotherapy	LoE: IV		Protein powder Lingzi Bird nest Royal jelly			direction of any causal relationships.	It is important for nurses to keep abreast of current developments and trends in the field of CAM, which they can use to guide their assessments of CAM.
12	Chui PL, Abdullah KL, Wong LP, Taib NA. (2015). Quality of life in CAM and non CAM users among breast cancer patients during chemotherapy in Malaysia. *PLos One, 10*(10), 10.1371/ Malaysia	To compare the QoL in CAM users and non-users	Quantitative Cross-sectional survey Instruments: EORTC QLQ-C30 QLQ-BR23 546 Breast cancer patients undergoing chemotherapy LoE: IV	Age (range): 50-59 Education level: Primary (17.6%) Secondary (52.6%) Tertiary (29.8%) Income: <RM3000/ (65.5%) >RM 3000 (34.5%) Ca Stage: Early (59.1%) Advanced (40.9%)	Mind-Body practices Natural Products Traditional Medicine	Not identified	There were no significant differences between CAM users and Non-CAM users in global health status scores (p-value 0.40) CAM users had significantly higher marginal mean scores for financial difficulties than non-CAM users (p value 0.01) CAM users experienced higher score in: sexual enjoyment than non-users ($p<0.04$), systemic therapy side effect ($p<0.04$) and breast symptom ($p<0.02$)	<u>Strengths:</u> Reliable instrument High response rate (88.9%) <u>Weaknesses:</u> Time duration of CAM used was not identified	The use of CAM in low-middle income country related to financial problem CAM could improve QoL
13	Chui PL, Abdullah KL,	To assess CAM use and prayer-	Quantitative	Age (range): 50-59 years	Prayer- for- health Relaxation exercise	Not identified	Improve emotional health	<u>Weaknesses:</u>	Most of the CAM users were at

	Wong LP, Taib, NA. (2014). Prayer-for-health and complementary alternative medicine use among Malaysian breast cancer patients during chemotherapy. *BMC Complementary and Alternative Medicine, 14*(1), 425. Malaysia	for- health among breast cancer patients	Cross-sectional survey Researcher-administered questionnaires 546 women with breast cancer LoE: IV	Education level: Primary (21.8%) Secondary (53.3%) High school (24.9%) Income: <RM3000/USD 994/month (72.0%) >RM3000/USD 994/month (28.0%) Ca Stage: Early (61.9%) Advanced (38.1%)	Massage Meditation Tai chi Yoga Healing touch NPS (vitamin & mineral) Cleansing diet Antioxidant capsules Cactus juice Spirulina		being (92.0%), recommended by others (68.2%), and perceived to be an effective cancer treatment (46.4%)	Some information in the discussion part was not congruent with the data in the provided table	advanced stages of cancer, had higher education and income
14	Eyigor, S., Uslu, R., Apaydın, S., Caramat, I., & Yesil, H. (2018). Can yoga have any effect on shoulder and arm pain and quality of life in patients with breast cancer? A randomized, controlled, single-blind trial. *Complementary Therapies in Clinical Practice, 32*, 40-45. Turkey	To examine the effects of yoga on shoulder and arm pain, quality of life (QOL), depression, and physical performance in patients with breast cancer.	Quantitative A randomized, controlled, single-blind trial LoE: II		Prospective, randomized study included 42 patients. The patients in Group 1 underwent a 10week Hatha yoga exercise program. The patients in Group 2 were included in a 10-week follow-up program. Our primary endpoint was arm and	Not identified	The group receiving yoga showed a significant improvement in their pain severity from baseline to post treatment, and these benefits were maintained at 2.5 months post-treatment. When compared to the control group, there were no statistically significant differences between the 2	<u>Strengths:</u> The first study where the effect of yoga on shoulder and arm pain was assessed in patients with breast cancer High rate attendance was high The treatment was not DVD-based but was performed in a class environment.	Yoga was an effective and safe exercise for alleviating shoulder and arm pain, which is a complication with a high prevalence in patients with breast cancer.

					shoulder pain intensity.		groups with respect to the parameters assessed at the end of week 10.	Weaknesses: Short duration. Longer interventions might be more sensitive in reflecting the benefits of these interventions, particularly those pertaining to the strength outcomes. Small number participants.	
15	Fong SSM, Ng, SSM, Luk WS, Chung JSC, Ying M& Ma AWW (2014). Effects of Qigong exercise on upper limb lymphedema and blood flow in survivors of breast cancer: A pilot study. *Integrative Cancer Therapies, 13*(1), 54-61. Hong Kong	To investigate the immediate qigong exercise on upper limb lymphedema, arterial resistance, and blood flow velocity in women with breast cancer	A single-blinded non randomised controlled trial Treatment investigation 23 post-mastectomy breast cancer survivors (n =11 qigong group/n = 12 control group) LoE: III-1	Age (means): Qigong (58 y) Control (53y) Education level: Not identified Income: Not identified Cancer stage: Not identified	18 forms Tai Chi Internal Qigong approximately 6 minutes	Not identified	There was a significant increase in the maximum systolic arterial blood flow velocity (SV) and minimum diastolic arterial blood flow velocity (DV) after qigong exercise (P<.05	Weaknesses: Bias may occur since the participants already had per-study qigong experience Small sample size Population was quite heterogeneous No long-term effect	Qigong has short effect in improving circulatory status and limb circumference Qigong could reduce standard treatment effects such us upper limb lymphedema and poor circulatory status
16	Gul A, Ustundag H & Andsoy II. (2014). Quality of life in women with breast cancer and the use of complementary	To evaluate quality of life and CAM use among patients with breast cancer	Quantitative Cross-sectional survey Questionnaires	Age (mean): 50 yo Education level: No formal education (5.7%)	Praying (81.6%) Exercise (44.82%) Herbs (37.93%) Most frequent herbs used (green tea, stinging nettle and ginger)	Not identified	Participants who use CAM felt good psychologically and physically	Weaknesses: Small sample of participants Pervious QoL rate was unknown.	Women with breast cancer who used CAM had moderate level of QoL The use of CAM could improve QoL

	and alternative medicine. *Holistic Nursing Practice, 28*(4), 258-264. Turkey		87 women with breast cancer treated with Radical, mastectomy radiotherapy, chemotherapy, hormonal therapy LoE: IV	Primary (33.4%) High school (29.4%) College (31.0%) Income: Not identified Ca Stage: Not identified			The highest QoL score were physical and social aspects Lowest score; vitality and general health	QoL of CAM users and non-users could not be compared due to only 4 participants were not using CAM involved in the study	of patients particularly emotional and physical wellbeing
17	Gulluoglu BM, Cingi A, Cakir T & Barlas A. (2008). Patients in Northwestern Turkey prefers herbs as complementary medicine after breast cancer diagnosis. *Breast Care, 3*, 269-273. Turkey	To define the prevalence, pattern, and predictors of complementary and alternative medicine (CAM) use in breast cancer patients in north western Turkey	Quantitative Study A cross-sectional survey Self-administered questionnaires 129 patients LoE: IV	Age (Mean): 52 years old Education level: Primary school (45%) Income: Not Identified Ca Stage: Stage II (41%)	Herbal medicines/nettle (77%)	Relatives (61%) or Friends/word of mouth (61%) Physician supported patients to use CAM (46%)	To improve general health status (n = 21; 46%)	<u>Weaknesses:</u> Small sample size The findings would not appropriately represent nationwide characteristics of physician attitude patterns towards CAM.	Nearly half of the physicians who knew about their patient's CAM use supported their patients in their choice This finding is in sharp contrast to the attitudes of physicians from Western countries Only 1 case of a contact sore due to CAM use was reported as an adverse event
18	Han, S., Jang, B.-H., Suh, H. S., & Hwang, D.-S. (2019). Complementary medicine use and costs in patients with breast cancer who experienced treatment-related side effects: A	To investigate the prevalence and expenditure on complementary medicine in patients with breast cancer who experienced treatment-related side effects.	Quantitative Cross-sectional survey 100 participants completed the survey LoE: IV	Age: 55 years Income per month, 24% reported<2 million KRW (< US$1723), 33% reported 2–4 million KRW (US$1723-3447), 27%	Herbal medicine dietary supplements, and folk remedies The total direct medical cost of complementary medicine per patient per year was	Other breast cancer patients (83%), internet (41%), television (29%), and family or friends (20%). Patients who got the information	Symptom relief (6%) Felt no change in symptom after using complementary medicine (43%)	<u>Strength:</u> A total response rate of 83% was achieved. <u>Weaknesses:</u> Small sample size Did not ask the effect of complementary	The most expensive Korean medicine was uninsured herbal medicine Women with breast cancer reported a considerable financial burden to utilize complementary

	cross-sectional survey in Korea. *Complementary Therapies in Medicine, 44*, 210-217. South Korea			reported 4–6 million KRW (US$3447-5170), 7% reported 6–8 million KRW (US$5170-6894), and 9% reported ≥8 million KRW (≥US$6894).	calculated to be US$1,584.05.	through their physician were only 17% (data not shown)		medicine on symptom by each complementary medicine that they used.	medicine, but only 17% of patients got information about complementary medicine through their physician, while 83% of patients got information through other breast cancer patients Clinical practice guidelines or other strategies are needed to inform patients with breast cancer and physicians about cost-effective complementary medicine
19	Huang SM, Chien LY, Tai CJ, Chen PH, Lien OJ & Tai CJ. (2015). Effects of symptoms and complementary and alternative medicine use on the yang deficiency pattern among breast cancer patients receiving chemotherapy. *Complementary Therapies in Medicine, 23*(2), 233-241.	To describe the effects of the Yang deficiency pattern among breast cancer receiving chemotherapy	Quantitative A longitudinal study Face-to face interview with structured questionnaires 153 women receiving chemotherapy for breast cancer treatment LoE: IV	Age (mean): 53 years Education level: Not identified Income: Sufficiency (70.4%) Insufficiency 19.6%) Cancer stage: Stage I&II (90) Stage III&IV (63)	CAM use during chemotherapy (3 months) including tai chi qi gong natural products (multivitamins, fucoid complex, tian xian liquid, dietary supplements, *Genodermalucidum*, *Antrodiacinnamomea*)	Not identified	More than 66% patients used CAM at least once before treatment Patients had higher symptoms severity score after chemotherapy (fatigue, sleep disturbance, dry mouth, distress and sadness [p=0.01]) CAM use was significantly	<u>Weaknesses:</u> Small sample size Not experimental study	Patients used CAM after starting chemotherapy The use of CAM could decrease symptoms severity by increasing meridian energy There were significant differences in meridian energy among patients using CAM and not using CAM The use of CAM has positive

	Taiwan						associated with meridian energy High symptoms severity scores were associated with lower meridian energy Patients practicing Tai chi had significantly higher meridian energy		influences toward meridian energy
20	Hwang JH, Kim WY, Ahmed M, Choi S, Kim J and Han DW. (2015). The use of complementary and alternative medicine by Korean breast cancer women: Is it associated with severity of symptoms? *Evidence-Based Complementary and Alternative Medicine, 15*. South Korea	To investigate any difference in the severity of breast cancer symptoms between CAM users and non-users	Quantitative Cross-sectional survey Structured questionnaires 288 breast cancer survivors LoE: IV	Age (mean): >54 years Education level: <High school (58.5%) Income: <5 million won/month Ca Stage: Not identified	Exercise, yoga (53.9%), ginseng (53.4), mushrooms (46.6%), vitamins (40.4%), prayer, meditation (34.2%)	Not identified	The participants used CAM (67%) CAM users experienced side effects of standard treatment (89%) CAM users had higher severity of symptoms than non-users Most of the CAM users disclose about the use of CAM to their health care CAM providers (61.7%) The popularity of ginseng used as CAM reflects theirs Sociocultural background	<u>Weaknesses:</u> No information about standard therapy used	It is evident that CAM is used to alleviate symptoms of conventional treatments CAM usage could improve QoL The use of CAM is influenced by sociocultural background

21	Jafari N, Zamani A, Farajzadegan Z, Bahrami F, Emami H & Loghmani A. (2013). The effect of spiritual therapy for improving the quality of life of women with breast cancer: A randomized controlled trial. *Psychology, Health & Medicine, 18*(1), 56-69. Iran	To assess the effect of spiritual therapy on QoL of breast cancer patients undergoing radiation therapy	A randomized controlled trial Intervention: Spiritual therapy 65 patients with breast cancer (34 in intervention group and 31 in control group LoE: II	Age (mean): 47-48 Education level: Illiterate level Spiritual group (44.1%) Control (51.6%) Income: Not identified Cancer stage: Stage I (5) Stage IIA (8) Stage IIB (4) Stage IIIA (9) Stage IIIB (3) Stage IIIC (2) Stage IV (3)	Six weeks of Six Sessions Spiritual therapy: 1. Defining the course and introduction 2. Relaxation and Meditation 3. Control 4. Identity 5. Relationship 6. Prayer therapy	Not identified	After six weeks of intervention: Global health status score/QoL of intervention group increased from 44.37 (SD=13.03) to 68.63 (SD=10.86) There was a statically significant difference in all functional scales of EORTC QLQ-C30 ($p<0.05$) Progression in all function scale of EORTC QLQ-BR-23	<u>Weaknesses:</u> Participants were culturally homogenous from a single city in Iran Small sample size No follow up program conducted after six week intervention to assess the effects of spiritual therapy	There is evidence that spiritual therapy could improve quality of life of patients undergoing radiotherapy Spiritual therapy is effective in improving general health status including psychological and emotional aspects
22	Jaradat NA, Shawahna R, Eid AM, Al-Ramahi R, Asma MK, Zaid AN. (2016). Herbal remedies use by cancer patients in the West Bank of Palestine. *Journal of Ethnopharmacology*, *178*, 1-8. Palestine	To investigate the use of herbal remedies by women living with breast cancer	Quantitative Cross-sectional descriptive study Questionnaires 115 women receiving breast cancer treatment LoE: IV	Age: 50-59 Education level: Secondary (35.9%) University (28.2%) Income: Medium (59.2%) High (27.2%) Ca Stage: Not identified	The most commonly used herbs were: Ephedra alata (n=32) Nigella arvensis (n=26) Arum palaestinumn(n=26) Phoenix dactylifera(n=21) Oleaeuropaea (n=21) Annona muricata (n=17) Linumbienne (n=14) Trigonella Arabica (n=13)	Friends (26%), other patients (6.8%), attar (5.5%), public media (4.1%), pharmacists (2.7%), doctors (1.4%), Internet (1.4%), undeclared (52.1%) Sources of herbal: Wildlife (47%) Herbalist (20%) Friends (12.3%) Pharmacists (1.4%)	Herbal remedies enhance immunity, advised by someone else, herbal remedies are available and affordable, do not believe in chemotherapy, It is safe, herbal is effective	<u>Strength:</u> High response rate (89%)	The use of herbal therapy was associated with educational level Decoction was the most frequent method to use herbs Most herbs use lived in rural areas

23	Kalender ME, Buyukhatipoglu H, Balakan O, Suner A, Dirrier A, Sevine A, Bulbul F, Tatli AM, Ulas T & Camci C. (2014). Depression, anxiety and quality of life through the use of complementary and alternative medicine among breast cancer patients in Turkey. *Journal of Cancer Research and Therapeutics, 10*(4), 962-966. Turkey	To examine the association between complementary and alternative medicine (CAM) and the quality of life (QoL), anxiety, depression, and demographic characteristics of women with breast cancer.	Quantitative Cross-sectional study Self-administered questionnaires 122 patients with breast cancer LoE: IV	Age (mean): 46 years Education level: None (32.8%) Primary school (42.6%) Income: Not identified	Nettle (57%) Prayer and spiritual healing (49%).	Doctors' advice (18%) People's advice such as their partners, neighbours, relatives or some other acquaintance. (82%)	To cure cancer	<u>Weaknesses:</u> Data regarding the participants' income and cost of CAM were not mentioned	The use of CAM was related to financial issues There was no difference in CAM users and non-users in terms of anxiety and depression Women with breast cancer used different CAM depends on various ethnic populations
24	Kang E, Yang EJ, Kim SW, Nam SJ, Yang JH & Kim SW. (2012). Complementary and alternative medicine use and assessment of quality of life in	To investigated the use of CAM and the difference QoL between users and non-users	Quantitative Cross-sectional survey 425 women with breast cancer treated with: Mastectomy	Age (mean): 50.6 Education level: College (37.11%) Income:	Vitamin & mineral (41%) Ginseng products (33.6%) Exercise therapy (43.2%)	Not identified	Global health of CAM users and non-users were not statically different 57.8% of the participants	<u>Strengths:</u> High response rate (93.3%) Good sample size	Patients with higher education and income more likely to use CAM

	Korean Breast Cancer patients: A descriptive study. *Support Care Cancer, 20*, 461-473. South Korea		Lumpectomy Chemotherapy Radiation Hormonal therapy LoE: IV	2-4 million KKW/month (52.4%) Cancer stage: Early (n=186) Advanced (n=43)			satisfied with CAM CAM users more likely experienced arm symptoms (pain, numbness, stiffness and swelling) than non-users		
25	Kashani F & Kashani P. (2014). The effect of massage therapy on the quality of sleep in breast cancer patients. *Iranian Journal of Nursing and Midwifery Research*, *19*(2), 113-118. Iran	To investigate the effect of massage therapy on the quality of sleep in patients with breast cancer.	Quantitative Single blind-clinical trial 57 women with breast cancer selected by random sampling LoE: II	Age (mean): 43 years Education level: Control group (Illiterate33.5%) Experimental group (Diploma or less 52.26%)	Intervention: Massage therapy Effleurage massage technique for 20 minute/ 3 times per week in 1 month.	Not identified	Having sleep disorder: Trial group (43.35%) Control group (39.78%) Scores of quality of sleep before and after intervention was significantly different (p< 0.001)	<u>Strength</u> Using valid instrument <u>Weaknesses:</u> Short-term intervention Small sample size Allergic test was not performed.	Massage therapy can increase the quality of sleep in breast cancer patients
26	Kim YH, Kim HJ, Do Ahn S, Seo YJ & Kim SH. (2013). Effects of meditation on anxiety, depression, fatigue, and quality of life of women undergoing radiation therapy for breast cancer. *Complementary Therapies in*	To investigate the effects of meditation on anxiety, depression, fatigue and quality of life in women undergone radiotherapy	Open – label Randomized clinical trial 102 females with breast cancer (study group n=51, control group n=51) Instruments HDAS EORTC QLQ - C30	Age (mean): Intervention group (48.12) control group: (46.8) Education level: High school (49% and 56%) Income: No economic burden (49% and 60.8%)	Intervention: Meditation 'Danhak' Korean traditional exercise 60 minutes Brain Wave Vibration Meditation 2 times/week during six weeks radiotherapy course	Not identified	Brain Wave Vibration meditation is effective to reduce anxiety and fatigue during radiotherapy treatment. Meditation group decreased: anxiety significantly (p=.032) Fatigue (p=.30)	<u>Weaknesses:</u> Low response rate (102/252) Meditation session was very limited Long- term effects were not assessed	It is proven that meditation has short-term effects in improving quality of life among women undergoing radiotherapy

	Medicine, *21*(4), 379-387. South Korea		LoE: II	Cancer stage: Stage 0 (7) Stage 1(22) Stage 2 (20) Stage 3(2)			Increased Global quality of life by 13.29 points (p=.28)		
27	Knight A, Hwa YS & Hashim H. (2015). Complementary and alternative medicine use amongst breast cancer patients in the Northern Region of Peninsular Malaysia. *Asian Pacific Journal of Cancer Prevention, 16*, 3125-3130 Malaysia	To explore the use of CAM and the influencing factors in the Northern region of Peninsular Malaysia	Quantitative Cross-sectional descriptive study Structured questionnaires 100 Malaysian breast cancer survivors Only 31 of the participants used CAM LoE: IV	Age (mean): 51-53 Education level: Upper secondary (40%) Income: RM 2500.00 ($700.00/mont) Ca Stage: Not identified	Nutrition supplement /vitamins (16), herbal/natural products (8), traditional Healers (4), homeopathy (1)	Doctors (80%) Family and friends (60%) Print Media (51%) Medical staff (37%) TV and Radio (24%) Internet (14%)	Personal income Certain information about CAM	<u>Strength:</u> Various sources of participants <u>Weaknesses:</u> Lack of random selection sample would limit the generalizability of the results	There was no significant association between the use of CAM and education level Personal income and certain information of CAM were significantly associated with use of CAM
28	Lee YW, Chen TL, Shih YRV, Tsai CL, Chang CC, Liang HH, Tseng SH, Chien SC & Wang CC. (2014). Adjunctive traditional Chinese medicine therapy improves survival in patients with advanced breast cancer. *Cancer*, *120*, 1338-1344.	To investigate the association between TCM therapy and the survival of patients with advanced breast cancer treated with: Surgery Mastectomy Hormonal therapy Radiotherapy	A retrospective population-based Cohort study Data based review 729 of 1 million women with advanced breast cancer TCM users (115) Non TCM (614) LoE:III-2	Age (mean): Users (50.5) Non users (52.3) Education level: Not specified Income: Not specified Cancer stage: Not identified	TCM includes: Angelica sinensis Atractylodesmacrocephala Gardenia jasminoides, Glycyrrhizauralensis Menthahaplocaly	Not identified	During follow-up period 2.8 years: Number of deaths: TCM users: 32 deaths (27.8%) Non-TCM: 245 deaths TCM reduced mortality by 47% (unadjusted HR, 0.53; 95%CI, 0.37-0.77[P<. 001])	<u>Weaknesses:</u> Small sample size Low response rate There was no information regarding cancer stage of the participants.	Integration of TCM and standard therapy may improve the survival of breast cancer patients

	Taiwan								
29	Lin & Chiu. (2011). Use of Chinese medicine by women with breast cancer: A nationwide cross-sectional study in Taiwan. *Complementary Therapies in Medicine, 19*, 137-143. Taiwan	To explore the use of Chinese medicine under National Health Insurance among women with breast cancer	Quantitative Cross-sectional study Data based review 70,012 female with breast cancer LoE: IV	Age (Median): CM user (52.9) Non-users (54.6) Education level: Not identified CM users: Younger than 60 years old Had higher income	Chinese herbal medicine (96.8%), acupuncture/ Traumatology manipulative therapies (2.9%) Average CM cost per user: US$157.3 (exchange rate of US$1= NTD$32.842 Chinese Medicine provided by out-patient department hospital (70.5%)	Not identified	Not identified	<u>Strength</u> First study that provide data of the prevalence Chinese medicine used among breast cancer patients in Taiwan Adequate sample size The study provides valuable information for policy making. <u>Weaknesses:</u> Participants consent was not clearly explained Staging and biochemical data were not available	Women used combination Chinese medicine and Western medicine (96.0%) Potential drug interaction should be concerned There is a high demand of CAM use although comprehensive medical care has provided by NIH NHI accepted claim/ reimbursement only for licensed Chinese Medicine Physician practiced at hospitals or clinics
30	Muhamad M, Merriam S & Suhami N. (2012). Why breast cancer patients seek traditional healers. *International Journal of Breast Cancer, 2012*. Malaysia	To explore why breast cancer patients seek traditional healers	Qualitative in-depth interviews 11 Breast cancer survivors LoE: IV	Age (range): 34-75 Education level: Year 6th –PhD Income: Not identified Ca Stage: Not identified	Herbs (n=5), egg (n=1), White turmeric (n=1), egg, herb, prayer (1), Quranic healing (2), Herbs and vitamins (1)	Family Friends	Recommendation from family and friends, sanction from family, perceived benefit and compatibility, healer credibility, reservation with Western practice and system delay, afraid of western medicine	<u>Strengths:</u> Good sample size Information provided is precise Using appropriate design	Lack of sources and trained personnel provide CAM Perceived that traditional healers are more friendly The use of CAM influenced by families and the role of Islamic religion and culture

31	Mujar, N. M. M., Dahlui, M., Emran et al. (2017). Complementary and alternative medicine (CAM) use and delays in presentation and diagnosis of breast cancer patients in public hospitals in Malaysia. *PLoS ONE, 12*(4), e0176394. Malaysia	To evaluate whether the use of CAM among newly diagnosed breast cancer patients was associated with delays in presentation, diagnosis or treatment of breast cancer.	This multi-centre cross-sectional study 340 giving a response rate of 48.3%	The median age was 53 years (23 to 74 years). Education: secondary education level. Median household income of RM2, 900 (~USD 708) per month. Approximately, 17.4%, 37.6%, 33.5% and 11.5% were diagnosed at Stage I, II, III and IV respectively	Biological based practices (75.9%), mind-body medicines (38.6%) and whole medical system (35.4%) Nutritional supplements (multivitamin) Special diet (herbs, juices) Prayers Others (meditation, tai chi, yoga, qigong) Traditional Chinese medicine Cupping Homeopathy Ayurveda Ozone therapy Massage	Not identified	The delay in presentation rate was 35% (n = 119), delay in diagnosis was 41.8% (n = 142) and delay in treatment was 35.3% (n = 120	<u>Weaknesses:</u> Low response rate	Studies on CAM use among breast cancer had found that CAM use is influenced by demographic, lifestyle and clinical factors Malays are dominated by strong community relationships where family and friends involvement greatly influence the patients' treatment seeking behaviour
32	Naja F, Fadel RA, Alameddine M, Aridi Y, Zarif Y, Hariri D, Mugharbel A, Khalil M, Nahleh Z & Tfayli A. (2015). Complementary and alternative medicine use and its association with quality of life among Lebanese breast cancer patients: A cross-sectional study. *BMC Complementary*	To assess the prevalence, types, socio-demographic and to evaluate the association between CAM use and QoL	Quantitative Cross sectional survey Questionnaires 180 Breast cancer patients LoE: IV	Age (mean): 53 Education level: High school (31.1%) Income: $500-1000/month Cancer stage: Early (55%) Locally advanced (24.4%)	Special food (honey, black seed, camel milk, soy, pomegranate, and ginger). Herbal teas (green tea), dietary supplements (prebiotic, graviola pills), spiritual healing (Zam-Zam water, prayers), vitamin & mineral supplements, folk medicine.	Not identified	Believe in advantages of CAM (91.2%), managing cancer complications and slowing its progression (76%), reduce side effects of conventional therapy (34.2%), to feel more control over health (31.5%), family tradition/culture (30. %), strengthen immunity	<u>Strength:</u> High response rate (94.7%) <u>Weaknesses:</u> Small sample size Some of the participants did not competed QoL assessment questionnaires. QoL assessment toll was the first developed and used in Lebanon	The use of CAM was not based on informed recommendation from health professionals The use of CAM was associated with an advanced stage of the cancer Patients did not disclose about the CAM use to their physician The use of CAM had no clear

	and Alternative Medicine, 15, 444. Lebanon			Metastatic (20.6%)			(24.6%), provides energy (15.1%), provides hope/prayer (13/7%), relief from sorcery and spell (6.6%), disappointment from conventional therapy (4.1%), curiosity (4.1%)		influence on a patients' quality of life. Reasons not to use CAM: Lack of belief in benefits of CAM (33.6%) Afraid of side effect (28.0%)
33	Ovayolu O, Sevig U, Ovayolu N & Sevinc A. (2014). The effect of aromatherapy and massage administered in different ways to women with breast cancer on their symptoms and quality of life. *International Journal of Nursing Practice, 20*(4), 408-417. Turkey	To assess the effects of aromatherapy and classic massage on breast cancer symptoms and QoL	Randomised controlled trial Treatment: aromatherapy massage 280 assigned into 4 separated groups women who received chemotherapy Instruments: QoL scale Rotterdam Symptom Checklist LoE: II	Age: >40 years Education level: FG, MG, AMG • Non-literate (52.9%), (35.7%), (45.7%) • Primary (31.4%), (37.1%), (37.1%) Income: Low (35.7%) Medium (64.3%) Cancer stage: I-III	Fragrance group: Essential oils including lavender, chamomile, jasmine, violet, rosemary and eucalyptus to be smelled 5 minutes three/week over 1 month Classic massage group: 35 minutes' massage with olive oil Aromatherapy massage group: 35 minutes' classical massage with aromatherapy oils Duration: 6-10 weeks	Not identified	There was a highly significant difference between control and study groups in terms of QoL scale score for general health being, appetite and sexual function ($p<0.001$), physical symptoms and activity, and medical interaction ($p<0.05$) No significant difference between all groups regarding sleep, perception, social relation and work performance subdomains ($p>0.05$)	<u>Weakness:</u> Small sample size	Majority of the participants were urban residents. Had medium/low income and education level. Fragrance, massage and aromatherapy, massage have long positive effects in increasing the total QoL score and decreasing the physical and psychological symptoms of chemotherapy Aromatherapy massage is the most effective to improve QOL and general wellbeing

							There was a statically difference between the control and intervention groups in terms of mean psychological, physical and total scores ($p<0.001$)		
34	Shaharudin SH, Sulaiman S, Emran NA, Shahril MR & Hussain SNAS. (2011). The use of complementary and alternative medicine among Malay breast cancer survivors. *Alternative Therapies in Health and Medicines, 17*(1), 50-56. Malaysia	To determine the prevalence of complementary and alternative medicine (CAM) use by breast cancer survivors.	Quantitative A cross-sectional study Self-administered questionnaires 116 Malay breast cancer survivors LoE: IV	Age (range): 21 to 67 years Education level: Secondary (58%) Income: <RM 1000/month Monthly cost of CAM: RM100 to RM149 (31.88 USD to 47.50 USD) Ca Stage: Stage II (46.6%)	Dietary, prayer, Malay traditional Medicine, dietary Supplements, spirulina, vitamin C, evening primrose oil, herbal products	Family members (50.7), doctors/health care CAM providers (37.0%), friends (31.5%), printed materials/mass media (13.7%) Participants consulted with their physicians regarding the safety of CAM use (50%)	To assist in healing body's inner strength (57.6%), to cure and prevent cancer from spreading (41.1%), to reduce stress (16.4%).	<u>Strength:</u> Good response rate (91.2%)	CAM users (64%) The CAM users were found to be older, had secondary education levels, and were from middle-income household The participants began to use CAM while undergoing clinical treatments CAM used was effective and they contented with the CAM use (85%).
35	Saibul N, Shariff ZM, Rahmat A, Sulaiman S & Yaw YH. (2012). Use of Complementary and alternative medicine among breast cancer survivors. *Asian Pacific Journal of*	To determine the patterns of CAM use among breast cancer survivors as well as to examine socio-demographic, clinical, physical activity, anthropometric and dietary	Quantitative A cross-sectional survey Enumerators-interviewed questionnaires 394 Breast cancer survivors	Age (mean): 52.7 years old Education level: Mean (9.5 year) Income: RM2202.5 Ca Stage: Stage II (54.1%)	Vitamins (47.2%), spiritual activities (33.2%), other dietary supplements (30.7%)	Friends and family members (62.5%), physicians (25.0%), mass media (13.9%), books and magazines (12.5%), other CAM users (11.8%), CAM	To increase their body's ability And to perform daily activities (70.9%), to enhance immune functions (58.3%), improve physical and emotional well-being (31.7%),	<u>Weakness:</u> Non – probability sampling	Breast cancer survivors satisfied with their CAM use (98%) Women perceptions about CAM: Increased their body's ability to perform daily activities (78.4%)

	Cancer Prevention, 13, 4081-4086. Malaysia	factors associated with CAM use.	LoE: IV			practitioners (9.7%), Internet (9.0%).	recommended by physicians (8.5%) To relief of symptoms and stress associated with side effects of conventional treatments (4.5%) Prevention of cancer recurrence (6.5%)		Improved their physical and emotional well-being (57.8%) Reduced side effects of conventional treatment (30.2%). There was no participants reported adverse effects of CAM use
36	Sirisupluxana P, Sripichyakan K, Wonghokul T, Sethaboupha H & Pierce P. (2009). The meaning of complementary therapy from the perspective of Thai women with breast cancer. *Nursing and Health Science, 11*, 64-70 Thailand	To explore the meaning of CT from the perspective ofThai women with breast cancer	Qualitative Study Heideggerian phenomenology In-depth interviews 17 Thai women with breast cancer who used CAM LoE: VI	Age (range): 37–60 years old Education level: High education background Income (range): 3000–60 000 Thai Baht /month ($US90–1818) at the time data collected Ca Stage: Not identified	Raw mushrooms wood ear, mushrooms, shiitake mushroom, coffee, vitamins and other products, such as selenium, shark cartilage, or flower pollen, meditation, changed diet, exercise and pray	Not identified	Women believed the use of CAM could: Strengthening immunity Increase immunity. Mental powers, cheerfulness, hopefulness, and confidence	<u>Weakness:</u> How participants obtained information regarding CCAM was not explored	The meaning of CAM: Cancer-controlling treatment Mental strengthening Mind and body therapy, self-determination, natural therapy, conventional therapy integration. CAM used as a main treatment, and combination with conventional therapy.
37	Tarrasch, R., Carmel-Neiderman, N. N., Ben-Ami, S., Kaufman, B., Pfeffer, R., Ben-David, M., & Gamus, D.	To evaluate the effects of reflexology treatment on quality of life, sleep disturbances, and fatigue	Quantitative Non RCT Seventy-two women were recruited to the study as	Age between 31	Reflexology treatments were provided by a senior reflexologist, who graduated a 3-year course in one of the colleges accredited by the Israeli		Significant differences in fatigue, sleep, pain, and QOL were detected between the reflexology and control groups:	<u>Strength:</u> The first report on the effect of reflexology on pain-insomnia-fatigue cluster in breast cancer patients during	Reflexology may have a positive effect on fatigue, quality of sleep, pain, and quality of life in breast cancer patients during radiation therapy

	(2018). The effect of reflexology on the pain-insomnia-fatigue disturbance cluster of breast cancer patients during adjuvant radiation therapy. *The Journal of Alternative and Complementary Medicine, 24*(1), 62-68. Israel	in breast cancer patients during radiation therapy	follows: 47 chose to participate in the experimental arm and 25 women chose to participate in the control arm.		Reflexology Association, with 13 years of clinical experience.			adjuvant radiation therapy. <u>Weakness:</u> Not randomization procedure. Lack of an active control group, it may be that the choice of participation in the reflexology group has resulted in some expectations leading to an inherent bias. Small sample size	Reflexology prevented the decline in quality of life and significantly ameliorated the fatigue and quality of sleep of these patients. An encouraging trend was also noted in amelioration of pain levels. The results of the present study indicate that reflexology may have a positive effect on fatigue, quality of sleep, pain, and QOL in breast cancer patients.
38	Tian H, Qin W, Wu W, Guo P, Lu Y, Liu P, Liy Q & Su F. (2015). Effects of traditional Chinese medicine on chemotherapy-induced myelosuppression and febrile neutropenia in breast cancer patients. *Evidence-Based Complementary*	To determine whether TCM can reduce the incidence of chemotherapy-induced leukopenia, neutropenia, and FN in breast cancer patients	Quantitative cohort retrospective study 812 Breast cancer patients Treatment group (453) Non-treatment 359 LoE: III-3	Age (mean): Group 1 (50,3) Group 2 (47.1) Education level: Not specified Income: Not specified Cancer Stage: I-IV	Treatment group: TCM (Jian pi to regulate gastrointestinal function for better assimilation) and chemotherapy Non-treatment: Only chemotherapy	Not specified	There were significant differences between the two groups. TCM group had a significant lower rate of severe leukopenia, neutropenia and FN compared with non TCM (43% vs 71%, p<0.00001; 72% vs 79%, p=0.005;	<u>Strength:</u> Sufficient sample size <u>Weakness:</u> Not RCT	TCM could reduce side effects of chemotherapy TCM might safe to be used with conventional treatment TCM is affordable

	and Alternative Medicine, 2015. China						6%vs 24%, p<0,0001) There was no patients suffering from renal damage during chemotherapy and TCM treatment		
39	Vanaki Z, Matourypour P, Gholami R, Zare Z, Mehrzad V & Deghan M. (2016). Therapeutic touch for nausea in breast cancer patients receiving chemotherapy: Composing a treatment. *Complementary Therapies in Clinical Practice*, *22*, 64-68 Iran	To elicit descriptions of how Touch Therapy is used with cancer patients, providing a basis for the systematic use and evaluation of TT with patients	Quantitative-Randomized controlled trials Intervention: Therapeutic touch 108 women undergoing chemotherapy LoE: II	Age (mean): 49.7 years Education level: Without a high school diploma Test group (14.7%) Placebo (44.4%) Control (38.9%) Income: No income Test group (72.2%) Placebo (86.1%) Control (83.3%)	Six phases Therapeutic touch: Preparing the environment Evaluating and preparing the patient Practitioner preparation Assessment Intervention Reassessment	Not identified	The mean duration of nausea in intervention group was significantly lower than placebo and control group (p<0.001 and p<0.001)	<u>Weakness:</u> The practitioner skills and experiences were varying. This may result in bias	Therapeutic touch can reduce duration of nausea during chemotherapy
40	Wanchai A, Armer JM & Stewart BR. (2016). A qualitative study of factors influencing thai women with breast cancer to use complementary and alternative medicine. *Pacific*	To identify the cultural and social structure factors that influence Thai Women with breast cancer to select CAM care practices to promote their health and well-being	Qualitative-ethno nursing of Leininger In-depth interviews 17 women with breast cancer LoE: IV	Age (means): 49.5 Education level: < high school (n=10) > than high school (n=7) Income: <US$330/month (n=10)	Some participants believed that herbal medicines were not harmful as Western medicine. Religious belief (pray, meditation) enabled participants to complete their chemotherapy course.	Family Friends Support group Media (internet, TV, radio, books)	Themes of Factors influencing the use of CAM: 1. Kinship Making decision to use CAM influencing by family and friends 2. Social factors	<u>Strength:</u> Results from this study are important to develop nursing care in Thailand <u>Weaknesses:</u> Findings may not represent to other women in other cities of Thailand	Some CAMs are expensive (natural products) The use of CAM was affected by sources of information, economic status and belief. Learn to use herbs from old books of

	Rim International Journal of Nursing Research, *20*(1), 60-70. Thailand			>US$330/month (n=7) Cancer Stage: I (n=3) II (n=9) III (n=5)			Support group and media were contributed in the use of CAM 3. Economic status Economic status was the most important factor to continue or not to continue the use of CAM 4. Beliefs and lifestyles	and other countries. Types of CAM use was not explored	their older family members (ancestor)
41	Wanchai, Armer JM, & Stewart BR. (2012). Performance care practices in complementary and alternative medicine by Thai breast cancer survivors: An ethnonursing study. *Nursing and Health Science, 14*, 339-344 Thailand	To explore how Thai breast cancer survivors make decision regarding CAM use	Qualitative ethno nursing study In-depth interviews 17 Thai breast cancer survivors LoE: IV	Age (range): 24-63 years Education level: <high school (n=10), completed high school (n=2), bachelor degree (n=4), vocational school (n=1) Income: <10000 bath (<$333)/month >10000 ($>333-666) Average earning per month in Thailand was $622	Herbs (one of the participants reported having diarrhoea after consumed ornamental plant Mind-body medicine (meditation, prayer or listen Buddha teaching), massage	Family friends/ neighbours, other breast cancer survivors, television, radio Internet, report form books, magazines or newspaper. Some participants did not disclose CAM practice to their doctors because they afraid of disapproval from doctors	Believed that tumour would collapse, expecting lump would disappear, promote health and well-being	<u>Weaknesses:</u> Participants recruited only from one province in Thailand Study did not focus in particular type of CAM	Most of the patients did not disclose about the use of CAM to their physician since they were afraid of disapproval to use CAM Some participants consult the use of CAM to health care CAM providers

42	Wang, C., Zhang, Y., Yang, M., Liu et al. (2018). Bloodletting puncture and cupping as an adjuvant therapy for breast cancer-related lymphedema in female adults: A non-randomized controlled pragmatic trial. *Journal of Traditional Chinese Medical Sciences, 5*(3), 255-263. China	To evaluate the effectiveness of bloodletting puncture and cupping in relieving breast cancer-related lymphedema.	Quantitative a non-randomized controlled study 75 total patients, 50 were in the treatment group, and 25 were in the control group		The treatment group (n=50) underwent bloodletting puncture and cupping every 5 days for 15 min/session (one session per day) combined with exercise training once a day for 30 min; the control group (n=25) underwent the same exercise training alone.		The present study showed that bloodletting puncture and cupping safely and effectively reduced arm circumference and relieved upper limb pain on the affected side in patients with BCRL.	<u>Weaknesses:</u> Short follow-up duration, small sample size, and non-randomization.	Bloodletting puncture and cupping can effectively reduce arm circumference and relieve upper limb pain in patients with BRCL. Our results provide sufficient basis for exploring cupping as a long-term therapy for managing BRCL.
43	Wang, H & Chung U. (2012). Use of complementary and alternative medicine among breast cancer survivors in Taiwan. *Asian Pacific Journal of Cancer Prevention, 13*(9).	To investigate CAM use among breast cancer survivors in Taiwan	Quantitative Descriptive research design Structured questionnaire 230 breast cancer survivors	Average age 56 years old Education level: senior high school (43.0%) Stage 2 (41.0%)	Prayer Reading books Taking anti-oxidants Eating various grains Vegetarian diet Massage, hypnotherapy, qigong, Taichi	Not identified	Feeling more comfortable and relaxed, reduce stress levels	<u>Weakness:</u> Provides only general information	Provided insight for patients' education and health promotion regarding CAM use.
44	Wong K, Tan EY, Chen JJ, Teo C & Chan PM. (2014). The use of traditional Chinese medicine among breast cancer patients:	To evaluate the prevalence and pattern of TCM use among Chinese breast cancer patients, and to identify patients who were	Quantitative – survey Structured questionnaires 296 breast cancer patients	Age (mean): Use TCM (53.0) Education level: None: 9/104 Primary: 29 Secondary: 47 Higher: 18	TCM / standardised herbs formulas	Family, friends, TCM Practitioners, doctors	Not identified	<u>Weaknesses:</u> Types of TCM and dosage of treatment were not specifically mentioned	TCM is used after breast cancer diagnosis Doctors did not asked patients about the use of TCM

	Implications for the clinician. *Annual Academic Medicine Singapore, 4*, 74-78. Singapore	most likely to choose TCM	LoE: IV	Non TCM Age means: (57.0) Cancer stage: I: 34.8% II: 30.7% III: 9.5% IV: 2.0%					TCM information mostly obtained from less credible sources It was believed that TCM is safe
45	Yagli, & Ulger. (2015). The effects of yoga on the quality of life and depression in elderly breast cancer patients. *Complementary Therapies in Clinical Practice*, *21*(1), 7-10. Turkey	To investigate the effects of yoga on the QoL in patient with breast cancer	Quantitative Quasi-experimental Intervention: Yoga 10 patients in yoga group 10 patients in exercise group LoE: IV	Age (mean): Yoga (68 years) Exercise (68 years) Education level: Not specified Income: Not identified Cancer stage: Not identified	8 sessions classical yoga program including warming and breathing exercise, asanas, relaxation in supine position, and meditation	Not identified	Quality of life score after yoga intervention was better than before intervention (P<. 05) There were a significant difference in depression, pain, fatigue and sleep quality in all groups (p <0.05	<u>Weaknesses:</u> Small sample size Unclear study design	There is evidence that yoga increase the quality of life elderly patients with breast cancer Yoga could reduce the severity of pain and fatigue as well as improve sleep quality
46	Yildirim, Y. (2010). Patterns of the use of complementary an alternative medicine in women with metastatic cancer. *Cancer Nursing, 33*(3), 194-200. Turkey	To examine the patterns of CAM use among women with metastatic cancer	Quantitative cross-sectional study Questionnaires 68 women with metastatic cancer LoE: IV	Age (mean): 52.7 (12.8) Education level: Primary school graduates (47.1%). Income: Not identified	Herbal therapy (34.6%) Nutritional supplements (17.9%) Multivitamins (34.6%) Honey (46.2%) Pectin (15.4%) and shark cartilage (3.8%). Prayer (16.7%)	Friends (38.1%), family members (23.8%), healthcare CAM providers (11.9%), did not discuss their CAM use with their physicians or nurses (60%).	To treat the cancer (35.6%) To achieve physical and emotional wellbeing (31.3%) To boost the immune system (20%) Relieve pain and other cancer and treatment-related symptoms (11.1%)	<u>Weaknesses:</u> Sample was small, and findings were limited to a single inpatient setting of a single region in Turkey. The questionnaire did not include information about the dose and frequency of supplements	There were no significant differences between users and nonusers of CAM regarding age and education level Patients felt CAM used was helpful and beneficial for their disease. Four patients reported nausea, vomiting, or allergic reaction as

									an adverse effect due to CAM use.
47	Zhuang SR, Chiu HF, Chen SL, Tsai JH et al 2012. Effects of a Chinese medicinal herbs complex on cellular immunity and toxicity – related conditions of breast cancer patients. *British Journal of Nutrition, 107*, 712-718. Taiwan	To investigate the effects of Chinese medicinal herbs complex on the immune cell count of breast cancer patients receiving chemotherapy of radiotherapy	Quantitative A randomised placebo-controlled trial Experimental 66 women with breast cancer LoE: II	Age (mean) Control group: 53.5 years Experimental group: 49.9 years Education level: Not identified Income: Not identified Cancer Stage: I-IV	Placebo: A capsule containing maize starch (115.6 mg), magnesium stearate (2.5.mg),β-cyclodextri (363.7 mg) and caramel (18.2mg) Dosage: 9 capsules/day/6 weeks RG-CMH capsule: A sinensis extrac (64.5mg), C pilosula extract (27.1mg),G.tsugae (3.0mg), rose geranium power (273.6 mg), maize starch (129.3mg) and magnesium stearate (2.5mg) Dosage: 9 capsules/day/6 weeks	After 6 weeks of intervention: There was no significant differences in concentrations of platelet, erythrocytes, Hb and haematocrit The percentage of leucocytes and neutrophils was decreased in both experimental and placebo group Toxicity conditions related chemotherapy: Anorexia (control group 81.5%; test group 90.3%)	Not identified	<u>Strength:</u> The first study investigated Chinese herbs efficacy in breast cancer patient in Taiwan <u>Weaknesses:</u> Small sample size The herbs may not available in other settings	The RG-CMH treatments may delay or ease the reduction of neutrophyl levels during chemotherapy The RG-CMH may improve immunity of breast cancer patients
48	Zulkipli, A. F., Islam, T., Mohd Taib, N. A., et al. (2018). Use of complementary and alternative medicine among newly diagnosed breast cancer patients in Malaysia: An	To determine prevalence of CAM use among newly diagnosed breast cancer patients prior to seeking conventional treatment.	Quantitative a cross-sectional study A total of 400 patients were interviewed, of whom 139 (34.8%) were CAM users.	Age: 57.0 ± 16 years. The monthly household income for most of the participants was <RM3500 (n = 218, 61.9%). Most of the	Dietary supplementation, spiritual healing, traditional Chinese medicine	Family, friends, and breast cancer survivors	Most of the participants used CAM because of they were influenced by their family members. The patients' presumption that their physician	<u>Weakness:</u> The findings might not reflect the overall situation in terms of the type of CAM used by breast cancer patients in Malaysia, because the study sample	The main reason for not informing their doctors about their use of CAM was that they felt that the doctor would not understand why they were using it (39%).

	early report from the MyBCC study. *Integrative Cancer Therapies, 17*(2), 312-321. Malaysia		LoE: IV	participants were married (n = 276, 69.0%), and many were in employment (n = 17, 42.8%)			would give them a pessimistic response to the use of CAM might be hindering disclosure.	was drawn from an urban population that contains a large number of Chinese.	The majority of CAM users (95.6%) claimed that they had not experienced any side effects when using CAM. The majority of CAM users do not disclose the use of CAM to their physicians, therefore health care CAM providers should ensure that those patients who are likely to use CAM are appropriately counselled and advised.

Appendix 2: Final Ethics Approval

Juliana Christina

From: Human Research Ethics
Sent: Friday, 10 November 2017 2:27 PM
To: Julie Christina; Wendy Abigail; Anita De Bellis; Ann Harrington
Subject: 7792 SBREC Final approval notice (10 November 2017)

Importance: High

Dear Juliana,

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University considered your response to conditional approval out of session and your project has now been granted final ethics approval. This means that you now have approval to commence your research. Your ethics final approval notice can be found below.

FINAL APPROVAL NOTICE

Project No.:	**7792**
Project Title:	Women's lived experiences in the use of complementary and alternative medicine for breast cancer management in Indonesia
Principal Researcher:	Ms Juliana Christina
Email:	chri0217@flinders.edu.au
Approval Date:	10 November 2017
Ethics Approval Expiry Date:	**30 September 2021**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comment(s):

Chair Comment:

Please remove feedback session to participants. Inviting them to attend a public session will compromise their anonymity. Please arrange with them to email study feedback or to access it through the cancer support centre FB page.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. **Participant Documentation**
   Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **10 November** (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on **10 November 2018** or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, principal researcher or supervisor change);
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes / additions to information and/or documentation to be provided to potential participants;
- changes to research tools (e.g., questionnaire, interview questions, focus group questions);
- extensions of time.

To notify the Committee of any proposed modifications to the project please complete and submit the *Modification Request Form* which is available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Rae

Mrs Andrea Fiegert and Ms Rae Tyler
Ethics Officers and Executive Officer, Social and Behavioural Research Ethics Committee
Andrea - Telephone: +61 8 8201-3116 | Monday, Tuesday and Wednesday
Rae – Telephone: +61 8 8201-7938 | Tuesday, Thursday and Friday

Email: human.researchethics@flinders.edu.au
Web: Social and Behavioural Research Ethics Committee (SBREC)

Manager, Research Ethics and Integrity – Dr Peter Wigley
Telephone: +61 8 8201-5466 | email: peter.wigley@flinders.edu.au
Research Services Office | Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001

CRICOS Registered Provider: The Flinders University of South Australia | CRICOS Provider Number 00114A
This email and attachments may be confidential. If you are not the intended recipient,
please inform the sender by reply email and delete all copies of this message.

Appendix 3: Permission letter for data collection (Cancer support group Batam)

CISC
CANCER INFORMATION & SUPPORT CENTRE
CABANG KOTA BATAM

No : 010/CISC/X/2017
Ref : **Permission Letter For Research**

Batam, 12 October 2017

To,
Juliana Christina (PhD candidate)
College of Nursing and midwifery
Flinders University, Adelaide
South Australia, GPO BOX 2100

Subject: Permission for conducting research

Dear Juliana,

I am pleased to inform you that I have no objection to give you permission in respect of your research request of studying.

Research title:

Women's lived experiences in the use of complementary and alternative medicine for breast cancer management in Indonesia under the principal supervisor Dr Wendy Abigail.

Setting:

Cancer Information & Support Center (CISC) Kota Batam Kepulauan Riau, Indonesia

Date data collection: November 2017 – November 2018.

I would also like to remind all rules in CISC should be followed during the data collection process.
I wish you all the best for the conduct of the project.

Your sincerely,

[redacted]

Ir. Bastoni Solichin,M.Hum
(The coordinator of CISC in Batam)

Sekretariat : Gedung M3G, Jl. Yos Sudarso, Kota Batam. Tel. 456900

Appendix 4: Permission letter for data collection (Cancer support group Bandung)

BANDUNG CANCER SOCIETY

SEKRETARIAT : Jl. Samiaji Dalam I no. 98/66, Bandung – 40172.

E-mail : BCS.Bandung@yahoo.com

No : 002/BCS/IX/17 Bandung,13 September 2017

Matter : Research permission

To
Dr. Wendy Abigail PhD, RN BN (Hons), GCH (Diabetes), GCED (Higher Ed), FPA Cert.
Senior Lecturer
College of Nursing and Health Sciences
Flinders University
GPO Box 2100 Adelaide 5001
South Australia

Regarding to your previous letter about research permission, **we can assist the student in the implementation:**

Name : Juliana Christina
Student No : 2090726
Research tittle : Women lived experiences in the use of complementary and alternative medicine for breast cancer management in Indonesia.
Setting : Bandung Cancer Society, Bandung, Jawa Barat, Indonesia.

With following requirements:
1. In line with the research administration procedures in Bandung Cancer Society
2 Submit the research result to Bandung Cancer Society

For further information please contact the coordinator of Bandung Cancer Society during working hours Telephone

Thank you for your attention.

Regards,

(BCS Coordinator)

Appendix 5: Letter of Introduction

Flinders UNIVERSITY
College of Nursing & Health Sciences

Dr Wendy Abigail, PhD, RN BN (Hons), GCH (Diabetes), GCED (Higher Ed), FPA Cert
Senior Lecturer
College of Nursing and Health Sciences
Flinders University
GPO Box 2100 Adelaide 5001
South Australia
Ph (61-8) 8201 5433
Fax (61-8) 8276 1602
Email: wendy.abigail@flinders.edu.au
Web:http://www.flinders.edu.au/people/wendy.abigail

Letter of introduction

Dear Sir/Madam,

This letter is to introduce Ms Juliana Christina who is a PhD candidate at the College of Nursing and Health Sciences at Flinders University, Adelaide, South Australia. She has attached a copy of her student card, which carries a photograph, as proof of identity. Juliana is undertaking research leading to the production of a thesis and other publications on the subject of "***Women's experiences in the use of complementary and alternative medicine for breast cancer management in Indonesia***".

In order to be part of the study, you will need to be a woman diagnosed with breast cancer, or a complementary and alternative medicine practitioner who is willing to undergo a face-to-face in-depth interview.

Juliana would be most grateful if you would volunteer to spare the time to assist in this project by granting an interview, which explores certain aspects of this topic. The interview will take approximately 45-60 minutes to be completed. However, you can stop the interview if you wish and refuse to answer any question. You will also have the opportunity to ask Juliana to delete your responses if you do not wish them to appear in the thesis. One of the major outcomes of this study is that Juliana hopes to gain a better understanding of nursing clinical practice of complementary and alternative medicine in managing women with breast cancer in Indonesia.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting theses, report or other publications. You are free to discontinue your participation in this study at any time without any penalties.

Any enquires you may have concerning this project should be directed email to Dr Wendy Abigail (wendy.abigail@finders.edu.au) or by telephone on +61 8 82015433, or by fax on +61882761602.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee. The secretary of this committee can be contacted on (+6182013116) or email human.researchethics@flinders.edu.au.

Thank you for your attention and assistance.

Your sincerely,

Dr Wendy Abigail
Senior Lecturer

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number INSERT PROJECT No. here following approval). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

INSPIRING ACHIEVEMENT

ABN 65 542 596 200. CRICOS No. 00114A

Appendix 6: Information sheet

Juliana Christina
PhD candidate
College of Nursing and Health Sciences
Flinders University
Adelaide, South Australia
GPO BOX 2100
Email: chri0217@flinders.edu.au

INFORMATION SHEET
For women with breast cancer
Interview

Title:
Women's experiences in the use of complementary and alternative medicine for breast cancer management in Indonesia

Researcher:
Juliana Christina
College of Nursing and Health Sciences
Flinders University
GPO BOX 2100
Adelaide SA 5001
Email: [redacted]

Dr Anita De Bellis
College of Nursing and Health Sciences
Flinders University
GPO BOX 2100
Adelaide SA 5001
Email: [redacted]

Supervisors:
Dr Wendy Abigail
College of Nursing and Health Sciences
Flinders University
GPO BOX 2100
Adelaide SA 5001
Email: [redacted]

Associate Professor Ann Harrington
College of Nursing and Health Sciences
Flinders University
GPO BOX 2100
Adelaide SA 5001
Email: [redacted]

Description of the study:
This study is entitled *'Women's experiences in the use of complementary and alternative medicine for breast cancer management in Indonesia'*. This project is being conducted by *Juliana Christina* as her PhD thesis at the College of Nursing and Health Sciences, Flinders University, South Australia.

Purpose of the study:
This project aims to explore Indonesian women's experiences in the use of complementary and alternative medicines for breast cancer management.

1. To explore what Indonesian women's know about complementary and alternative medicines for breast cancer management
2. To assess what Indonesian women's perceptions about complementary and alternative medicines for breast cancer management
3. To investigate Indonesian women's expectations and attitudes toward use complementary and alternative medicines for breast cancer management

What will I be asked to do?
If you have breast cancer and have used complementary and alternative medicines, you are invited to attend a one-on-one interview with a researcher. The researcher will ask you questions about your experiences related to the use of complementary and alternative medicines for breast cancer management. For example the questions are *'Please tell me about your experience in using*

inspiring achievement

complementary and alternative for breast cancer management?' and *'Could you tell me why do you interested to use complementary and alternative for breast cancer management?'*. Your participation is entirely voluntary. The interview will be no longer than 60 minutes. The interview will be conducted in a private, quiet and convenient meeting room located at the supports group facility when the meeting is not being conducted, or at the mutually agreed location. The interview will be audio recorded using a digital voice recorder to assist with analysing your responses.

What benefit will I gain from being involved in this study?
By being involved in this study, you will have the opportunity to share your experiences and ideas regarding the use of complementary and alternative medicine for breast cancer management. The sharing of your experiences can be a therapy that helps to reduce your psychosocial distress. Indeed, by sharing your experience, you have an opportunity to contribute your ideas and views to improve the quality of care of other women with breast cancer in Indonesia.

Will I be identifiable by being involving in this study?
Your identity will not be revealed in any written material in the thesis. A name that is not yours will be used in any publication and for the purpose of analysis.

Are there any risks or discomforts if I am involved?
The researcher anticipates no physical and emotional risks from your involvement in this study. However, if you have any concerns regarding emotional discomfort, anxiety and /or distress during or after the interview, please do not hesitate to contact the researcher Juliana Christina (+62 895325117148). If you feel emotionally upset during the interview, the researcher will immediately stop the interview and will not recommence the data collection unless you are agree to do so. If needed you can directly contact the Psychiatric clinic of Hasan Sadikin Hopital Bandung located at Jalan Pasteur No.38, Pasteur, Sukajadi, Kota Bandung Jawa Barat 40161, ph +62 222551111 (for participants recruited in Bandung) and Psychiatric clinic of Embung Fatimah public hospital located in Jalan letjen Soerapto Blok D 1-9, Batu Aji, Bukit Tempayan, Batu Aji, Kota Batam, Kepulauan Riau 29432, ph +62 778 36446 (for participants recruited in Batam Island) for free consultation service. Or you can ask the researcher to assistance to access the consultation service. If you do not participate in this study, your ongoing treatment in hospital and activity at the support group would not be effected.

How do I agree to participate?
Participation in this study is voluntary and if you decide not to take part or decide to withdraw at any time this will not affect you in any way. Once you agree to participate, please fill in the contact sheet and the consent form then put in the box which is provided in the Bandung Cancer Society reception's desk or nurse stations. The contact sheet and consent form are attached with this information sheet. The researcher will then collect and contact you by phone or text to arrange the best time and place for the interview or you could contact the researcher as below. You will also have the opportunity to clarify your responses or to request that the audio recording is turned off. Once recorded, the interview will be transcribed and stored as a computer file on a password secured computer.

Recognition of contribution /Time /Travel Cost?
You will receive no payment for your participation in this study.

How will I receive feedback?
You will receive feedback, during the interview if required, after the interview has been conducted and the study has been completed. You will be given the opportunity to ask questions or any uncertainties related to your answers to the researcher's questions during the interviews. After the interview, the researcher will thank you for the information you gave during the interview.

Feedback also will be given after the completion of the study. The researcher will also provide feedback by giving a presentation of project which you will be invited to attend. The researcher will

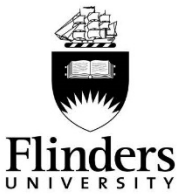
send the invitation via the contact details that you have given prior to the interview. The results may also be published in international nursing journals or at conferences.

Should you require further details about the project, you may contact Juliana Christina via e-mail chri0217@flinders.edu.au or by phone +**62 895325117148**.

Thank you for taking the time to read this information sheet and I hope that you will accept my invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7792). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix 7: Consent Form



CONSENT FORM FOR WOMEN'S PARTICIPATION IN RESEARCH
(By interview)

Women's lived experiences in the use of complementary and alternative medicine for breast cancer management in Indonesia

I .....
being over the age of 18 years hereby consent to participate in an interview for the research project on: **Women's lived experiences in the use of complementary and alternative medicine for breast cancer management in Indonesia.**

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
   - I may not directly benefit from taking part in this research.
   - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
   - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
   - Whether I participate or not, or withdraw after participating, will have no effect on any service that is being provided to me.
   - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
6. I agree/do not agree* to the tape/transcript* being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed. **delete as appropriate*
7. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's signature……Date……...

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name: Juliana Christina

Researcher signature ..... Date .....
NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Items 8 and 9, as appropriate.

8. I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

Participant's signature.....Date.....

9. I, the participant whose signature appears below, have read the researcher's report and agree to the publication of my information as reported.

Participant's signature.....Date.....

Appendix 8: Approved recruitment poster

Women's lived experiences in the use of complementary and alternative medicine for breast cancer management

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inspiring achievement

WOMEN VOLUNTEERS NEEDED

You may be eligible to participate if you:

- Have breast cancer at any stages and have used complementary and alternative medicine
- Able to be voluntarily be involved in a face-to face interview

If you would like more information on the project and how to volunteer to participate, please contact:

Juliana Christina
chri0217@flinders.edu.au
+62 895325117148

This research project has been approved by the Flinders University Social and Behavioral Research Ethics Committee (Project number: 7792).For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Hi Women,

Your experience may help others to improve their quality of life.

Please share your story

inspiring achievement CRICOS No. 00114A

Women's lived experiences in the use of complementary and alternative medicine for breast cancer management

CAM PROVIDERS VOLUNTEERS NEEDED

You may be eligible to participate if you are:

- Work as complementary and alternative medicine practitioner
- Able to be voluntarily involved in a face-to face interview

If you would like more information on the project and how to volunteer to participate, please contact:

Juliana Christina
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This research project has been approved by the Flinders University Social and Behavioral Research Ethics Committee (Project number:7792). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

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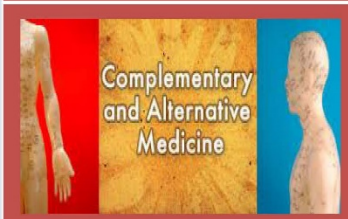

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