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*‘People who are together with me’*

**The Personal Social Networks of Women Living with Breast Cancer  
in the Lower Southern Region of Thailand**

**A dissertation presented in fulfilment of the requirements for  
the degree of Doctor of Philosophy  
in  
Nursing**

**At Massey University, Palmerston North, New Zealand**

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## ABSTRACT

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Living with breast cancer is a complex, long, and changeable journey. Due to my personal experiences of breast cancer in my family, and (breast) cancer clubs being promoted in the Thai health policy to support cancer care, this study's aim was to explore the experiences of the personal social networks of women living with breast cancer in the lower southern region of Thailand. A qualitative collective case study approach was used to purposively examine eleven personal networks, comprising eleven women with a breast cancer diagnosis and their significant network members. Data were collected during eleven months of fieldwork, through interviews, (participatory) observation, and network mapping.

Analysis of the longitudinal data revealed that personal social networks were identified as the '**people who are together with me**'. These people were predominantly family and they were held together by family relationships and feelings of *ห่วง /Khong/* (the Thai southern dialect that means a combined feeling of 'attachment' and 'concern or worry about'). Throughout the breast cancer journeys in the lower southern region of Thailand, an ongoing interplay between the contextual factors related to the breast cancer disease and its treatment, the health system, and normal life resulted in four unique patterns of living with breast cancer. These were: i) living with mature networks; ii) living with complexities in family circumstances; iii) living with complexities in the management of the breast cancer, and family circumstances; and iv) for some women, having a long-term involvement with a breast cancer club. Through cross case analysis, five core characteristics of networks emerged. These characteristics were the: i) interplay between support, supporters, and relationships; ii) hierarchies of member significance; iii) different degrees of relationships and feelings of *ห่วง /Khong/*; iv) fluidity of networks; and v) network life cycle. These characteristics were underpinned by criteria related to the disease, relationships, and cultural differences.

These study findings have important implications for nursing, especially related to the nursing of people with long-term conditions such as breast cancer. First, personal social networks can form part of the health care team; second, family and family relationships are important and impact on both the women's support needs and access to resources; third

complexities in clinical management of the disease as well as complexities in family circumstances have a high impact on the support needs and ability of the network to provide the necessary support; fourth, an involvement of non-family members in the core supporter group of a network is a significant sign of difficulties in family support provision; fifth, it is crucial that nurses understand the nature of networks; and sixth, there are considerable individual differences of needs for formal network support (cancer clubs) related to perceptions of needs, preferences for types of support, and barriers to participation. These findings provide an in-depth examination of the women's personal social networks, and their functions and actions in providing support for women that extended past coping with their breast cancer and its treatment into also supporting the women to meet their responsibilities within their everyday lives. While most personal social networks were resourceful and supportive, gaps in support emerged over time in some networks. Consideration of personal social networks would enable more opportunities for nurses to individualise care to the social and cultural contexts of women's lives and their specific support needs.

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## ABBREVIATIONS

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<b>APN</b>	Advanced practice nurse
<b>ASR</b>	Age-standardised incidence rate
<b>C(no.)</b>	Case no. (1-11) <i>For example: C1 = Case no. 1, C2 = Case no.2, ...</i>
<b>CM</b>	Club manager
<b>Doc</b>	Data from documents <i>For example: a hospital letter / report</i>
<b>E-Int</b>	Electronic interview
<b>ECG</b>	Electrocardiography
<b>Fn</b>	Field notes
<b>Gr Int</b>	Group interview
<b>HRQoL</b>	Health-related quality of life
<b>Int</b>	Interview
<b>IPD</b>	Inpatient department
<b>NM</b>	Nurse manager
<b>OPD</b>	Outpatient department
<b>p. (no.)</b>	Page number <i>For example: p. 2 = page no. 2, p. 10 &amp; 11 = page no. 10 and 11, p. 1-3 = page no. 1, 2, and 3</i>
<b>PCUs</b>	Primary care units
<b>QoL</b>	Quality of life
<b>Tel Int</b>	Telephone interview



## GLOSSARY: THAI WORDS

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### Thai words

### Meanings

ไอ้ นั้น /*Ai-Nan*/

Something that could be implied to a negative thing such as cancer

อนามัย /*Anamai*/

Primary care units

บัตรทอง /*Bahd-dhong*/

An informal name of the financial programme of the universal coverage scheme

ชาวปักษ์ใต้ /*Chao-pak-tai*/

The southern Thai persons

ใจแห้ง /*Jai-hang*/

A heart was getting dried: Feeling of hopelessness and sadness

กำลังใจ /*Khamlung-jai*/

Power of mind

คนใน /*Khon-nai*/ and

*คนใน* /*Khon-nai*/ means a family member and *คนนอก*

คนนอก /*Khon-nok*/

/*Khon-nok*/ means a non-family member.

ข้อง /*Khong*/

A combined feeling of ‘attachment’ and ‘concern or worry about’).

[the southern dialect]

เกรงใจ /*Kreng-jai*/.

Feelings of *เกรงใจ* /*Kreng-jai*/ are a combination of deference and consideration, *เกรง* /*Kreng*/ means to be to be in awe of, to fear, and *ใจ* /*jai*/ means heart or mind. When these words are compounded together *เกรงใจ* /*Kreng-jai*/ means to be reluctant to impose upon and/or to have consideration for. It is important to realise that *เกรงใจ* /*Kreng-jai*/ refers to an attitude toward an individual.

เครือข่ายทางสังคม /*Krua-kai-tang-sang-khom*/

Personal social networks

ลุง /*Lung*/

Uncle. This word is also placed before the name of a male who is not a relative but seems older than the speaker’s parents.

หมอ /*Mor*/

Doctor

เนื้อร้าย /*Neau-raay*/

Carcinoma

ป้า /*Pa*/

Aunt. This word is also placed before a female name of people who are not relatives but seem older than the speaker’s parents.

## Thai words

## Meanings

ภาษาปักษ์ใต้  
*/Pa-sa-pak-*  
*tai/*  
พี/*Pee/*

The southern dialect

An elder sister or brother. This word is also placed before either a female or male name of people who are not relatives but seem older than the speaker.

ศูนย์ถันยเวช  
*/Soon-Than-Ya-Wade/*

A name of the Centre of Excellence for Breast Cancer situated in the lower southern region of Thailand

วัง/*Wang/*  
[the southern dialect]

Keep monitoring





# CHAPTER 1

## Introduction and background to the study

---

### Introduction

My personal experiences of living with breast cancer in my family, and a Thai health policy emphasis of formal support clubs for patients with chronic diseases, including breast cancer, but low success in terms of membership numbers, provoked my professional and personal interests about the ‘personal social networks’ of women living with breast cancer in the circumstances of the lower southern Thailand (my hometown region). This chapter provides the overall background of the study, research questions, information related to breast cancer as a disease, and the regional contexts of personal social networks when living with breast cancer.

### Background

My personal experiences relating to breast cancer began in 2005 when I received a call from my older sister who said ‘**I’ve got breast cancer**’. For the next five years I took part in my sister’s breast cancer journey as her significant supporter and an observer of her journey. Through the observer’s lens, I could see that living with breast cancer in the lower southern region of Thailand (my sister’s home) was complicated, with many difficulties related to accessing treatment and everyday living. Significantly, two scenes are still imprinted on my mind. The first is the streams of personal support for my sister from relatives, friends, neighbours, acquaintances, friends of friends, and others helping her continue with treatment. Another is the period after medical treatment was completed. A number of support role adjustments were required for all family members, including my sister with breast cancer, because my father was now unwell.

During the same period of time, the Thai health policy had emphasised the development of formal support clubs as part of health services for patients with chronic diseases including breast cancer. While focusing on this health policy for over a decade, Thai health development policy has aimed to reach ‘health for all’. Social networks can be viewed as a vehicle or means by which to influence resource sharing and patients’ ability to take care of

themselves. Developing cancer clubs is a strategy used as one health service for breast cancer patients. Nationally there are more than 20 groups to socially connect cancer patients, including four breast cancer patients' groups (National Health Security Office, 2006). One formal network of breast cancer patients (a breast cancer club) is located at Songklanakarind Hospital, the cancer centre in the lower southern region. The group of breast cancer patients at Songklanakarind Hospital was founded by the patient care team for breast cancer of the hospital in 2005. The ultimate goal was to develop a self-help group of breast cancer patients as a supportive resource for breast cancer in the lower southern region of Thailand. In 2010, there are around 20 breast cancer patients participating in the monthly activities, while around 30 women join in the yearly activities (Songklanakarind Hospital, 2010). However, even though many women living with breast cancer in this region elected to have this club as part of their support networks, others, including my sister and some of her breast cancer friends who were encouraged to access the support provided through this formal network, decided not to participate in the club.

This personal experience of personal support and networks, and the situation of the formal support group in the region related to breast cancer were significant. I became aware of the amount of support breast cancer patients need, and the amount provided by their supporter groups in their breast cancer journey that I had never been aware of when I had nursed women with breast cancer in hospitals. However, some differences between informal and formal support forms were notable. Consequently, my professional challenge was to develop a deeper understanding of the personal supporter groups of these women when they are living with breast cancer, so that the quality of breast cancer care can be further improved.

In this study, these groups of supporters are called '**personal social networks**' because they belong to a particular individual. These network memberships are identified personally by the women with a breast cancer diagnosis and/or their relevant people and primarily involve people with personal social relationships between them such as family-related relationships, kinship and friendship. The personal social networks in this study are similar to the '**personal communities**' Spencer and Pahl (2006) described as an entire set of personal relationships of a particular individual, containing only those who are considered important.

## Research Questions

While there has been ample research about social networks and people with breast cancer, there are some major limitations in the knowledge as most studies only include a component of the networks. The focus of studies about the impacts of support networks as part of personal social networks varies from physical to psychosocial outcomes. For example, Kroenke, Kubzansky, Schernhammer, Holmes and Kawachi's (2006) study focused on survival rates, while Kroenke et al's (2013) study investigated the quality of life after breast cancer diagnosis in relation to personal social networks. Many studies focus only on particular roles of social support networks such as that of Pistrang, Solomons and Barker (1999) who explored the role of empathy and self-disclosure from peer support and of Till (2003) who evaluated the navigator role of support groups. Most studies use quantitative designs and some use secondary data such as Arora, Finney-Rutten, Gustafson, Moser, and Hawkins (2007) who used secondary data from the Comprehensive Health Enhancement Support System (CHESS), a computer-based system, to investigate perceptions about the helpfulness and the impact of social support, which is a positive aspect of personal social networks. Goodwin et al. (2001) measured the effect of group psychological support, a formal support network, on survival in metastatic breast cancer through their interventional research. Additionally, few published studies have been completed in the Thai context. Therefore, Thai people's in-depth experiences related to personal social networks when living with breast cancer are not yet part of this literature.

As a result, the research questions for this qualitative case study are:

1. What are the experiences of personal social networks of women with a breast cancer diagnosis and their significant supporters?
2. How do the contextual factors of living with breast cancer in the lower southern region of Thailand influence their personal social networks?
3. How do the women with a breast cancer diagnosis become involved a breast cancer club and why?

Even though breast cancer patients comprise both female and male in this study I investigate only the experiences in personal social networks of female breast cancer patients because they are the majority group. As the international, national and regional contexts may impact on personal social networks, next I will provide information related to breast cancer, the Thai health care system related to breast cancer, regional geography and Thai cultural values related to people's socialisation in the research setting.

## Breast cancer in Thailand

Breast cancer was the most common female cancer and the principal cause of female cancer-related mortality worldwide for many years. In 2008, breast cancer was reported as the most prevalent female cancer in most countries (Bray, Ren, Masuyer, & Ferlay, 2013). In the same year, the American Cancer Society (2011) estimated the number of new cases per year was over a million, and a half million of female deaths were caused by breast cancer globally. In 2012 breast cancer became the second most common cancer of women after lung cancer, reflecting the effect of a larger number of female smokers who have gone on to develop lung cancer (International Agency for Research on Cancer, 2012). However, the breast cancer incidence rate is still increasing with over half of new cases occurring in economically developing countries (American Cancer Society, 2011; International Agency for Research on Cancer, 2012).

In the Asian continent which comprises both economically developed and developing countries, breast cancer incidence rates are in the intermediate to low range<sup>1</sup> compared to global figures; however they are now rising more rapidly than in Western countries. Survival rates of breast cancer have increased in most countries including the Asian countries (American Cancer Society, 2011; Anderson & Jakesz, 2008). However, the peak age at diagnosis of a female breast cancer in Asia tends to be lower than that in the West. The median peak age at diagnosis in the Asian region ranges from 40-50 whereas in the West it is between 60- 70 (Green & Raina, 2008; Leong et al., 2010).

No biological differences in the breast cancers occurring have been noted either in Asia or the West (Leong et al., 2010). The differences in incidence are mainly attributed to the effects and distribution of different risk factors. The increasingly urbanised and westernised lifestyle, the success of family planning policies, particularly the extensive use of oral contraceptives (and postmenopausal hormone replacement therapy), and the changes in reproductive patterns, such as delayed childbearing and having fewer children, are identified as the crucial factors that are influencing the changing breast cancer incidence patterns in Asia, towards the Western-type profile (Bray et al., 2013; Jemal et al., 2011; Leong et al., 2010; Moore et al., 2010). Variations in levels of health care-related resources and individual awareness of breast health are recognised as major factors affecting the pattern of differences

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<sup>1</sup> The high rate is more than 100 cases per 100,000 population, the elevated rate is 50-100 cases per 100,000 population, the intermediate rate is 30-50 cases per 100,000 population and the low rate is 10- 30 cases per 100,000 population.

of mortality and survival rate between the Western and Asian regions (Agarwal, Pradeep, Aggarwal, Yip, & Cheung, 2007; Green & Raina, 2008; Jemal et al., 2011; Leong et al., 2010). Additionally, these differences are also caused by economic, cultural, and health system factors (Shulman, Willett, Sievers, & Knaul, 2010).

In Thailand, breast cancer has been the most common Thai female cancer for many years (Khuhaprema, Attasara, Sriplung, Wiangnon, & Sangrajrang, 2013; Khuhaprema et al., 2012; Khuhaprema et al., 2010). Its incidence rate is clearly increasing, from 20.8, to 25.6, and 26.4 per 100,000 population in 2003, 2006, and 2008 respectively. This increase is likely to have come from a combination of better diagnosis, information systems and data management, rather than from an absolute increase in the incidence rate (Khuhaprema et al., 2013). In terms of peak age of female breast cancer in Thailand, in 2001 - 2003 an increasing incidence occurred within a group of 45 and older (Khuhaprema et al., 2010). Since 2006, the trend of shifting in female breast cancer incidence rate to a younger age-group can be observed (Attasara & Bausom, 2011; Attasara & Bausom, 2012; Attasara, Srivatanakul, & Sriplung, 2010; Khuhaprema et al., 2013; Khuhaprema et al., 2012). Kotepui and Chupeerach (2013) argued that the shifting of breast cancer figures in Thailand and increasing incidence rates may reflect an impact of intense environment exposures. This argument is consistent with an earlier study about pesticide exposure and women's health (Garcia, 2003) which revealed that some organochlorine pesticides have been associated with breast cancer.

More than half of females with breast cancer in Thailand are diagnosed with stages II and III <sup>2</sup> (Attasara & Bausom, 2011; Attasara & Bausom, 2012; Chaiweerawattana, Laowahutanon, & Suwamkaysorn, 2014; Ekachampaka, 2011) and almost all of these diagnoses are infiltrating duct carcinomas (a histopathological type of tumour) (Kotepui & Chupeerach, 2013). The Thai breast cancer mortality rate is low (6.3 per 100,000). Nevertheless, the survival rate of Thai breast cancer is at an intermediate rate, lower than the rates in China and Singapore (Green & Raina, 2008; Sankaranarayanan et al., 2010).

From 1999 to 2010, the age-standardised incidence rate (ASR) of female breast cancer in the southern region of Thailand came close to the nationwide incidence, following an

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<sup>2</sup> The system of breast cancer staging in Thailand is the TNM system. The cancer stages of diagnoses range from early to advanced, I to IV stages based on i) size and extent of primary tumour (T), ii) absence or presence of regional lymph node involvement (N), and iii) absence or presence of distant metastases to other parts of body (M). (See details of the TNM staging system in Appendix I).

incremental increase, from 10 to 27.8 cases per 100,000 population. However, it is predicted to continuously increase in the future with the incidence of women aged 50 and above increasing at a higher rate than for women below 50 (Virani, Sriplung, Rozek, & Meza, 2014). These shifting figures are likely due to the combination of a health transition in lifespan and a shifting from a population pattern of infectious diseases to chronic diseases, in particular increasing rates of obesity and diabetes (Virani et al., 2014). In the capital city of the lower southern region—Songkhla, the breast cancer ASR has been steadily rising and was at 23.7 cases per 100,000 population in 2008 (Khuhaprema et al., 2013; Khuhaprema et al., 2012; Khuhaprema et al., 2010). In Phatthalung—a small town 104 kilometres from Songkhla, the annual number of breast cancer patients in Phatthalung Hospital doubled between 2008 and 2010 (Medical Record Department of Phatthalung Hospital, 2010). However, one factor influencing this statistical increase was an improvement in capability for breast cancer care of the hospital which, as a result, received more referrals.

## The lower southern region of Thailand

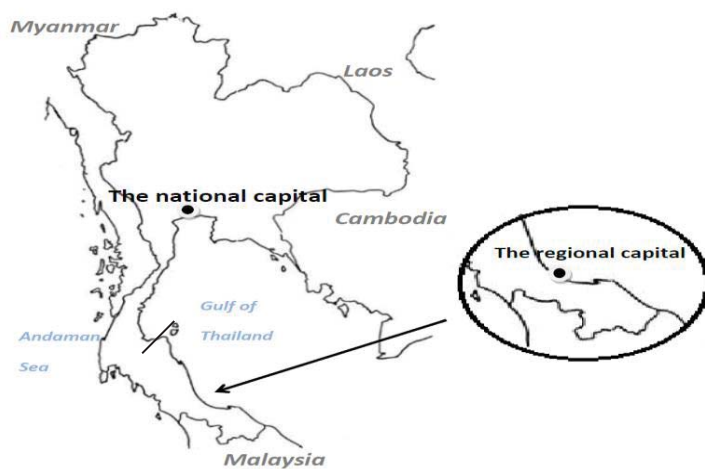


Figure 1.1. Map of the Lower Southern Region of Thailand.

The Southern Region of Thailand is on the Malay Peninsula and comprises 14 provinces, and the area is divided into two regions related to health care management; the upper and lower southern regions with seven provinces each. The lower southern region is an area around 30,000 km<sup>3</sup> with both the western and eastern coasts and bounded by the northern part of Malaysia. The regional population is around 44.8 million and five metropolitan areas are situated in this region (General Register Office Department of Provincial Administration, 2013). Furthermore, the three most southern provinces have been areas of insurgency for more than 10 years. The distance between the national capital (Bangkok) and the lower

southern capital (Songkhla) is in approximately 1,000 kilometres. This region is connected with Bangkok and other parts of Thailand by railway, road, and air.

The lower southern region's population consists mainly of three different ethnic groups,— Thai, Chinese-Thai and Malay-Thai which represent the southern Thai or ‘ชาวปักษ์ใต้/*Chao-pak-tai*/. Both Thais and Chinese-Thais are predominantly Buddhist and Malay-Thais are mainly Muslim. The main language is Southern Thai, *ภาษาปักษ์ใต้/Pa-sa-pak-tai*/. Nonetheless, most Malay-Thais use the Patani Malay dialect to communicate among themselves. Most inhabitants of the region are also fluent or understand the central Thai dialect, the Thai official language (Pongpaiboon, 2004). These geographical and social environments form the regional circumstances that influence the women's support networks.

## **Breast cancer care in the Thai Health System**

The Thai Health System is grounded in modern/western medical perspectives, clustered centres, and resource sharing. Furthermore, the integration of traditional and alternative medical perspectives within the health system, both formally and informally, forms a special characteristic of this health system. This system is also grounded by the ideas of equity and efficiency, particularly in relation to geographical coverage and resource sharing. This national system functions as a framework for health service provision, with services such as breast cancer care then individually designed within each health setting. It provides guidelines and standards for breast cancer care including processes of access and referral. Breast cancer care in the lower southern region then is characterised by four dominant features as follows.

### **Multi-level care and setting distribution**

Breast cancer care in Thailand, including the lower southern region, is managed through five levels of care: self-care, primary health care, primary care, secondary care, and tertiary care. The care provided related to breast cancer screening, investigation, and therapies, are differentiated based on the complexity of medical treatments and number of inpatient beds (Bureau of Policy and Strategy, 2005). Advanced screening procedures, investigation and treatments are provided at the higher levels. For example, mammography machines are situated in some provincial and all higher level hospitals and radiation therapy is available only at the university hospital. Some provincial hospitals could provide breast cancer care

depending on the breast cancer specialists they have. (The classification of breast cancer care within five levels is provided in Appendix III).

The referral system is a key strategy to manage all levels of breast cancer care. Breast cancer care delivery, however, has to manage under limitations of settings and system. Regional hospitals, which have the capacity to provide tertiary care, receive referrals from the lower level settings in their clusters. In contrast, the university hospital, which is the educational sector-based hospital, has a limited numbers of referrals and a limited number of in-patient beds. This is because hospital facilities and resources are prioritised for educational and development approaches in health. Tertiary-level hospitals (see Fig. 1.2) are located in the cities and some settings are located in areas with insurgency. As a consequence, women accessing breast cancer care are likely to have to access a number of different services and levels of care and also have to travel receive higher levels of care.

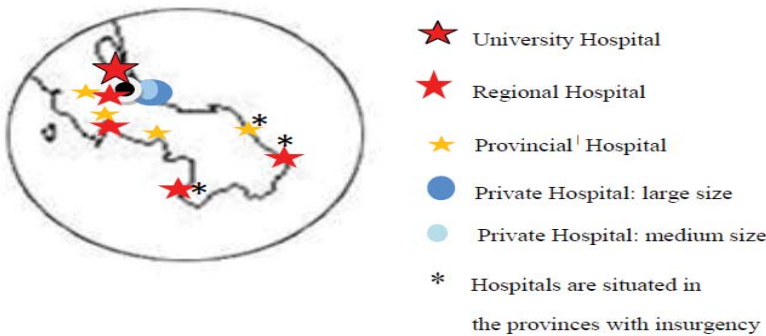


Figure 1.2. The Distribution of Hospitals with Capacity of Providing Secondary and Tertiary Levels of Breast Cancer Care in the Lower Southern Region.

### Traditional and alternative medical perspectives in breast cancer care

The Thai health system, currently, has integrated traditional and alternative therapies into the services as complements or adjuncts to modern medical perspectives, including services for breast cancer patients. In particular conservative and applied Thai Traditional Medicine<sup>3</sup> and Chinese Traditional Medicine are delivered through the services in the formal health settings

<sup>3</sup>The Conservative Thai Traditional Medicine is a pure Thai traditional approach, while The Applied Thai Traditional Medicine is the integration of part of the assessment and investigation of modern medical perspective into Thai Traditional Medicine (Bureau of Alternative Medicine, 2014).

by their licensed traditional professionals<sup>4</sup> and/or certificated traditional professionals<sup>5</sup>. Within all public hospitals, the modern medical perspective is positioned as the mainstream therapy for breast cancer patients. Many alternative and traditional therapies related to (breast) cancer are provided in communities around the region. (The classification of breast cancer care regarding alternative medical perspectives in Thailand is provided in Appendix IV).

In practice, doctors rarely refer their breast cancer patients to these services. On the other hand, even though many alternative therapists in communities do not have licences and some of their therapies are integrated with supernatural approaches, (breast) cancer patients frequently access these services.

### **Financial support programmes and breast cancer care**

A financial sub system has been created to ensure equity in health care accessibility for all Thais. This sub system comprises four financial support programmes and all Thai people have to participate in at least one: i) civil service welfare (for civil and state enterprise employees and their families); ii) social security welfare (for private employees and subgroup of civil employees); iii) private health insurance (for anyone who can afford it); and iv) universal coverage (for anyone who does not have i or ii) (Bureau of Policy and Strategy, 2005). However, everyone can choose to voluntarily pay for all of their treatments. The majority of health services are delivered by the public sector, which can provide health care for clients through any financial programme. In contrast, those accessing private services mainly use personal health insurance and self-payment, though the other financial programmes can provide partial financial support depending on their conditions. Some private settings are connected with the three government support programmes as well.

Those covered by the civil service welfare financial support programme are eligible to access care at any public settings and some private settings which joined this programme. Those covered by the social security welfare and universal coverage scheme, have to initially seek care at the setting where they are registered. A patient will be referred from the lower to a higher-level setting within the regional cluster if necessary. People with private health

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<sup>4</sup>**Licensed traditional professionals** include a) Licensed medical professionals of (Applied) Thai Tradition in medicine, pharmacy, and midwifery b) Licensed medical professional of Chinese Traditional medicine (The Institute of Thai Traditional Medicine, 2013)

<sup>5</sup>**Certificated traditional professionals** are such as Thai Traditional Massage, Herbal Sauna and Acupuncture practitioners (The Institute of Thai Traditional Medicine, 2013).

insurance are able to access any setting, depending on the individual conditions of their programme.

The variety in financial programmes leads to different levels of eligibility for care and different access and referral processes, which are likely to impact on women's access to breast cancer diagnosis and treatments. The different programme also contributes different facilities for supporting and roles of the support networks.

## **Breast cancer clubs supporting breast cancer care**

In Thailand, formal cancer social networks include more than 20 groups that have been developed through the network of the cancer patient project which was begun by National Health Security Office in 2003, including four breast cancer patients' groups (National Health Security Office, 2006). This project was still promoted through the implementation of the 10<sup>th</sup> National Health Development Plan (2007-2011). As a result of this project, since 2005 a breast cancer club, situated at the university hospital in the lower southern region, was founded by the patient care team for breast cancer at this hospital. This club has been active in developing a regional self-help group of breast cancer patients. The club activities are designed to support the women, mainly arranged during office hours, usually include health education, experience sharing and a yearly travel trip by group members. All breast cancer patients of the hospital are invited to be club members. However, women may choose not to participate. When living with breast cancer, not only the disease and the health system, but also social cultures may affect the women's personal social network characteristics.

## **Thai values affecting personal social networks**

To understand how people live together during critical life periods, such as a breast cancer journey, and everyday lives, understanding their socio-cultural contexts is important. Three categories of values reflecting the collective identity<sup>6</sup> of Thais are likely to affect the

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<sup>6</sup> **Collective identity** (sometimes, the term 'social identity' is used instead) is clarified in the sense that it indicates a joint awareness and recognition that members of group share the same identity (David & Bar-Tal, 2009). Individuals define themselves in terms of their relationships to others and social groups of self-representation with different origins, sources of self-worth and social motivation (Brewer & Gardner, 1996). The commonality shared is based on ascribed characteristics such as ethnicity or gender or religion or on achieved states such as occupations, communities, or nations (Brewer & Gardner, 1996). Accordingly, collective identity comprises two levels: the micro level pertains to individual society members' recognition of and categorization as belonging to a group such as village or city communities; and the macro level, pertains to notion of collective identity (David & Bar-Tal, 2009).

formation and working of personal networks. These are Thai values that operate within the nation, within communities and within families.

### **Thai values as part of the national identity**

The ways of living together in Thai contexts are underpinned by many social values; five Thai values that are part of the national identity could affect supporter roles (Klausner, 2000). Thai people are obligated to live with others in society with i) compassion, ii) tolerance, iii) respect and gratitude to benefactors such as (pseudo) parents, supporters, and helpers, and iv) provide reciprocal help. Additionally, ties and mutual assistance in a family, both those related by blood and by marriage are important. However, Klausner (2000) argues that the impact of globalization and economic growth models are resulting in a decrease in adherence to these values and in differences in practices.

Another value which is unique to Thai people and which has a high influence on expectations and performance of supporter roles among Thai people is *เกรงใจ/kreng-jai/*.

Feelings of *เกรงใจ/kreng-jai/* are a combination of deference and consideration, *เกรง/kreng/* means to be to be awe of, to fear, and *ใจ/jai/* means heart or mind. When these words are compounded together *เกรงใจ/kreng-jai/* means to be reluctant to impose upon and/or to have consideration for. It is important to realise that *เกรงใจ/kreng-jai/* refers to an attitude toward an individual (Klausner, 2000). Degrees of *เกรงใจ/kreng-jai/* are inversely related to the closeness in relationships. In common, feelings of *เกรงใจ/kreng-jai/* towards family members are of a lower degree than toward acquaintances, and also to other support network formation and operation. There are also two categories of cultural values related to community characteristics which could affect personal social network characteristics.

### **Cultural values related to community characteristics**

Communities with different characteristics, related to relationships among members and dominant religions, tend to have different cultural values. These values influence social behaviours reflecting the collective identity of the community members.

### *Cultural values of village and city communities*

Communities in the lower southern region of Thailand, in general differ with regard to their locations in urban, suburban, or rural areas. Some people live in agrarian villages, while others live in towns, city suburbs, or inner-city areas. Two different characteristics related to relationships among members are founded in village and city communities.

The term '**Village community**' is used to identify the characteristics of the traditional Thai village communities based on the concept of human relationships (Kemp, 1991). In particular most agrarian villages are located in rural areas and were founded many generations ago. Accordingly, the community members have had long term interactions and relationships with neighbours. Their neighbours are identified as (quasi) kin, friends, or neighbours rather than acquaintances. The '**city community**', on the other hand, is mostly not agrarian-based. Communities include inner city, city suburbs, towns or villages of a housing estate. These community members are more independent in their life style with few everyday interactions among the community members. Accordingly, these two types of communities' values of sharing in daily life are different. The common sharing in activities of everyday life forms part of the collective identity of the village members but rather less for the city members.

### *Cultural values of Buddhist, Muslim, and mixed religious communities*

In Thailand, Buddhism is the Thai national religion, and over 90% of the population identify with this. Around 6% identify as Muslim, and around 2% identify with other religion such as Christian and Hindu. Around a half of all Thai-Muslims live in the southern part of Thailand, in particular, the lower southern region (Social Statistical Office & National Statistical Office, 2014). Accordingly, three types of communities related to predominant religions are found: Buddhist, Muslim, and mixed religious communities. The unique characteristics of each religious identity may lead to particular patterns of supporter roles among their community members.

Members of **Buddhist communities** value the general Thai norms or the national identity (as previous revealed) rather than a specific identity related to religion. This might be because of the predominance of Buddhism in Thailand. In contrast, members of **Muslim communities** tend to value a stronger collective identity regarding the Muslim way of life. Their collective identity strongly relies on **Allah's** teaching and instruction for their everyday living in practice. As a result, members are identified both as Muslim and differentiated from others. For example, in a conservative Muslim village, it is unacceptable

to provide support across genders to people who are not family members in private. In **mixed religious communities**, even though Muslim residences are one subgroup and their every living practice is religion-based, it is more flexible than living in conservative Muslim communities. However, although Thai Muslims maintain, express and symbolise their identity stronger than Buddhist Thais, it can be said that in Thailand, Muslims, Buddhists and other religions share identical social values as the national identity (Yusuf, 1999). Furthermore, when focusing at family level, family living style in everyday living that depends on family circumstances and cultural ways may impact on the support system among family members.

### **The ways of family living**

The living style in Thai families differs from Western styles. Thai children tend to leave their parents when they have their own family. A sense of obligation to one's parents is valued and this is one reason that many married children still live with their wife's or husband's parents in the same house or compound and many unmarried adult children continue living with their parents (Klausner, 2000). For the adult children who live separately from their parents, many still continue their caregiver or supporter role for their parents. As well, elderly parents may go and live with their children and this is more usual than living alone at home or in aged residential care.

These three levels of Thai values are inter-related, and all reflect the characteristics of Thai people as a collective culture even when there are religious or community differences. They are socio-cultural contexts influencing social behaviours in normal living and are likely to affect supporter role expectations and performance between the women and their significant supporters.

### **Conclusion**

In this chapter, I have described the background to this study and the key contextual factors of the study setting—the lower southern region of Thailand, related to breast cancer, the population, the health system, and cultures. This information provides a basis of this study and setting to enhance an understanding of the study cases.

## Thesis structure

This thesis is presented in **nine** chapters. Next, **Chapter 2** provides the reviewed literature of social networks within three inter-related levels. This literature elaborates a number of notions and issues of consideration in social network studies: the general concepts of social networks, social networks and health, and social networks and breast cancer worldwide and in Thailand. **Chapter 3** explains the study framework, design and method. The instrumental collective case study of Stake (1995) and the community-up ethical framework can be applied within both the individual and collective levels of fieldwork. In this chapter, the study design and method are described with parallel discussion on their benefits and challenges in practice. Next, the study findings are presented in Chapters 4, 5, 6, 7, and 8. In **Chapter 4**, the unique contexts of the setting gathered from fieldwork are elaborated as a foreground to the cases. Then, in **Chapters 5, 6, and 7 the 11** case descriptions and discussion through 11 vignettes present the intense, holistic, and unique personal circumstances within multiple levels. These three chapters are depicted following the concepts of living with mature support networks, living with complexities in family circumstances, and living with complexities in health service and family circumstances, respectively. **Chapter 8** delineates the results from a cross-case analysis, the five core characteristics of networks related to the network membership, linkages, and dynamics throughout the women's journeys with breast cancer. Finally, **Chapter 9** completes the thesis by summarising the themes and patterns of network characteristics and their development. The implications of the study findings for nursing policy, practice and education are discussed. The limitations of the study and recommendations for further research and practice are presented

## CHAPTER 2

### Literature Review

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*“...it has become clear to me that the static, structural-functional model of society does not work at the level at which real people interact... It is not enough for students of social behaviour to ask: ‘What is the pattern of social relations? And ‘How is this pattern maintained?’ ... They must also ask: ‘How do such patterns emerge? And ‘How are they changing?’ It seems to me that these are the essential questions,... We must be able to explain the is, the being and the becoming of social institutions. To do this it is necessary to examine other influences besides those of custom, coercion, and the moral order”.*

*Jeremy Boissevain (1974, p. 5-6)*

### Introduction

The literature reviewed in this study comprises three levels of network notions; the general concepts of social networks, previous studies related to social networks in health and those specific to breast cancer. This literature provides a preliminary framework of social networks in general and specifically the phenomenon of living with breast cancer. Further, the literature provides a working framework for me to explore what personal social networks may look like and how they can be explored during fieldwork, specifically related to real life contexts. Lastly, literature will be employed in the discussion chapter to relate the study findings to extant knowledge of social networks.

### Social networks

This section clarifies the components and understanding of the structures and functions of social networks to date. This enables the development of a conceptualised social network; this blueprint of social networks of women with breast cancer will be used in fieldwork to gather both objective and subjective data. Accordingly, this section presents concepts of social networks by reviewing literature about i) the comparison between social networks and social support, ii) social network classifications, and iii) social network characteristics.

## Social networks and social support

Throughout the literature, several key terms are used interchangeably in studies of the components of social relationships, particularly between social networks and social support (e.g. Berkman & Krishna, 2014; House, Umberson, & Landis, 1988). As ‘**personal social networks**’ are the cases of this study, it is important to initially clarify the term ‘**personal social networks**’ and identify the differences and/or similarities between social networks and social support as defined and discussed in the studies of social relationships

Mitchell (1974) argues that Barnes first introduced the term ‘social networks’ in 1954 and the particular concepts of social networks which researchers have focused on are the interactional and structural aspects (Mitchell). Both dimensions are used to elucidate a set or web of relationships (e.g. Heaney & Israel, 2008; Luke & Harris, 2007) /connections (e.g. Pescosolido & Levey, 2002; Valente, 2010) and linkages (e.g. Mitchell, 1974; Pescosolido & Levey, 2002) that surround individuals. Heaney and Israel also discuss the term ‘**social support**’ which they contrast with social networks. They claim it was introduced by John Cassel in 1976 to describe a protective factor to reduce individuals’ vulnerability (Heaney & Israel, 2008). It is used to mainly identify the support aspect of social relationships, with the function and quality of support aspects being divided into categories such as emotional, instrumental, informational, and appraisal support (Schwarzer & Leppin, 1991). Other social scholars have also identified and differentiated social networks and social support under the social relationships umbrella as shown in Table 2.1.

**Table 2.1**

*Comparison of the Clarifications of Social Networks and Social Support*

<b>Authors</b>	<b>Social Networks</b>	<b>Social Support</b>
Ell (1984)	Structural and interactional aspects of individual’s social contacts	Sub system of social networks
House <i>et al.</i> (1988)	Structure which characterises a set of relationships	One of relational outcomes or functional nature or quality of relationships
Schwarzer and Leppin (1991)	A set of structural properties of social relationships	One of relational outcomes: cognition and behaviours
Heaney and Israel (2008)	Relational structure	One of relational functions
Berkman and Krishna (2014)	The provision of social support	One of psychosocial mechanisms of network functioning

Both social networks and social support are the concepts used to describe social relationships, however, the term social network, tends to be clarified within interactional properties regarding structural, interactional and functional dimensions, while ‘social support’ is seen as only a dimension of support or a positive function or outcome of social networks. However, negative outcomes, such as insufficient support caused by (mal or) dysfunctional networks, may also be mentioned if negative interactions or support behaviours such as angry criticism and hassling occur or if some network members are not able to be supporters (Heaney & Israel, 2008). Table 2.1 demonstrates how for this research, it is the broader concept of social networks that needs to be focused on to gather the full set(s) of data of each case.

## **Social network classifications**

In social sciences, social networks are frequently classified into various types, related to the scholar’s perspectives. For example, a focus on the centrality of networks is used to distinguish and sort the data collection methods and data from network informants (Valente, 2010). From this perspective, social networks can be categorised into egocentric and sociocentric networks (Smith & Christakis, 2008). Egocentric (or individual or local) networks consider only direct links (dyadic relationship) to the focal persons<sup>7</sup> (egos) that make up study population. The egocentric networks look like a wheel in which the ego or focal person is the hub of a wheel and the members (alters) of the network are the rim of a wheel; they connect directly to the hub by their social contacts/relationship/tie. On the other hand, sociocentric (or sociometric, complete, or global) networks, consider the entire sample of network links, both direct and indirect.

In another view, Vassilev et al. (2010) also delineated that social networks have two types—individualised and community-like—that are determined through their complexity. The individualised networks are similar to egocentric networks that are groups of relationships occurring only between focal persons and their network members directly, without relationships between members themselves. In contrast, community-like networks (or networks of networks or personal communities) are explained as a set of individualised relationships; it is not only the interconnections between the focal persons and their network members but also the independent relationships between each member. Thus, egocentric

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<sup>7</sup> ‘**The focal person**’ means the person who is identified as at ‘**the centre of networks**’ i.e. the woman with a breast cancer diagnosis is a focal person of her network. Accordingly, in this study the women with a breast cancer diagnosis who are the centre of their network are called ‘**the central women**’.

networks are similar to individual networks, sociocentric networks are the whole networks and community networks can be both whole networks and partial networks (networks of networks), depending on the focal person's perception. Significantly, the linkages of community networks are more complicated than the linear relationships of egocentric/individual networks.

Focusing on community-like networks or personal communities or personal networks, Spencer and Pahl (2006) stated that personal communities or personal networks seem like micro-social worlds, defined as clusters of people who know each other within local communities or organizations, or the entire set of personal relationships of a particular individual. The personal communities contain only those who are considered important in people's lives. This perspective represents the focal person's orientation. The personal communities could be classified into five types underpinned by a cluster of features. These are i) friend-based personal networks; ii) family-based personal networks; iii) neighbour-based personal networks; iv) partner-based personal networks; and v) professional-based personal networks (Spencer & Pahl, 2006). These categories are useful for research that has a narrow focus on the role(s) of a particular network group, for example Procidano and Heller (1983) studied perception of social support networks from friends and family. However, my study anticipates that the case networks could comprise all or at least some of Spencer and Pahl's categories.

The interactions between the focal persons and their network members can be both direct and indirect. The network type can therefore be both ego and sociometric depending on the focal persons' perceptions. Personal networks are sometimes generated for dealing with particular issues such as conflicts in workplaces, controversies in societies or a critical period of life (e.g. living with critical illness). The main compositions of these networks might not be friends, family members, partners or neighbours, but could be the persons who are affected by similar issues as the focal person, such as self-help groups of particular patients.

Another area of network research is how they are created. Turkat (1980) distinguished two ways networks are formed—natural and devised social networks. This perspective has been applied when devised networks have been used as a supportive intervention for particular people, for example mentally ill persons. In contrast, a natural social network is defined as the network which is formed around the interpersonal patterns of the individual with family, friends, and neighbours and the first relational focus is social exchange between them.

Turkat stated a devised social network might perform specific functions or tasks such as volunteers for disabled people. So accordingly, the devised network is organised for related functional roles, rather than just social roles. Nevertheless, volunteer groups might be natural and informal networks as well. Self-help groups and mutual aid groups such as breast cancer clubs tend to be used more frequently to support the people with difficulties, devised networks become parts of community-like networks. Thus Ell (1984) proposed that there is a need to examine the outcomes of peer-group participation. Due to different personal experiences and personalities, some people might appreciate the devised groups, and then feel free to create their social relationships among devised group members, while some might feel harmed by the activities of these groups (Ell, 1984; Helgeson, Cohen, Schulz, & Yasko, 2000).

As a whole, social networks can be examined from a variety of perspectives depending on the study's objectives. However, in general, social networks can be seen as individualised and/or community-like, personalised and/or organizational-like (e.g. club of particular groups, volunteer groups), and naturalised and/or devised networks. Actors of networks can have both direct and indirect relationships independently. It is evident that the perception of who is important is central to all networks. As mentioned previously in Chapter 1, for this study where the case networks are related to a particular life event, the term '**personal social networks**' will be used rather than the more general social network term.

## **Social network characteristics**

In studies related to network characteristics, Berkman and Krishna (2014) describe the development of these studies, particularly in the health arena, through three sequential waves. The first wave is a social structural era as it is a series of assessments about numbers of close persons, memberships of religious and voluntary groups, and social ties, connectedness, integration, activity and social isolation. The second wave is the psychological aspect of social networks. Social support was captured rather than structural aspects. Later, the third wave of network studies has developed mathematic models or graphs to describe network structure and function. Through my literature review with regards to these three waves, a number studies elucidate four significant characteristics that are considered when social networks are the study unit of analysis. These are i) formal constructive characteristics, ii) informal characteristics, iii) ongoing interaction with contexts, and iv) dynamic by nature.

### *Formal constructive characteristics of networks*

In both quantitative and qualitative network studies, the features of networks with regard to network structure, interaction, and function (including social support) have been employed to depict characteristics of social networks. The network structure refers to the overall members and linkages; the interactional characteristics refer to the quantity and quality of relationships themselves; and the functional dimension refers to the operational properties resulting from social processes among network members leading to either positive or negative outcomes. Factors or indicators related to quantitative and qualitative aspects of the three dimensions of networks are shown in Table 2.2.

**Table 2.2**

*Quantitative and Qualitative Indicators / Factors Related to Social Network Dimensions*

Network Dimensions	Indicators /Factors	
	Quantitative	Qualitative
<b>Structure</b>	<p><b>Size:</b> number of network members</p> <p><b>Density:</b> actual numbers of links divided by possible numbers of links</p> <p><b>Dispersion:</b> range of sources of social contacts</p> <p><b>Homogeneity:</b> similarity of network members in terms of a number of characteristics</p> <p><b>Clustering:</b> clusters of dense links existing in networks</p>	<p><b>Homogeneity:</b> members' demographical similarities</p> <p><b>Centrality:</b> a person (s) inhabits a prestigious or critical position in the network</p> <p><b>Proximity (intimacy):</b> emotional closeness</p> <p><b>Positions and roles:</b> such as positions and roles in family (father / mother /children)</p> <p><b>Complexity:</b> relationships which serve many functions such as friend, caregiver, and colleague</p> <p><b>Formality:</b> relationships exist in the context of organisational or institutional roles such as co-workers or the breast cancer club members</p> <p><b>Equivalence:</b> the dyad share equal power and influence</p>
<b>Interaction</b>	<p><b>Frequency:</b> numbers of contact</p> <p><b>Durability:</b> times of relationship establishment</p> <p><b>Intensity:</b> emotional closeness</p>	<p><b>Meaning / Value of relationships:</b> perception or interpretation on relationships that can be positive / negative</p> <p><b>Linking forms / patterns:</b> such as reciprocity, one way relationship, strength, weakness, close, connectable, giver</p> <p><b>Multiplexity:</b> numbers and types of different roles, relationships, or modes of interaction</p> <p><b>Symmetry:</b> the balance of exchange across a link</p>
<b>Function</b>	<p>Number of network functions / support types</p>	<p><b>Mobility:</b> ability to provide positive or expected impacts / outcomes</p>

(Sources: Berkman & Krishna, 2014; Heaney & Israel, 2008; Israel, 1985; O'Reilly, 1988; Pilisuk & Froland, 1978; Scott & Carington, 2011; Valente, 2010)

Some network indicators are used to describe both quantitative and qualitative dimensions such as network homogeneity; however, homogeneity in a quantitative form is numeric, while qualitative homogeneity is a demographical description. Furthermore, there is some overlap between dimensions. For example, emotional closeness links to intimacy, a qualitative structural dimension and it is also used to measure quantitative intensity, an interactional dimension. Relationship forms and patterns are used to describe characteristics of both network structure and interaction. This means three network dimensions have interacting and overlapping characteristics. Investigating networks' characteristics following these indicators seems to result in a 'formal' construct of a network with boundaries, but the variable nature of social relationships means that roles, interactions, connectedness, emotions, positions, including their meaning and values are changeable within networks and so an 'informal' conception of a social network would allow a wider window into how such a network can support the women with a breast cancer diagnosis.

### ***Informal characteristics of networks***

In the book *Friends of friends: Networks, Manipulators and Coalitions*, Jeremy Boissevain (1974), a social anthropologist working on social networks, discusses the understanding of network characteristics through the formal constructive dimensions (structure, relationships, and function) which he named 'the structural-functional model'. He argued that using this model tends to explain social behaviours only in terms of system and so behaviours can be predicted with regards to social norms. However, in reality, many actions or social behaviours are unpredictable because of the multiplexity of linkages between people. In this book, he introduces an integrated concept of '**content, structure and sentiment**' to capture this multiplexity of interactions among network members rather than the stand alone structural-functional concept. People carry more than one role and many relationships; thus linkages between them can be examined in terms of objective criteria (such as being helpful, useful, supportive) and subjective criteria (such as feelings of like, dislike, love). With regard to this concept, he suggests a model of social network zones as shown in Fig. 2.1 to clarify the variety of linkages between network members and these linkages are both intimate and extended.

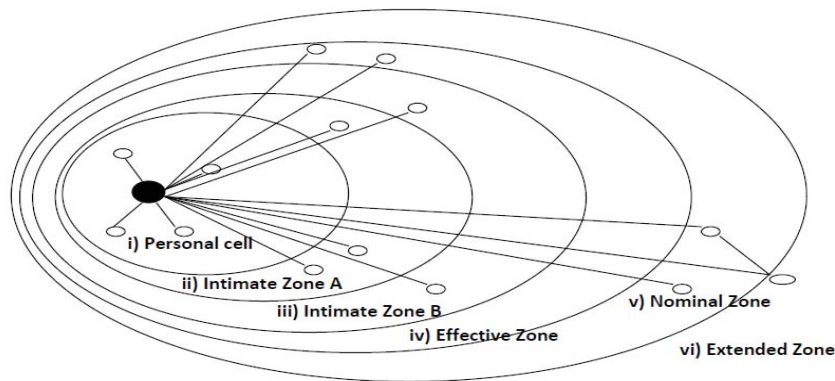


Figure 2.1. Model of social network zones.

(Source: Boissevain, 1974, p. 47)

The layers of networks presented in this model give regard to different relationship values based on both objective and subjective criteria and these are explained as different zones of members in a network. Berkman (2000) considered that Boissevain's model is a practical tool for understanding how and why social networks influence different health-related outcomes. This is important for this study as Boissevain's (1974) concept about the integration of content, structure, and sentiment of social interactions, highlights the nature of interactions between all dimensions of formal constructive characteristics of networks enhancing network diversity.

Boissevain (1979) re-emphasised his argument on structural-functionalism in network study again in the book *Network Analysis: A reappraisal*. He highlights that network analysis should focus on the nature of network characteristics related to social processes rather than method, classification and networks-as-things-in-themselves. Boissevain emphasises that network analysis should be shifted away from structural-functionalism to capture the nature of interactional properties of networks through answering simple questions "who links to whom, what is the nature of that linkage, and how do these linkage characteristics affect behaviours" (J Boissevain, 1974 , p. 393)

To understand the natures of personal social networks, asking simple questions regarding the informal characteristics of networks should be considered. However, the three constructive dimensions of networks can still be core concepts that maintain a focus on a network level rather than individual level.

### *Ongoing interaction with contexts*

When social networks are functioning, they seem to interact with many contextual factors such as health conditions, personalities, family components, types of jobs, and community cultural customs, which then influence different characteristics within people's social networks. This adds a conditional or contextual dimension. Furthermore, O'Reilly (1988) stated that some network members can be supporters, some can be non supporters, and some can be both supporters and non supporters, depending on individual and contextual factors. Boissevain (1974) additionally delineates three groups of environmental factors affecting social networks: biological factors (e.g. sex, age), individual personality (e.g. introversion, extroversion), and physical environment (e.g. place of residence, climate). Therefore, the contexts of relationships need to be included.

The conditional dimension mentioned previously seems similar to the concept of “**Person-Environment Fit**” theory which was initially developed from the studies related to stress and coping (Shinn, Lehmann, & Wong, 1984). In a study of social networks, social support, and health status, Ell (1984) raised the issue of Person-Environment Fit which identified the environmental factors and personal characteristics that could enhance or constrain individual network participation. His assumptions are that the creation of social networks may be enabled or constrained by environmental factors such as specific family composition, living arrangements, social position, social competence, while individual characteristics, for instance ethnicity, gender, age, socioeconomic status, affiliative need, and social skill, can influence network characteristics as well. He also proposed another factor which might affect the social network's operation, that is opportunities for reciprocity (relationships which include both giving and receiving by each person); for example, opportunities to participate in community activities or formal supportive groups. In my view, the opportunities for reciprocity can be seen as an intermediate outcome that is affected by personal and environmental factors and opportunities for reciprocity can enhance or inhibit network participation. The personal factors of both focal actors and network members, and cultural values influencing social behaviours should thus be a part of network study as proposed for this research.

### *Dynamic by nature*

New members, indeed, can join a network and people can leave it. In the same way, links can be added or deleted and relationships are changeable. Valente (2010) found that membership change is another factor that has been researched and the changes in networks

can occur in two levels: the individual and the network. Social network forms and operations are continuously moving within time parameters (Snijders, Van de Bunt, & Steglich, 2010). Thus social networks are dynamic by nature. For that reason, social network characteristics are unlikely to be static, but rather changeable pictures. Therefore understanding what and how social networks form around people with long-term illness and the dynamics and changes within such networks is very important for personnel working in health-related contexts.

## **Social networks and health related outcomes**

Much empirical knowledge in social networks and health-related outcomes has been reported. Particularly, many studies on the associations between social networks and living with chronic/life threatening illnesses such as cardiovascular disease, cancer and depression revealed the desirable or positive outcomes of social networks, categorised into indirect and direct health-related outcomes. Indirect health-related outcomes relate to individual abilities (potentials), for example a more positive outlook of life, finding inner strength, and an awareness of living (Arman, Rehnsfeldt, Carlsson, & Hamrin, 2001; Coward & Kahn, 2005; Glover & Parry, 2009; Landmark & Wahl, 2002; Singtipphun, 2013), confirmation as a person (Sjölander & Berterö, 2008), improvement in coping (Ell, 1984; Sjölander & Berterö, 2008), improved self-management and self-care practices (Vassilev et al., 2010), seeking health services, access to care and social support (Ell, 1984; C.H Kroenke et al., 2006). As a result of the indirect health-related outcomes (individual abilities), the direct health-related outcomes could change, such as an improved sense of well-being or health-related quality of life (HRQoL) (Bloom, Petersen, & Kang, 2007b; Bloom, Stewart, Johnston, Banks, & Fobair, 2001; Cimprich, Ronis, & Martinez-Ramos, 2002; Landmark & Wahl, 2002), physical and emotional recovery (Bloom et al., 2007b; Bloom et al., 2001) and reduction of mortality rates and rise in survival rates (Ell, Nishimoto, Mediansky, Mantell, & Hamovitch, 1992; Waxler-Morrison, Hislop, Mears, & Kan, 1991). Moreover, the social network can induce social potential as social capital as well (Luke & Harris, 2007; Vassilev et al., 2010).

However, negative outcomes resulting from social networks were also reported in some network studies of people living with chronic/life threatening illnesses. Examples include insufficient support from spouses and hospital staff (e.g. Landmark & Wahl, 2002; Manne et al., 2003), feeling of overprotection by spouses (e.g. Hagedoorn et al., 2000), perceiving lack of or being overwhelmed with information (e.g. Der Molem, 1999), negative interactions, discomfort or harm and stigmatised feelings with peer support group

participation (e.g. S. Campbell et al., 2013; Helgeson et al., 2000), relationship difficulties in family (e.g. Landmark & Wahl, 2002), emotional distress and decreased quality of life of caregivers (e.g. Pitceathly & Maguire, 2003; Wagner, Bigatti, & Storniolo, 2006). I would argue it is possible that different focal persons and network members interpret the same support actions differently. Furthermore, some support actions may be not justified (or are difficult to justify) either positively or negatively. Otherwise actions can be perceived along a continuum from supportive to unsupportive.

Hammer (1983) conceptualised four models of relationships between social networks and health. **Model 1** is that illness leads to reduced social contact, such as mentally ill people tending to have fewer social activities. **Model 2** describes how social networks affect health by mediating health-related activities such as both healthy and unhealthy behaviours and use of health services. For the first and second models, social networks do function as a mediator directly related to health activities. **Model 3** shows how social networks buffer the negative effects of stress on health, for example people who are diagnosed with cancer, while, **Model 4** illustrates how social feedback maintains or distorts social behaviour, with physiological consequences.

Another conceptual model of how social networks impact on health, based on the social integration theory of Durkheim and attachment theory of Bowlby, is proposed by Berkman, Glass, Brissette, and Seeman (2000) and Berkman and Krishma (2014). This model identifies that social conditions and social networks can provide opportunities for psychosocial mechanisms such as social support, social influence, social engagement, person-to-person contact, and access to resources and material goods. Consequently, psychosocial mechanisms impact on health through three pathways—the health behavioural pathway (smoking, eating, help-seeking behaviour), the psychological pathway (self-efficacy, coping effectiveness, depression), and the physiological pathway (immune system function, mortality rate, transmission of infectious disease). These mechanisms are influenced by four categories of macro social conditions: culture (e.g. norms and values, social cohesion); socioeconomic factors (e. g. inequity, discrimination, poverty); politics (e.g. laws and public policy), and social changes (e.g. urbanization, economic recessions). Berkman et al's model provides a larger picture than Hammer's Models. We can see the association between social networks and health as sequential reactions from societies and groups right down to the individual. As a result, the health-related outcomes occur. However, this model does not mention the reverse effects from health to social interactions, which Hammer does include.

All in all, social networks can enhance or constrain positive health-related outcomes, and also can inhibit or enable negative health-related outcomes. Since social networks are created and then function, they impact on health associated with the individual, family, group, community and societal levels differently for indirect health related outcomes (or individual abilities) or direct health outcomes. This reviewed research supports Boissevain's (1974) mapping concept of social networks and Berkman (2000) discussion on this model mentioned in the previous section that layers of relationships in networks were interpreted based on a number of factors and could lead to a diversity of network outcomes. Accordingly, outcomes, benefits, or disadvantages of social networks cannot be described as one thing. Moreover, as social networks can be both the cause and outcomes of people's health, if only direct, positive and one way interactions are considered, this may create a distorted picture of networks.

## **Social networks and breast cancer**

When breast cancer enters into women's lives, it is not only the women but also the people surrounding them that become part of this journey. These people are involved in the women's journey as their supporters. Literature related to social networks of women living with breast cancer comprises two major parts. The first part is about multiple burdens in related to breast cancer with regard to the individual, spouses, families and national and global burdens. Another major part is of the notions related to social networks in breast cancer journeys.

## **Multiple burdens in relation to breast cancer**

Experiences of living with breast cancer have revealed an abundance of burdens. There are the burdens on the breast cancer patients, their families and supporters, the health sector and society generally (Grunfeld et al., 2004; Hanson et al., 2000; Pitceathly & Maguire, 2003). Secondly, the physical, psychological, occupational and economic impairments from this disease and its treatments result in patient suffering which might be prolonged over five years or more (Arozullah et al., 2004; Bradley & Bednarek, 2002; Hanson et al., 2000). Two factors, the age of the woman at breast cancer diagnosis and the treatments they received, were important determinants of the woman's quality of life. In particular, the younger groups showed poorer quality of life outcomes in the social domain than other age groups, while the middle age groups showed better quality of life outcomes (Bloom, Petersen, & Kang, 2007a; Cimprich et al., 2002). Infertility-related problems caused by adjuvant treatments are also a

concern (Gammon & Thompson, 1990; Partridge et al., 2004). As mentioned previously, one-third of women diagnosed with breast cancer will die from the disease. However, some authors also report positive perceptions of living with breast cancer, such as finding inner strength (Elmir, Jackson, Beale, & Schmied, 2010).

In terms of family effects, numerous studies on the burdens of breast cancer revealed difficulties for spouses, children, other family members and careers with varying regard to psychology, relationships, occupation and economics, and quality of life. Psychological distress is consistently identified with the women's husbands and their caregivers in their family (Chirikos, Russell-Jacobs, & Cantor, 2002; Grunfeld et al., 2004; Pitceathly & Maguire, 2003). The causes of psychological burdens were recounted such as an increase in the patient's symptoms, relationship difficulties, illness of family members, and changes of life style and role (Pitceathly & Maguire, 2003). These authors also investigated family members' perceptions of their burdens and the impacts on affection and interactional distress and found they were not considered as major. Relationship burdens existing between patients and their husbands were things such as communication avoidance, separation and/or termination of relationships and problems related to sexuality. Shifts in role and emotional distress were stressed as children's relationship burdens (Walsh, Manuel, & Avis, 2005). The burden of the caregiver role was identified as one burden existing in the family, and a particularly emotional aspect for both the patients and themselves (Thomas, Morris, & Harman, 2002). Occupational and economic burdens on family caregivers can occur with regard to the loss of time for work more than financial difficulty. Women with breast cancer who had long-term survival and work reported having economic disruption (Arozullah et al., 2004; Chirikos et al., 2002). Studies that have probed whether the quality of life of husbands and family caregivers dropped show variable results. However, particular parts of the quality of life, a decrease in physical ability and social function were reported most (Y. Kim & Given, 2008; Wagner et al., 2006). In contrast, some studies have identified positive features such as improvement in the closeness between family members brought about by the meaningful period of emotional support and the communication regarding the problems and concerns that they faced (Walsh et al., 2005).

As well as burdens on the women, their families and other supporters, national and international burdens were reported, particularly in relation to economics. The economic burden is a mega-national issue as cancer-specific medical care costs can be one component of the overall economic burden. In the United States, the medical care expenditure of breast cancer has the highest cost of female cancers (Brown, Riley, Schussler, & Etzioni, 2002). In

the future, there is potential for economic impacts related to the workforce as in some countries, mentioned previously, the incidence of breast cancer now tends to be higher in working aged women.

## **Social networks in breast cancer journeys**

Breast cancer, its treatments and difficulties associated with access to cancer care, can cause many significant burdens on patients, their significant persons, their societies, and their resources. This includes tangible and intangible resources made available as practical supportive systems for those women and their relatives, not only in a treatment phase but also the post treatment phases of living with breast cancer after the completion of treatments. Social networks have been identified as one potentially useful strategy for patients with life-threatening conditions because they can provide both supportive resources and systems (Arman et al., 2001; Ell et al., 1992; Pilisuk & Froland, 1978). Active social networks can be helpful in addressing difficulties in accessing cancer care. When breast cancer burdens are incurred, the social networks of these women can be their buffers to the burdens related to: emotional distress; relievers of worries; and stress, for the women and/or supporters who help the women continue responsibilities in normal life. Therefore, the women can better deal with their disease and its consequences. A number of studies on women living with breast cancer and their social networks have been published. However, many of them (e.g. Arman et al., 2001; Beasley et al., 2010; C.H Kroenke et al., 2006) focus on individual network components and their impacts rather than on a whole network's features and its development. Figure 2.2 shows the directions taken by the studies related to social networks when living with breast cancer that are reviewed in this literature.

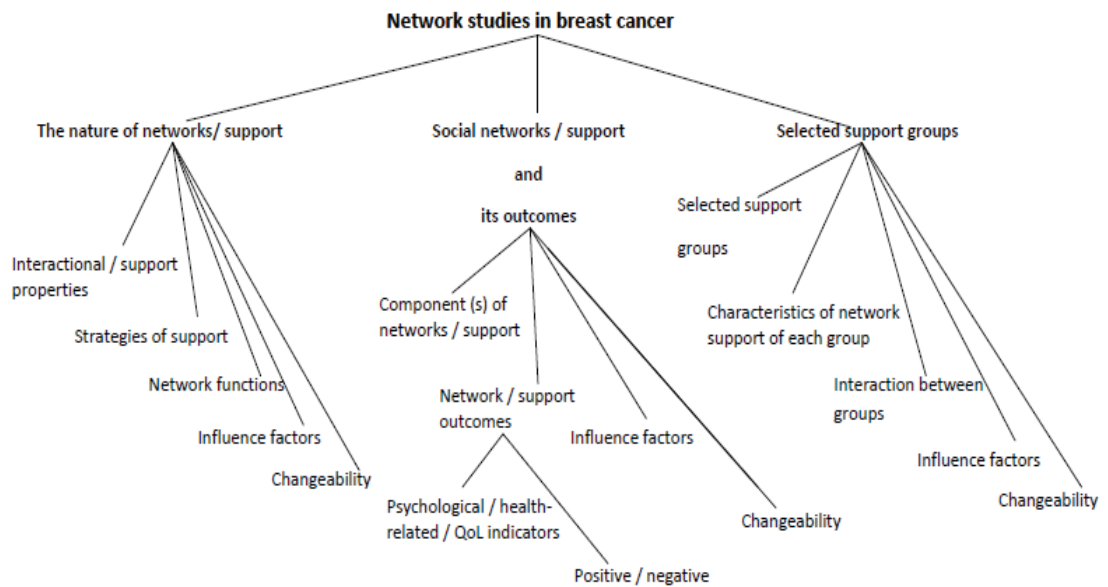


Figure 2.2. Network notions in network studies in breast cancer.

With regard to Fig. 2.2, there are three lines of research pursued through network studies in breast cancer: the natures of social networks or social support; social networks or support and its outcomes; and selected support groups. These three lines each have sub categories related to network components, outcomes, contextual factors and the changeability or dynamics of networks.

### *Natures of social networks*

Firstly, studies on the natures of social networks (including social support) of women with breast cancer revealed that features of their social networks induced interactional (and support) properties, strategies of support, and support related issues (e.g. Nelles, McCaffrey, Blanchard, & Ruckdeschel, 1991). Changeability is a network facet which is an added feature of other network studies (e.g. Arora et al., 2007). Additionally, the identification and discussion of contextual factors related to the nature of networks are included in some studies (e.g. Given, Given, & Kozachik, 2001).

Landmark, Strandmark and Wah (2002) used qualitative methods to explore social support experiences of Norwegian women newly diagnosed with breast cancer. Different interactional properties were identified within forms, sources, and outcomes based on the women's experiences with their social support when they were diagnosed with breast cancer. Positive and negative interactions were reported as enhancing or inhibiting social support.

Support provided based on these women's experiences came from varied sources, close relatives, friends and colleagues and from staff of organisations and institutions. The authors found that these social networks were complex and dynamic and that a multidimensional and layered approach is required to make a clear network picture.

For the purpose of this study, the framework used by Nelles et al. (1991) was narrow, of greater interest was their finding in their review of network changeability. They reviewed 11 studies that used the term social support for the network function performed for an individual under stress by applying coping theories. They categorised the support provided to patients and families throughout their cancer journey into three strategies: problem focused (action focused on either the origins and/or environments related to stress), emotion focused (feeling or thoughts to manage negative reactions to stress), or perception focused (ways to redefine stress). This study also found that network changeability in terms of support efficacy was common over the cancer course that can take a long period of time. Likewise, Arora et al.'s study (2007) uncovers how patients received much support in periods close to diagnosis, but that helpful support decreases significantly within the first year of the journey. Hence, interactions between support and phases of disease and network dynamics within the multiple dimensions should be considered when social networks are investigated.

However, while support and coping were linked in Nelles et al.'s (1991) study, other studies on the nature of networks identified these differently, and used the responsive functions of networks as a basis. In Bloom's study (1982), networking was identified as an accommodation to stress and adjustment to breast cancer. Vassilev et al.'s (2010) study reviewed literature of both quantitative and qualitative network studies and chronic illness (including breast cancer) and defined network functions in terms of support management in the long term providing the support needed for medical treatments and with the women's day to day responsibilities. Interestingly, this study also uncovers the significant function of supporters as mediators in the relationships between patients and health professionals. The women's companions revealed that they articulated concerns and participated in negotiation between patients and health professionals and improved each other's understanding. Furthermore, in Given et al.'s (2001) study, changes in the health care system was mentioned as affecting the support needs from personal supporters. One such change in health care for chronic illnesses, including breast cancer, was the change from in-patient care to ambulatory and/or home setting care. All these emphasise again that multiple roles and functions related to both illness and everyday living have the potential to be one of the network characteristics.

### *Social networks or support and outcomes*

A number of studies are related to the components of social networks or support and their outcomes. The network outcomes comprise psychological-related, health-related indicators and quality of life. These studies mainly investigate desirable outcomes such as optimistic worldviews, finding inner strength, heightened awareness of living, successful coping, self-management, better mental health, better survival rates and health-related quality of life (Arman et al., 2001; Coward & Kahn, 2005; Ell et al., 1992; Glover & Parry, 2009; Landmark & Wahl, 2002; Michael, Berkman, Colditz, Holmes, & Kawachi, 2002; Singtipphun, 2013; Vassilev et al., 2010).

However, there were also some unintended outcomes found within this social network research. These included people becoming overwhelmed with information and women's overprotection from network members who were trying to be supportive (Der Molem, 1999; Hagedoorn et al., 2000). Support experiences while living with breast cancer were revealed in Landmark and Wahl's (2002) study as 'For better and worse' because of the extra burden on the closest supporters such as husbands and other family members. Another instance that showed the differences in perception among patients and supporters was illustrated by Peters-Golden's (1982) study. His illustration was that women would withdraw from support, probably because of an incorrect assessment of their support needs and priorities by network members.

Many network studies on women with a breast cancer diagnosis investigate an association between social networks and/or social support, and survival. Consistently, high levels of social support had a positive association with survival or a lower risk of death (e.g. Chou, Stewart, Wild, & Bloom, 2012; C.H Kroenke et al., 2006; Maunsell, Brisson, & Deschenes, 1995). However the association between social networks and survival rate does vary within the women diagnosed with different stages and types of breast cancer. Beasley et al.'s (2010) study reveals no association between social networks and breast cancer-specific mortality in the women diagnosed with invasive breast cancer. Instead these authors indicated an association between participation in community and religious activities and lower overall mortality. Chou *et al.*'s (2012) study examined the relationship between social support and survival among women with an invasive breast cancer diagnosis including localised, regional and remote disease. They found that network size was not related to survival, though, higher frequency of social contact with close supporters enhanced higher coping skills, by emotional support and opportunities for sharing information. Kroenke et al.'s (2006) study examined social ties and survival among women diagnosed with the first to fourth stage of

breast cancer. This study reveals an association between socially isolated women and an elevated risk of mortality. Another study of Kroenke et al. (2012), also found an association between social network size and mortality depending on levels of social support and burdens of the women with invasive breast cancer.

In my point of view, as social support is a supportive resource in common for these breast cancer patients, the positive relation to survival rate was its common consequence. The different findings on the association between social networks and survival rate may link to the components selected to measure social networks. For example, in Beasley et al.'s (2010) study, social connectedness was regarded only as the frequency of contacts with close persons and participation with communities and religious activities. In Kroenke et al.'s (2012) study, social networks were investigated through only the number of supporters reported by participants. Moreover, most studies seem to keep focus on supportive aspects rather than focusing on both supportive and unsupportive aspects of the social networks. It is very possible for the quality of social networks to not have a positive association with quantitative aspects of networks such as size and number of groups involved. Many other factors could influence the network quality.

### *Studies on specific groups of supporters*

Some network studies focused on selected groups of supporters such as spouses, family, friends, and peers. Characteristics of the networking of selected support groups are reported in relation to the supporter role and its outcomes (e.g. Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Friedman et al., 1988; Hasson-Ohayon, Goldzweig, Braun, & Galinsky, 2010; Roy, 2011). Interactions between groups related to providing and receiving support is focused on in some studies (e.g. Arora et al., 2007). Moreover, factors influencing the differences in support needs and performance within or between groups are also discussed in some studies (e.g. Arora et al., 2007; Waxler-Morrison et al., 1991).

Focusing on spousal support, Roy (2011) highlights how being married or in a long-term relationship can predict a better outcome for breast cancer patients. There are, however, several underlying factors to consider. In *Breast cancer patients' perceptions about their husbands' support in a cross-cultural context*, Kagawa and Wellisch (2003) found that two differences among ethnic groups indicated cultural differences in perceptions of husband's support. Euro-American, Chinese-American, and Japanese-American women held different expectations of their husband's support and placed different values on their husbands' verbal and non-verbal communications related to their breast cancer. It seems then that a cultural

context should be included as a factor affecting supporter role expectation, performance and meanings. In Hasson-Ohayon, Goldzweg, Braun, and Galinsky's (2010) study, experiences of social support of Israeli women and their spouses when living with breast cancer were investigated. The spouses expressed a higher level of psychological distress than patients and in this case both patients and spouses revealed similar levels of natural support received from each other. These husbands, however, reported less support from family and friends.

Moreover, the women remained significant supporters in their families even though they were diagnosed with breast cancer. These findings were mainly discussed in relation to gender difference and cultural expectations on sick and supporter roles. It seems that Israeli social norms are that men are expected to hide needs and to have lower ability to taking care others. With such cultural differences in social behaviours, it follows that spousal supporters in some countries may not always be the most significant supporter. A shifting in roles between support receivers and providers among network members, especially in families is possible in a long journey with breast cancer.

Among studies on the family support, Snyder and Pearse (2010) reveals most participants affirmed that their family support was central for their coping with their diagnosis, therapies and life after the completion of cancer therapies, especially that received from female relatives. Additionally, people who could provide firsthand information, insights, and hope were valued. This reflects the expectation on kinds of support from families. Family cohesion was one factor that led to good support being provided by family by blood and family by marriage and achieving the best adjustment to breast cancer (Friedman et al., 1988). Another study on immigrant Punjabi (a South Asian ethnicity) women with a breast cancer diagnosis identified six strategies that families used to support the women. They are i) providing practical and everyday support; ii) coping through faith; iii) positive talking; iv) advocating on behalf of the women; v) monitoring disclosure and discussion of breast cancer; and vi) never leaving her alone. These six strategies were motivated by family responsibilities and obligations. These family strategies were different from caring patterns in Western families where individuals could make autonomous decisions. Additionally, many family members prioritised the other persons' needs over their own personal and work related needs and responsibilities (Balneaves et al., 2007). This also emphasises that different cultural contexts, collective identity and obligations relating to the supporter roles of group or community members impact on network characteristics. Accordingly, the cultural values affecting the collective identity of Thai people in the lower southern region should be carefully considered as a factor that is likely to affect the women's personal social networks.

Network studies focusing on groups of friends establish varied findings, but this supporter group seems to make one of the significant network sets for breast cancer patients and their families. Chou et al.'s (2012) study reveals that an increase in frequency of contact by friends was identified as having association with lower risk of death. Similarly, friendship was identified as important for survival and the extent of contact support is claimed to be significant, particularly for women with breast cancer who were unmarried or worked outside of the home (Waxler-Morrison et al., 1991). Additionally, male partners reported the most significant support for them came from friends (Hasson et al., 2010). These results mean support through friendship may not equally influence everyone. Dakof and Taylor (1990) explored the perception of 55 cancer patients (including breast cancer patients) about their social support. Support activities from friends were distinguished into positive support behaviours (such as expressions of concern and affection and practical assistance) and negative support behaviours (such as avoiding contact and having extremely pessimistic views about the disease). Furthermore, support from friends was identified as an important part of emotional support. Friends continued to provide the women with supports, mainly in an emotional-focused way (Arora et al., 2007). Accordingly, groups of friends are emphasised as one of the significant parts of networks, but one that is not static.

Some other research has looked into the effects of peer support groups. Generally, these groups are generated based on the perception that people with similar experiences can be a good support through activities such as sharing and or exchanging experiences. The most common peer support groups reported in cancer are breast cancer groups (Hoey, Ieropoli, White, & Jefford, 2008). Five models of peer support include i) one-on-one via face to face communication, ii) one-on-one via telephone, iii) face-to-face groups, iv) telephone groups, and v) internet groups. Peer support groups can bring a positive impact to breast cancer-related issues by decreasing feelings of isolation, and encouraging and promoting positive health behaviours. However, evaluations of peer support programmes of cancer patients have not reported an association with the quality of life of participants (Hoey et al., 2008). Campbell et al.'s study (2004) reviewed 17 articles related to the peer support programmes of cancer patients (more than half of them were groups of breast cancer patients) which had used either surveys or randomized controlled trials. The programme participants tended to be more highly educated, middle class (in income), married and quite young. Furthermore, Helgeson et al. (2000) investigated the benefits of social support groups and one of their study findings is that peer groups were helpful for women who lacked support from close persons such as partners or other family members. These studies' findings reflect that

support networks in a formal form as peer support groups were not suited for every people. This relates to individual differences and preference.

In terms of peer support outcomes, Gottlieb and Wachala's (2007) study reveals that peer group participants felt less alone, felt they better understood disease-related issues, and were more hopeful. However, inappropriate impacts resulting from peer support participation were also uncovered by some participants such as feeling uncomfortable about sharing and having difficulty dealing with a peer group member's death (H. S. Campbell et al., 2004). Different types of peer support groups also reported different characteristics of participants. Telephone and internet support groups were reported as beneficial to patients who were home based, lived at a geographical distance or desired privacy. Though, barriers, such as lack of computer equipment and/or skills, and also time, reduced participation in an internet group activity. (H. S. Campbell et al., 2004). Hence, peer support groups are an option for women with breast cancer and women's participation in any of these forms would extend their personal social networks.

The interactions between groups of supporters also are the focal point of some studies. For example, Manne et al.'s (2003) study investigated family and friend support in cases where partners were providing inefficient support and this was affecting the coping efficacy of the women with breast cancer. This study found that the support provided by family and friends was associated with coping efficacy of these women. This reflects an interaction between groups of supporters affecting network characteristics and changes. Dakof and Taylor's (1990) study also highlighted different characteristics of support activities among spouses, family, friends, and others regarding the women's perceptions of helpfulness. These different interpretations about support provided were discussed in relation to 'the wished-for-helpful responses' or 'expectation' of the supporter role of each group. For example, while emotional and practical support was indicated as helpful and expected from spouses, family and friends, different expectations for practical assistance was mentioned for friends and acquaintances.

In summary, notions raised in the literature on the studies of networks supporting breast cancer patients can be distinguished into three categories as shown in Figure 2.2. It is noteworthy that even though network analysis in many areas, including networks in health, used mapping methods to identify social networks, no network studies in breast cancer have used network mapping as a method of developing an understanding of social networks of these women. What the review reveals is a limitation around the complexity and development of networks as a whole and the dynamics relating to their structural,

relationships, function, change and the interactions with their contexts. Yet this would seem vital if the roles of networks in supporting people with long-term illnesses such as breast cancer are to be fully understood and very relevant to the support for women with breast cancer in lower southern Thailand.

## **Social networks and breast cancer in Thailand**

The studies of social networks of breast cancer in Thailand are rare and limited to only two selected groups of supporters: family and peers. My literature review covers the only five published network-related studies. One study is a review of family caregiver characteristics of cancer patients; three of them investigated outcomes of breast cancer support groups using randomized controlled trial studies. Another study explored the experiences of families which had women with breast cancer.

Meecharoen, Northouse, Sriapo-ngam, and Monkong (2013) conducted their study on family caregivers for cancer patients (including breast cancer) in Thailand by reviewing 23 Thai studies, predominantly unpublished theses that used quantitative or qualitative approaches. Most of these studies were based on the family stress and coping theory of Lazarus and Folkman, a different focus from the review by Nelles et al. (1991). Family caregivers of cancer patients comprise blood-related family members such as parents, siblings, children, and other relatives, married family members such as spouses and daughters or sons-in-law who live in the same house, and also others who were unpaid caregivers without family relationships. Some of the reviewed studies reported family burdens related to caregiver needs in the family. Qualitative data reveals the meaning of being caregivers of cancer patients had four dimensions i) an opportunity to return a favour to patients, ii) family members are able to provide better care than people who are non-family, iii) the family care comprises sympathy, understanding, and willingness to take care of the patients, and iv) the job is a family responsibility. In addition, qualitative data related to Muslim caregivers illustrate that all caregivers believed in God or Allah's decrees and help. Their will was extended by their religious beliefs and spiritual strength. The outcomes of this review mean relationships among network members, social obligations and religious beliefs are factors with the potential to impact on the social network characteristics for Thai cancer patients.

Three studies used support group programmes for breast cancer patients as an intervention and evaluated the programmes' outcomes (Heebchinda, Junda, & Sumdaengrit, 2014; Thadmala & Sangchart, 2012; Wonghongkul et al., 2010). These studies' participants were breast cancer patients in different phases. The investigated outcomes ranged from

psychological outcomes, support to quality of life. However the results showed an inconsistency among programmes' outcomes, especially in quality of life indicators. This inconsistency might relate to the complexity of living with breast cancer and the dynamics of support needs throughout phases of the disease.

Lastly, Junda's (2004) qualitative study used an ethnographic method to explore experiences of Thai families when living with women diagnosed in the early stages of breast cancer. "Doing what is the best for us/our health" emerged as the main concept underlying the support and interactions in the families as they adjusted to life with breast cancer. The study's findings were synthesised and presented through 'Junda's model of Thai family's experiences and management of breast cancer'. Significantly, interactions within and between groups of family systems and social systems were strongly mentioned. These families revealed several methods for managing their breast cancer: intra-family support, interactions, and communication in family. 'The concept of socio-cultural practices and beliefs' is established as an influential family factor in the management of breast cancer and related issues. This concept includes Buddhist beliefs and practices, the social hierarchical order, gender roles and perceptions of cancer. For example, due to the sense of social hierarchy the family had, one-way communication with doctors was not questioned. This study's findings advocate that socio-cultural environments are influential on social networks through the interaction between them. Junda's study has a significant message for my study as it implies that the Thai socio-cultural contexts in lower southern Thailand related to health and normal life may have the potential to create some uniqueness in the support networks of women with breast cancer in this region.

## **Conclusion**

As can be seen through this literature review, social networks are complex, diverse and dynamic in relation to the occurrence of ongoing interactions within network dimensions and their contexts. Few published studies, in particular those on the social networks of women living with breast cancer, focused on the nature of a whole network. Conducting research following this way has the potential to be able to achieve an in-depth understanding of the women's (and their related persons') experiences of personal social networks when living with breast cancer in a specific region—lower southern Thailand. The next chapter will describe the research framework, design, fieldwork practices, data analysis, and quality control of the study.



## CHAPTER 3

### Methodology

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*“A case study is expected to catch the complexity of a single case. A single leaf, even a single toothpick, has unique complexities—but rarely will we care enough to submit it to case study. We study a case when it itself is of very special interest. We look for the detail of interaction with its contexts. Case study is the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances”.*

*Robert E. Stake (1995, p. xi)*

#### Introduction

In the previous chapter, descriptions in the literature of social networks of people living with a long term illness such as breast cancer were shown to be complex, dynamic, and existing within multiple contexts. The purpose of this study was to achieve understanding of the experiences of personal social networks of women with a breast cancer diagnosis, how and why the contextual factors of living with breast cancer in the lower southern region of Thailand influence the networks and how these women become involved in a breast cancer club. I therefore chose a qualitative collective case study research approach rather than a quantitative network analysis approach (e.g. Freeman, 2011; J. Scott, 2013; J. Scott & Carrington, 2011). The choice was made to maintain congruence between the research questions that related to understanding of the phenomena of interest, the research design, and the processes of conducting fieldwork, data analysis, and reporting the case. In this chapter, the research design and method are described parallel with discussions on both their benefits and challenges.

#### Qualitative case study

Qualitative case study suits researchers who would like to study a unique case that is “...a specific, complex, functioning thing... ..through personal experiences, in-depth understanding and valuing each person...” (Stake, 2000, p.436). However, case study has been defined in a number ways and Luck, Jackson, and Usher (2006) argue that this causes a

definitional problem resulting in different conduct and results. Hamel, Dufour and Fortin define case study as “...an in-depth study of the cases under consideration, and this depth has become another feature of the case study approach...” (1993, p. 1). Case study as defined by Stake, however, is focused on cases or issues of interest rather than methodology. Stake argues that (p. 435) case study “...is not a methodological choice but a choice of what is to be studied...” In this way Stake holds that “the case’s uniqueness, particular context, issues, and story” (p. 448) are much more central. More recently Yin has defined a case study as “an inquiry that investigates a contemporary phenomenon in-depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident” (Yin, 2009, p. 18).

I finalised a framework of my research approach a priori following Stake’s definition that focused on what a case(s) is, and how cases interact with their unique or specific contexts. Though this definition has become widely applied, for this study, furthermore, the study framework followed Luck et al.’s (2006) proposition of a pragmatic approach. They argue for the need to customise case study by focusing on the flexible and pragmatic use of this method, rather than the definition of case study. This proposition is related to the case study that they define as “... a detailed, intensive study of a particular contextual, and bounded, phenomenon that is undertaken in a real life situation” (p. 104). These considerations are important because the relationship between design and method are the foundation for success. Researchers need to define the study approaches and perspectives that are related to the research issues/questions and then take the responsibility to design a logical outline with the appropriate methods specific to their studies (Hancock & Algozzine, 2006).

Positioning my case study design with regards to Stake’s (2000) and Luck et al.’s (2006) perspectives, the phenomenon of interest in this study was “personal social networks” rather than the women themselves. Thus the study of the case not only helps to describe the phenomenon in a specific context, but also helps investigation of the complexity (Stake, 2000; Zainal, 2007). Stake suggests using “issues” to provoke the concern of complexity and contextual interactions. Case issues are preliminary conceptual frameworks and/or research questions. Stake elucidates the important function of using issues in case study: “...we want to appreciate the uniqueness, complexity of a case, its embeddedness, and interaction with its contexts... ..I choose to use issues as a conceptual structure—and issue questions as my primary research questions—in order to force attention to complexity and contextuality” (Stake, 1995, p. 16). The case study issues are not simple but woven with a consideration of the whole case, contextual factors and their interactions. Using case study allows for

diversity and different perspectives, based on function, characteristics, or disciplinary perspectives through which the case study is carried out (Stake, 1995). For this study, issue and research questions are the same: i) what are the experiences of personal social networks of women with a breast cancer diagnosis and their significant supporters; ii) how the contextual factors of living with breast cancer in the lower southern region of Thailand influence their personal social networks; and iii) how do the women with a breast cancer diagnosis become involved in a breast cancer club and why.

Three types of case study are distinguished by Stake (1995, 2000). i) **An intrinsic case study** is a particular case that is of intrinsic interest rather than it representing other cases or being a generic phenomenon. Intrinsic cases could be a medical case study of a specific breast cancer patient, a successful breast cancer club, or a breast cancer clinic. ii) **An instrumental case study** is of a particular case that is examined as being able to provide insightful information of issues (or research questions) to generate generalisations. iii) **A collective case study** reflects an instrumental case study extended to several cases. Individual cases (usually a small number) are chosen for study to understand them as a collective, or to enable better theorising. The case distinction into three types is underpinned by the difference of methods that will be use to explore case issues related to their uniqueness of cases or case issues that the researcher focuses on. “The more the intrinsic interest in the case; the more we will restrain our curiosities and special interests and the more we will try to discern and pursue issues critical to case” (Stake, 1995, p. 4).

However, case study has always been criticised about the potential for a lack of rigour, validity and scientific generalisation (Zainal, 2007). Four criteria are suggested by Lincoln and Guba (1985) that in case study could provide evidence for research rigour (and validity): i) credibility; ii) dependability; iii) confirmability; and transferability (See details in section: research trustworthiness). The use of thick description to preserve the meanings and interferences of data can confirm the study transferability (Houghton, Casey, Shaw, & Murphy, 2013).

With regard to the criticism of the lack of generalisability of case study findings, Stake argues that case study can generate grand generalizations which he defines as ‘naturalistic generalisations’. He describes the type of generalization based on the challenge that “...single cases are not as strong a base for generalising to a population of cases as other research designs. But people can learn much that is general from single cases... People learn by receiving generalisations, explicated generalizations, from others,... People also form generalisations from their experience” (Stake, 1995, p. 85).

Researchers do qualitative study because they intend to achieve an in-depth understanding rather than discovering new knowledge (Stake, 1995). Stake explains that understanding phenomena requires a long period of time with a high researcher investment to capture subjective and objective data which evolves over time in real life situations. He emphasises the importance of a researcher position of subjectivity. Stake claims that “... Subjectivity is not seen as a failing needing to be eliminated but as an essential element of understanding...” (Stake, 1995, p. 45).

Qualitative case study is used for exploration of phenomena in many disciplines in health and social care, including nursing. In the next section, the use of qualitative case study in nursing research will be explored.

## **Qualitative case study and nursing research**

Qualitative case study is used in many articles reporting nursing research as a well-accepted methodology to develop nursing knowledge from phenomena in nursing contexts (e.g. Anthony & Jack, 2009; Bergen & While, 2000; Jones & Lyons, 2004; Luck et al., 2006). As nursing phenomena are related to real-life contexts, such as the women’s experiences of their personal social networks, Luck et al. (2006) claim that case study can offer purposive and situational descriptions of phenomena in practical contexts. These authors emphasise this methodology for nursing studies to investigate real life phenomena related to the contextual knowledge that can be unfolded. Those authors argue that this methodology allows researchers to employ “multiple methods within a defined ontological and epistemological position, employing congruent data collection methods within bounded contexts” (p. 1). Some nursing studies used case studies to explore phenomena within cultural / trans-cultural nursing contexts, including individuals or collectives (Anthony & Jack, 2009).

Another reason supporting case study application in nursing studies is that nursing phenomena are person-centred (Jones & Lyons, 2004; Zucker, 2001). Nursing studies require an approach with sufficient flexibility at the outset of the study fieldwork because of the potential for unpredictable events when people and their real-life contexts are studied. The case study approach as a ‘comprehensive research strategy’ enables researchers to address this problem (Jones & Lyons, 2004). This is because case study consists of an in-depth investigation of cases or case issues using multiple methods with a holistic perspective and a capability to explore multiple dimensions of cases or case issues of interest (Yin, 1994). Accordingly, case study offers a flexible, pragmatic and rigorous approach

suited to nursing research (Luck et al., 2006). In Anthony and Jack's (2009) study, an integrative review of the use of qualitative case study methodology in nursing research, the authors argue that information that should be present in a case study report representing quality criteria of the case study including multiple data from primary and varied sources. These informational criteria contributed to overall methodological quality. High quality case study data are context dependent. Importantly, in case study the perspectives of groups of people and their interactions are significant features to be captured (Anthony & Jack, 2009).

Accordingly, a collective qualitative case study was employed in this study as a research approach to explore the participants' experiences of personal social networks. Multiple perspectives of the phenomena and the different and contradictory views related to women's personal social networks were anticipated and the following sections describe how the research was designed to capture these perspectives.

## **Research Design**

This section identifies and discusses the study design through three core angles. The research plan, application and benefits and/or challenges in practice are revealed.

### **The case(s)**

As mentioned previously, the study focus that is called 'case study' is the uniqueness of the cases, their contexts, issues, and stories. What I chose to study needs to be clarified. Stake (2000) explains that a case should be specific, can be simple or complex, but bounded. In social studies, the case is functioning, purposive, has distinctiveness and is also part of integrated systems. Therefore, my instrumental cases in my collective case study are 'the personal social networks of women living with breast cancer in the lower southern region of Thailand'. Further, in this study, '**personal social networks**' will be called '**networks**'.

### **Bounding the case**

The boundaries of cases are particularly important as they guide the framework of data collection and analysis to ensure that the study remains reasonable in scope. For social network studies, many boundary strategies are recommended. Marsden (2005) proposed three generic strategies of social network bounding: a positional approach (based on characteristics of objects or formal memberships criteria); an event-based approach (resting on the participation in some class of activities); and a relational approach (based on social

connectedness). Another strategy, which is the most straightforward, is the use of location boundaries.

Personal social networks, as described in the literature, are larger than individual level networks; however, they are smaller than those of community and society levels. They may be 'partial networks' which are defined by Mitchell (1974) as parts of the network which are attended to and selected from the total personal network. The networks of this study are focused around particular types of relationships related to the phenomenon of living with breast cancer. These networks are probably the total personal networks if the focal actors perceive that all members are identified as significant. Long (2001) delineates an actor<sup>8</sup>-oriented approach that was developed with an interest in explaining the different responses to similar structural circumstances and the creation of the differences that are constructions of the actors themselves. Long affirms that social lives are never so unitary as to be built upon one single type of personal experience, however they might have some degree of shared experience with other individuals.

I therefore chose an actor-oriented perspective related to events based around the women's everyday lives during their journey with cancer. Even though these women were living with this same circumstance or event that created the possibility of similarities, each woman will have her own individual contextual environment, which creates the uniqueness of her network, particularly the experiences of their personal networks related to living with breast cancer. The set of specific relationships or partial networks which were identified by the relationships connected with the particular events thus were prioritised; however, the everyday networks were not ignored because these relationships can be included in the cases.

As a result, I decided to bound the personal social networks of women through the women's perceptions of who was part of their networks. The women themselves were asked to describe their networks, who was included or excluded and why. Significantly, the cases in this study were the sets of interactions among the women and their members through both direct and indirect contact. The women and their network members were not themselves the case study, but both were the significant participants for facilitating an understanding of the nature of their personal social networks.

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<sup>8</sup> In many network studies, 'actors' is the term used to label network members, including the focal persons and other network members.

## **Number of cases and their selection**

Eleven personal social networks form the cases in this study. Although this is not a large number of cases, this number was informed by the research literature and the general expectations of the study. As qualitative studies seek to gather multiple perspectives with both similarities and differences between cases, a single case study may not deliver this need. To reach an in-depth understanding of the women's experiences, rich and detailed data related to the cases and their contexts should be provided for the reader. The smaller the number of cases, the more time the researcher needs to obtain rich data (Stake, 2000). Another reason for using the number of cases in this study is that I would like to be able to draw and use some recommendations from the findings. Firestone (1993) states that case to case and analytic generalisation can be made from qualitative studies which get data from a small sample size. Case to case generalisation is transferred learning from one case to another within a similar context. Firestone says that in qualitative studies, analytic generalisation does not rely on representative samples of a population. Instead the researchers are striving to generalise a particular set of findings to a broader theory. However, the sample size needs to be adequate and for qualitative studies this means not too small and not too large for the intended purposes of research. The sample sizes have to be controlled to achieve informational richness and theoretical saturation. Sandelowski (1995) argues that, nevertheless, the number in the sample size has to be decided through its suitability to the research purpose, method and appraisal of resources (or resource limitations i.e. number of investigators, time, and finance).

In this study, the case selection was conducted with a concern for representation of all the study issues, in line with Stake's suggestion (1995) that even in a collective case study, methods of case selection have to be used with a concern for this, as a small case number restricts the combinations that can be included. Hence, purposive and theoretical sampling techniques were used for case selection. Purposive sampling was used to select the hospitals in the lower southern region that had the capacity to provide breast cancer treatments and/or had a breast cancer club. All regional and university hospitals and some provincial hospitals were able to treat breast cancer, with some differences in hospital contexts, and only one hospital had a breast cancer club. Hence, two provincial, one regional and one university hospital were selected to be involved as the initial health settings for gaining access to women with a breast cancer diagnosis and to breast cancer club members.

In each hospital the nurses or the club manager identified potential women participants and

the breast cancer club members were identified by nurses or the club manager for me to make initial contact with and to introduce this study to them. This procedure was undertaken with regard to the women's physical and emotional health. During fieldwork, I also used the snowball technique to seek women with breast cancer by asking my participants if they knew of other potential participants.

As mentioned in Chapter 1, the setting's population is comprised of two major religious groups—Buddhist and Muslim—and religious collective identity related to social behaviours may be one potential factor influencing network characteristics. Consequently, I purposefully sought to involve both Buddhist and Muslim women. However, due to the civil unrest in three provinces of this region, women treated at hospitals in these provinces were not selected to this study as it would have been unsafe to undertake the necessary fieldwork.

As a result, the cases in this study are comprised of 11 personal social networks.

- Five networks of women treated at only provincial hospitals.
- One network of a woman treated at a regional hospital.
- Two networks of women treated at the provincial and university hospitals
- One network of a woman treated at the provincial, regional, and university hospitals.
- Two networks of women treated at only a university hospital and who were members of a breast cancer club. One of these was living in a province of insurgency

## **Participants**

To depict the nature of the study cases, it was important to explore the many experiences in each network, from the multiple perspectives of the network members. Accordingly, data was gathered from not only women with breast cancer but also from network members nominated by the central women.

### ***Key participants: Women with a breast cancer diagnosis***

The women with breast cancer who volunteered to participate in this study were the central women of their networks. They were counted as key participants of their network. Most of them were screened and then referred to me by nurses at surgical clinics of the selected hospitals or by a breast cancer club manager and some were referred to me by other women. After I gave them an introduction about this study, 15 women decided to participate, however, four women then chose not to participate because of their health, jobs and family duties. The characteristics of 11 central women are shown in Table 3.1

**Table 3.1**

*Women's Demographic and Breast Cancer-Related Experiences*

Demographic data					
<i>Ages (years)</i>		30-39	40-49	50-59	60+
<i>Married status</i>	<i>Single</i>		✓ <sup>M</sup>	✓ <sup>B</sup>	✓ <sup>B</sup>
	<i>Married</i>	✓ <sup>B</sup> ✓ <sup>B</sup> ✓ <sup>B</sup>	✓ <sup>B</sup> ✓ <sup>M</sup>	✓ <sup>B</sup>	✓ <sup>B</sup> ✓ <sup>M</sup>
Breast cancer – related experiences					
<i>Stages of diagnosis</i>					
<i>1<sup>st</sup> diagnosis</i>					
	<i>Stage I (+)</i>	✓	✓		✓
	<i>Stage II (+)</i>	✓			✓
	<i>Stage III</i>		✓	✓	✓
	<i>Unknown / unsure</i>	✓	✓✓		
<i>Recurrence</i>					
	<i>Stage IV</i>			✓	
<i>BC treatments</i>					
	<i>Breast surgery</i>	✓✓✓	✓✓✓	✓✓	✓✓✓
	<i>Other surgery</i>		✓		
	<i>Lymph node removal</i>	✓✓	✓✓	✓✓	✓✓✓
	<i>Chemotherapy</i>	✓✓✓	✓✓✓	✓✓	✓✓✓
	<i>Radiation therapy</i>		✓✓	✓✓	✓
	<i>Hormonal therapy</i>			✓	✓✓
<i>Years with BC</i>					
	<i>0-1</i>	✓✓	✓✓		
	<i>1-5</i>	✓		✓	✓✓✓
	<i>5+</i>		✓	✓	
<i>Phases of living with BC</i>					
<i>1<sup>st</sup> diagnosis loop</i>					
	<i>Pre-diagnosis</i>	✓✓✓	✓✓✓	✓✓	✓✓✓
	<i>Undergoing investigation +/- initial treatments</i>	✓✓✓	✓✓✓	✓✓	✓✓✓
	<i>Undergoing aggressive treatments</i>	✓✓✓	✓✓✓	✓✓	✓✓✓
	<i>Completed aggressive treatment</i>	✓✓	✓✓	✓✓	✓✓✓
	<i>Post treatments</i>	✓✓	✓	✓✓	✓✓✓
<i>Recurrence loop</i>					
	<i>(re) Pre-diagnosis</i>			✓	
	<i>(re) Undergoing investigation / surgery</i>			✓	
	<i>Undergoing prolonged chemotherapy</i>			✓	
<i>BC club participation</i>					
	<i>Yes</i>			✓	✓
	<i>No</i>	✓✓✓	✓✓✓	✓	✓✓

\*✓ = the central woman, ✓<sup>B</sup> = the Buddhist central woman, ✓<sup>M</sup> = the Muslim central woman

\*\* One central woman was diagnosed with a recurrence of breast cancer. Her first diagnosis was stage I breast cancer and her recurrence diagnosis was stage IV breast cancer. Her second surgery was a wide excision of the tumour with resection of sternum and ribs.

\*\*\*The stages of diagnosis and treatments based on the central women perceptions

\*\*\*\* 'Initial treatments' means pre-treatments which were required to start before the breast surgery such as mass excision and neoadjuvant chemotherapy / radiotherapy.

\*\*\*\*\* 'Aggressive treatments' means breast surgeries (and other related surgery), chemotherapy, and radiation therapy.

This table shows the central women involved this study had ages ranging from the thirties to sixties, and included both married and single women. The number of Buddhist participants was larger than the number of Muslim women. Most women were diagnosed with the first, second or third stage of breast cancer. However, some women did not know or were unsure about their breast cancer stages. During the period of data collection, only one woman had been diagnosed with recurrence of her breast cancer. Their experiences of living with breast cancer were varied, with differences related to the processes of diagnosis, referral and the breast cancer treatments they underwent. The women were also at different phases of living with breast cancer, related to how long they lived with this disease, ranging from less than one to over five years. Only two women (including the woman with recurrence of breast cancer) had lived with their breast cancer more than five years. Further, in this study these key participants will be identified as ‘**the central women**’ because they are the centre of their networks.

#### ***Referral participants: Network members***

Another group of participants was the network members. The central women were asked to identify their significant network members. These members were called referral participants. After the women identified their significant network members, I asked them if these members were able to be part of this study. The women then contacted the significant members that they preferred to participate in the study and arranged a meeting with themselves, the selected network members and me to inform them about the study. After this, 30 referral participants agreed to participate in the study to provide and share their experiences of being a personal social network member of a woman diagnosed with breast cancer. The number of referral participants for each case ranged from one to four, depending on the individuals’ desire to participate and the availability of both the central women and the network members. Most of them were the central women’s family related either by blood or by marriage. The women’s parents and siblings were identified by the central women as important, followed by their spouses, children and relatives including in-laws (i.e. aunts, nephews, nieces, and a sister in-law). Referral participants from the non-family group included friends, colleagues, and health professionals (See Table 3.2).

**Table 3.2***Referral Participants' Characteristics*

Case No.	1	2	3	4	5	6	7	8	9	10	11	Total
<b>Number of referral participants</b>	3	4	4	4	4	3	2	2	1	2	1	<b>30</b>
<b>Social position with the central women</b>												
Spouse	✓				✓	✓		✓				<b>4</b>
Child			✓		✓✓✓	✓						<b>5</b>
Parent / sibling	✓	✓	✓✓	✓✓		✓		✓		✓		<b>9</b>
Relative (including in-law)	✓	✓✓		✓			✓		✓			<b>6</b>
Friend		✓*					✓					<b>2</b>
Colleague			✓									<b>1</b>
Others**				✓						✓	✓	<b>3</b>

✓ = a referral participant

\*This friend is also the central woman's colleague

\*\*Others include a colleague of the central woman's sister and a health professional

## Ethics

This study was conducted among the local people in a particular community where people have specific beliefs, customs, traditional lifestyles related to living with breast cancer and normal living. In terms of involvement in the research settings, I considered both individual and collective rights of all the women and their network members. The study applied a community-up ethical framework that Batten (2008) adapted from the components of the community-up approach of Smith and Cram and the core ethical principles of Massey University. Batten's framework provides an ethical guideline for fieldwork within both individual and collective levels. Punch (1994) argues that these ethical codes should be used as guidelines to practices, rather than strict rules in fieldwork as strict application could possibly restrict the great outcomes. He stated — I am not arguing that the field-worker should abandon all ethical considerations once he or she has gotten in, but rather that informed consent is unworkable in some sorts of observational research (1994, p. 90). From ethical frameworks into practices, I conducted this study with three key ethical considerations; i) respectfulness, ii) informed consent; and iii) minimisation of harm.

## Respectfulness

Respectfulness was customised at both individual and collective levels. I wanted to convey respectfulness for i) persons, ii) social and cultural sensitivity, iii) justice, iv) privacy, and v) confidentiality. The respectful protocol, examples of application, its benefits and evidence of challenges when I applied the protocol into my fieldworks are discussed in Table 3.3.

**Table 3.3**

*Applications and Discussion of Respectfulness*

The required fieldwork protocol	Examples of applications	Benefits	Challenges
<i>For Persons</i>			
<p>a. I planned to deliver the crucial study information to the study participants and provide them the opportunities to ask their questions sequentially.</p> <p>b. The participants were able to make independent (re) decisions as whether to participate in the study or withdraw from the study at any time during fieldwork and their decisions would not influence to the quality of health care they received.</p> <p>c. The women were able to independently choose whether to be involved in the optional procedures of data collection.</p> <p>d. Being respectful when dialoguing, listening, observing and questioning was important.</p> <p>e. Face-to-face communication was the first priority as a communication channel between the participants and me.</p> <p>f. The participant's usual languages were planned to be used in dialoguing between the participants and me.</p> <p>g. Consideration of participants' convenience, comfort, and preference was demonstrated through asking them when and where they preferred to participate. I went to the participants' places instead of asking them to go to my place.</p> <p>h. The participants' health, jobs, and family related activities had priority over the study activities. Furthermore, the participants were able to postpone or cancel the appointments with me at any time.</p>	<ul style="list-style-type: none"> <li>• The study information was given to the women and referral participants (adult &amp; children, see Appendix V) through face-to-face communication with all women and some network members. Some were contacted through e-mail and telephone instead because of the distance of their living places from the study setting. I also provided sequential opportunities to all participants to ask me about the study throughout my fieldwork.</li> <li>• Before withdrawal from fieldwork, all women were asked for their final decision about permission to publish their experiences and related material. I conducted the agreement process with participants in an ongoing way to ensure that they had not changed their mind over time about the use of this data.</li> <li>• All women and most network members had face-to-face communications with me, except two network members who were not available for this procedure. Telephone and e-mail interviews were used instead depending on their preference.</li> <li>• I mainly used the southern dialect to communicate with most participants because it was their common language in daily living. For only two participants who were not locals to the southern region, I communicated with an official Thai language.</li> <li>• For example, one woman was a shop owner and had to work in her shop every day. To limit disturbances to her business, most activities of data collection with her were conducted at her shop and when she was free from her customers.</li> </ul>	<ul style="list-style-type: none"> <li>• Human freedom was respected related to not only themselves but also their responsibilities.</li> <li>• Helping the participants to have clearer understandings about this study and to have opportunities for re-decision before withdrawal or continuing with the study</li> </ul>	<ul style="list-style-type: none"> <li>• During the period of data collection one woman felt worried about a secret that she had shared with me being published and possibly leading to some difficulty in her life.</li> </ul> <p>However, I frequently provided her the opportunities to ask me about the study details. This helped her to clarify the process of the study findings publication which was designed with concern for the protection a participant's privacy and confidentiality.</p> <p>Finally, she decided to continue her participation in this study. However, I made a decision to exclude her sensitive data with respect to her perception from the report.</p>

The required fieldwork protocol	Examples of applications	Benefits	Challenges
<i>For social and cultural sensitivity</i>			
<p>a. I intended to behave as one of the local people and be generous to the participants and relevant persons in their wisdom, beliefs, customs, and knowledge.</p> <p>b. I would dialogue, listen, observe and question the participants and their relevant persons with respectfulness.</p> <p>c. I intended to position myself as a learner rather than an investigator.</p>	<ul style="list-style-type: none"> <li>• I tried my best to behave as one of the local people rather than a health professional such as calling myself by my nickname rather than a formal name; I dressed in casual clothes rather than formal ones. I used the southern dialect to communicate with them; and sometimes I shared lunch with my participants at their places.</li> <li>• I listened to and observed the participants' social behaviours, wisdom, beliefs, customs, opinions, and knowledge they shared with me without justification and criticisms particularly, in relation to sensitive information such as religions and traditional beliefs.</li> <li>• For Muslim cases, I was aware of their need for respect of four significant behaviours. <ul style="list-style-type: none"> <li>i) Do not disturb their time for religious performances such as prayers five times a day,</li> <li>ii) Friday afternoon is the time Muslim males go to perform religious activities at a mosque.</li> <li>iii) Some kinds of food are not allowed for Muslims, and I would not bring them to their places.</li> <li>iv) Do not discuss or participate in others' discussion or make comparisons between Buddhists and Muslims.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• To respect social and cultural sensitivity, not only the person (s) themselves were respected, but also their spirituality and their collective culture. This was the normal way their networks and societies were respected too.</li> <li>• Respectfulness for the participants' society and culture could provide a secondary benefit as it also shortened times for rapport building. Behaving as a local helped to develop my familiarity with them and their familiarity with me. As a result, the shorter the gap between us, the deeper and more holistic information gathered.</li> </ul>	<ul style="list-style-type: none"> <li>• Religious wisdoms, beliefs and opinions are always sensitive issues.</li> </ul> <p>As I was a Buddhist researcher involving Muslim participants, particularly in the traditional Muslim communities. Participants' (and other community members) closely observed me during fieldwork. I undertook all data collection with respectfulness in mind</p>
<i>For justice</i>			
<p>a. I had planned to position myself as the learner to learn the participants' experiences.</p> <p>b. Even though my position as a researcher was primary, sharing information, experiences and resources generously with the participants and responding to their requests for information were important too.</p>	<ul style="list-style-type: none"> <li>• I learned through all fieldwork activities, participants' experiences and their contexts.</li> <li>• I tried my best to not judge the participants' and their network members' behaviours and experiences shared with me and I avoided giving my opinions on personal interactions among the women and their network members.</li> </ul>	<ul style="list-style-type: none"> <li>• Learning and sharing helps to develop a sense of empowerment between researcher and participants</li> </ul>	<ul style="list-style-type: none"> <li>• I introduced myself to the participants as a local person who is a researcher student, a nurse, and a person who has experiences with breast cancer in their family.</li> </ul>

The required fieldwork protocol	Examples of applications	Benefits	Challenges
<i>For justice</i>			
	<ul style="list-style-type: none"> <li>The participants were able to interview, observe, question, me naturally and they also were able to ask me for knowledge, suggestions, or help related to breast cancer.</li> </ul>		<p>The participants then not only preferred to share their experiences with me, but also interacted with me regarding other positions.</p> <p>For example, all women asked me about my sister's experiences with breast cancer. Some asked me for breast cancer-related knowledge and suggestions (and also my personal experiences with my study and my personal life).</p> <p>I conducted interactional activities with participants with self-consciousness about which roles I took at that time. I also used field notes and researcher diaries to help me monitoring myself related to the roles taken.</p>
<i>For privacy</i>			
<p>a. Time and place of participation activities would be created by the participants.</p> <p>b. The events, periods, duration and frequency of observations would be conducted only with the women's permission.</p> <p>c. The women's network members and relevant documents were not accessed without the women's permission. The central women could choose to be involved when I met with her network members, if she preferred.</p>	<ul style="list-style-type: none"> <li>At the first meeting, I asked the women for their mobile numbers and also gave them my mobile number as a channel for our communication. I informed them that I was available to go to their places anytime which suited their lifestyle rather than my lifestyle. I made appointments with the participants at least one day before visits and told them that they were able to change the places, dates, and times or cancel if preferred.</li> <li>Arrangements for data collection activities with network members were done by the women. Most of these data collections were conducted with the women's</li> </ul>	<ul style="list-style-type: none"> <li>Participants' privacy was protected. This protocol was able to minimise harm for the participants' and related persons' lives.</li> </ul>	<ul style="list-style-type: none"> <li>Only three women volunteered to provide their medical documents and I did not ask for related documents from other cases. As mentioned previously these study findings were positioned as relying on the participants' perspective rather than professional perspectives.</li> </ul>

The required fieldwork protocol	Examples of applications	Benefits	Challenges
<i>For privacy</i>			
	participation or attention at the women's or network members' accommodations, and the women's workplaces.		
<i>For confidentiality</i>			
<p>a. Anonymity was planned for both the participants and health settings</p> <p>b. Photos which were able to be traced back to participants and related person would not be presented in any of the study's publications.</p> <p>c. Participants could choose to keep some things secret and private from data recording, decline to answer some questions, decline voice recording or delete voice records at anytime.</p> <p>d. The interview transcriber had to sign a transcribers' confidentiality agreement.</p>	<ul style="list-style-type: none"> <li>• Codes were used to differentiate participants of each case instead of pseudonyms.</li> <li>• Verbal and written information were given to the participants about their rights related to their confidentiality. (See Appendix V).</li> <li>• Before withdrawal from the field with each case, I made affirmation with them about the study publication. This activity was underpinned by my attention to provide the participants with opportunities to re-decide about this.</li> <li>• I and my supervision team reduced the chances of identifying participants and relevant persons by removing identity details.</li> <li>• One transcriber was used in this study with agreement of transcribers' confidentiality. (See confidential agreement in Appendix V)</li> </ul>	<ul style="list-style-type: none"> <li>• Participants' confidentiality and consideration of precautions for risk or harm were practiced.</li> </ul>	<ul style="list-style-type: none"> <li>• The study issue was personal and some information was perceived as sensitive for relationships among networks.</li> </ul> <p>I decided not to publish participants' photos. I and my supervisors carefully screened sensitive information.</p>

Table 3.3 demonstrates respect for diversity among individuals, people having multiple roles and positions, and the presence of religions, beliefs, wisdoms that are a sensitive part of human freedom and sensitive issues. These issues should be thought about within the consideration of respectfulness, informed consent and the ethical conduct of research.

## Informed consent

Obtaining informed consent is part of respecting voluntary participation in research. Christians (2000) explains that two necessary conditions of informed consent are "...the subject must agree voluntarily to participate—that is, without physical or psychological coercion... and ...this agreement must be based on full and open information..." (p. 138). The protocols to manage informed consent, its application in fieldwork and the challenging issues which were created following these concepts are presented in Table 3.4

**Table 3.4**

*Application and Discussion of Informed Consent*

The required fieldwork protocol	Examples of applications	Benefits	Challenges
<p>a. Data gathering could not be conducted without the health settings', the women's and their network members' permissions</p> <p>b. The independent decisions to participate following appropriate information given more importantly than the signing of the consent form.</p> <p>c. Signing consent forms was planned to be completed before conducting data collection. (forms for adult and children, see Appendix V)</p> <p>d. Even though, the informed consent forms were signed, the participants were able to repeal their permissions at anytime.</p>	<ul style="list-style-type: none"> <li>• The letter for health setting's permission and the consent form were developed and used in this study (See Appendix V).</li> <li>• I started initial access process to potential women when permissions from health settings were received by me.</li> <li>• I informed my participants about the study in particular the processes of conducting fieldwork, data management and reporting the study results both before and during data gathering. Significantly, their right to have independent decisions and re-decisions without any impact to the health services were emphasised.</li> <li>• The verbal and written forms of consent were significant in re-confirming their agreement during fieldwork as over time it was possible that participants could change their decisions.</li> <li>• I did the last confirmation of permission to use the participants' information and materials before leaving from fieldwork of each case.</li> </ul>	<ul style="list-style-type: none"> <li>• The participants had opportunities for independent (re) decisions for informed consent and all their decisions were respected without condition.</li> <li>• Risk of harms was also minimised.</li> </ul>	<ul style="list-style-type: none"> <li>• Signing a consent form was not a familiar activity for some participants and caused them to feel worried as if they were not able to refuse their agreement.</li> </ul> <p>Once I could observed this worry from some participants, I decided to conduct signing the written informed consent as the last step before leaving from field rather than before data collection.</p>

With regard to the evidence from the field mentioned in Table 3.4, fieldwork is complex as individual and contextual differences are always challenging. The challenge of informed consent application in the fieldwork of this study revealed different perceptions about the informed consent process. The signing of the form had the potential to cause emotional harm with the lay people who were not familiar with formal documents like this. This evidence is supporting the use of ethical protocols as guidelines rather than as strict rules. The process of ensuring informed consent as an ongoing pattern as described, rather than one step alone, is helpful in demonstrating the practical respectfulness given to participants and the minimization of harm for them.

### **Minimisation of harm**

It was possible that there were some risks of potential harm for participants and the researcher by being involved in this study. It was my responsibility to predict and minimise

the possible harm to these persons. Conducting research following my ethical protocols related to respectfulness also covered the consideration of harm for participants. Furthermore, performing regular self-assessment, self-monitoring, and formal and informal discussions with peers and supervisors was a practical way of being alert to any potential psycho-social harm to participants and myself.

For example, during the early period of my fieldwork, I found it difficult to decide how to share my family experiences with breast cancer with my participants as I wondered about the influence on their stories. I discussed this difficulty with my supervisors. The ideas given by my supervisors to guide me to a decision were: ‘You want to know about the participants’ personal stories. Why would they not be able to know about your personal stories?’ and ‘sharing and learning from the participants ... should be better than only gathering information from them’. I recognised that having interactions with participants in various positions and roles depended on situations. I needed therefore to recognise the positions and roles I performed and to monitor my own interpretations of events and actions accordingly.

When conducting fieldwork with regard to ethical considerations, however, I perceived that adjustment is crucial to seek the balance between particular study issues, and the individual and cultural contexts of both participants and myself as the researcher. I do agree that the ethical conduct of qualitative research is grounded with moral principles but also with regard to the need for flexibility related to contextual concerns.

## **Approval**

The study proposal was reviewed as part of my PhD programme confirmation. Next, the Human Ethics application (no. 11/67) was evaluated and approved by the Massey University Human Ethics Committee (see appendix V). Lastly, the ethics proposal was approved by the ethics committees of the four hospitals, from which the potential women were accessed.

## **Data collection methods**

The data gathering process of this study was created and underpinned by three main ideas. i) Holism and multiple perspectives should be captured through several methods. ii) Each method can be used as both a data gathering tool itself and as a facilitator to guide, or refine case study issues for others. iii) Each participant may feel more comfortable with some of the methods used, than with other methods. Accordingly, six methods of data collection were selected for their potential to capture the complexity of the cases. These methods were

interviews, observations, photos, diaries, document review, and mapping. Each was identified as either a ‘required’ or ‘optional’ data method. A discussion of the method protocols, their application, and challenges in fieldwork are shown in Table 3.5.

**Table 3.5**

*Application and Discussion on Data Collection Methods*

Method protocols	Examples of applications	Challenges
<b>Interview</b>		
a. A required procedure	<ul style="list-style-type: none"> <li>• After the women’s life style related to breast cancer and daily life were captured through conversation, observation and / or interview, I conducted interviews focusing on the persons involved in their life and related issues.</li> <li>• All interviews were conducted at their residence and their workplaces depending on the participants’ preference.</li> <li>• All interviews with the women were face-to-face individual interviews but mixed between individual and group interviews depending on the women’s preference. Telephone and e-mail interviews were used with network members who lived far away in other regions.</li> <li>• Interviews were audio-taped when I assessed the participants’ readiness to be recorded.</li> <li>• Field notes were written after interviewing to record interviewing components, the environment and other issues which were not able to be audio-taped. My field notes also include my initial analysis and reflection about my fieldwork practices</li> <li>• Only one transcriber was employed to transcribe all voice records.</li> <li>• All Thai transcripts of one case were translated into English. For other 10 cases, the significant parts of Thai transcripts were transcribed into English.</li> <li>• I did self-reflection through creating my researcher diaries (see examples in Appendix VI)</li> </ul>	<ul style="list-style-type: none"> <li>• I conducted more interviews with the first cases because with the early cases I had to find out the way to link the women’s experiences of living with breast cancer to experiences of their personal social networks.</li> <li>• Two telephone and e-mail interviews were conducted when these distant participants and I became known to each other through having conversation with the women about each other. I tried to minimize the limitation of a non face-to face interview, where I could not observe non-verbal language.</li> <li>• Participants responded differently to having their interviews audio-taped. Participants, such as nurses or teachers, who were familiar with this equipment, had no difficulty with me recording the interview. However, for people who were not familiar with the voice recorders, this equipment was a barrier. I recognised this in their unnatural and hesitating speaking pattern. One woman said to her network member who was interviewed by me that ‘Do you know your voice is recorded’. Later, I carefully used a voice recorder in the interview. I did not use the voice recorder at the first visit to each participant.</li> </ul> <p>Further, I used this equipment for a short period of time and (re) checked the participants’ responses. I, then, conducted the audio-taped interviews, if differences with and without the voice recorder were not significant.</p> <p>As a result, information in the first and second visits was mainly recorded in written form (field notes), rather than in audio-taped form.</p>
b. Face-to-face interviews were preferred.		
c. The plan to conduct in-depth interviews was expected to be a sequential step of conversations about the women’s stories of living with breast cancer.		
d. I had roles as both an insider and outsider in interviews.		
e. If the participants gave permission, interviews were voice recorded to capture the detailed information.		
f. Participants could cancel interviews, pause during interviews, or delete information.		
g. Decisions about time and place were made by the women.		
h. Data from other materials and methods of data collection could be used to guide interview issues.		
i. Field notes were created after every conversation and interview.		
j. Interviews were transcribed by a transcriber who signed a confidential agreement.		
k. I translated the transcripts from the Thai to the English versions.		
l. I needed to undertake self-reflection after each interview		

Method protocols	Examples of applications	Challenges
<b>Observation</b>		
<p>a. This method included two procedures: non participatory and participatory observation.</p> <p>b. Both procedures were optional procedures for participants.</p> <p>c. The focus of observational activities was the social interaction related to living with breast cancer.</p> <p>d. I anticipated that three types of social activities: everyday activities, social or community activities and a breast cancer club's activities could be observed in fieldwork.</p> <p>e. After observing, I needed to create my field notes as soon as possible.</p> <p>f. I needed to be aware of being both an insider and outsider.</p> <p>g. I planned to disclose my observer role to participants and relevant persons as much as possible.</p> <p>h. My self-reflection after observation was required.</p>	<ul style="list-style-type: none"> <li>• I started my observations by observing the breast cancer services at the selected health settings to develop my familiarity with settings for others to become familiar with me, and to practice the observation procedure.</li> <li>• Observational procedures formed part of all activities of fieldwork</li> <li>• The women's permission was gained before I undertook any observations.</li> <li>• Non-participatory observation was used to observe the interaction between the women and the relevant persons at their health settings, workplaces, participants' homes and breast cancer club setting.</li> <li>• I conducted participatory observations with some women at their hospital, with a network member at a traditional health centre, and with women who were members of a breast cancer club.</li> <li>• Information gathered through observation was recorded in field notes. (See examples of data from observation in Chapter 4).</li> <li>• I maintained a researcher diary to reflect on my observations and discussed this with supervisors in both Thailand and New Zealand.</li> </ul>	<ul style="list-style-type: none"> <li>• As I am both a researcher who is a local person of this region and also a nurse, it was a challenge to be both an insider and outsider during observations. When conducting observations in health settings, as I was familiar with health-related activities and environments, this was a possible barrier to achieving a holistic view.</li> </ul> <p>Similarly, when observing the participants' daily living, my familiarity with this local life style was a potential barrier as it was easy to make assumptions about things that I was familiar with</p> <p>Before I left New Zealand to conduct my fieldwork, my supervisors guided me to maintain both insider and outsider perspectives in fieldwork, I had to consider both familiar and unfamiliar things and both had to be recorded.</p> <p>"...Particularly, the things that you get used to with participants have the potential to be ignored in your observation".</p> <p>Moreover, when I was in field, I added to my fieldwork protocol that:</p> <p>"...Observations (and conversations) ... will be conducted to answer the main question: What data I am going to gather from the setting and its sub questions are</p> <ol style="list-style-type: none"> <li>What do they do, don't do?</li> <li>What do they say, don't say?</li> <li>What do they mean?</li> <li>What do they think, why?</li> <li>And what do I do, think and why?"</li> </ol> <p>(Researcher diary, 19<sup>th</sup> October 2011)</p>
<b>Photos</b>		
<p>a. An optional procedure for participants</p> <p>b. Photos were data and a mediator for other procedures.</p> <p>c. I needed to provide the women with an introduction to the method of them sharing their photos with me including the purpose and how to use their photos.</p>	<ul style="list-style-type: none"> <li>• I initially introduced this procedure to the women as an optional activity at the first or the second visit but no women wanted to be involved with this procedure.</li> <li>• I reintroduced the idea at different times, for example, if information and/or situations could lead to photos, I reminded my participants about the photos and asked if they wanted to participate in this activity or not.</li> </ul>	<ul style="list-style-type: none"> <li>• It was always going to be a challenge to publishing personal photos because of the possibility of identifying the participants and /or their relevant persons. Finally, I decided to publish only if photos, or image had no a picture of persons</li> <li>• Taking photos of critical events such as when people got sick seemed unusual in Thai contexts. This may be one reason why women were not interested in this activity.</li> </ul>

Method protocols	Examples of applications	Challenges
<b>Photos</b>		
<p>d. The issues of confidentiality were important considerations and I needed to discuss this with the women before they selected any photos for the study, since the selected photos could be published in academic outputs.</p> <p>e. The photos were to be selected by the women as significant to their social lives related to their breast cancer and these photos were either from the past, present, or new ones.</p> <p>f. Once the women decided to be involved in this procedure, the women and I then designed:</p> <ul style="list-style-type: none"> <li>- How to gather their significant photos.</li> <li>- How to bring a significant a photo and its story into this study and other issues if the women were concerned.</li> </ul> <p>g. After the photo stories were revealed, if issues needed further exploration I would do this through in-depth interviews.</p> <p>h. Before leaving the field, the women's permission for publishing photo was re-checked with them</p>	<ul style="list-style-type: none"> <li>• Only one woman chose to be involved with this procedure. She provided two types of images to this study: <ul style="list-style-type: none"> <li>i) The hand-made cards which were made by her supporters.</li> <li>ii) Her photos with her network members and others which were taken during special events</li> </ul> </li> </ul> <p>I decided to not publish these photos because of the need to maintain confidentiality as much as possible. However, these cards and photos were further used as prompts during interviews</p>	
<b>Diaries</b>		
<p>a. An optional procedure for participants.</p> <p>b. The stories written in diaries could be related to the women's social lives whilst living with breast cancer and other items which the women preferred to record and share.</p> <p>c. Several diary types were able to be created such as book, electronic, and voice-versions and the stories in the diary could be past, present, or on-going.</p>	<ul style="list-style-type: none"> <li>• After introducing this procedure, no participant wanted to maintain a diary.</li> </ul>	<ul style="list-style-type: none"> <li>• Barriers may have included the perceived complexity of diary creation, the participants' literacy ability, and the time commitment.</li> </ul>

Method protocols	Examples of applications	Challenges
<b>Diaries</b>		
<p>d. When I introduced this procedure to participants, I intended to include information about the functions of the diary in this study (in gathering information and / material related to their support networks), what kinds of record, what types of stories and how to create their own diaries</p> <p>e. Confidentiality was considered and the women would be provided with opportunities to ask for parts to be deleted and also to reconsider whether to share the stories in diaries or not.</p> <p>f. The audio-taped diaries were managed with the similar protocols of interview voice records.</p> <p>g. When the women decided to share their experiences through this procedure, discussion about the diary design and management was required diaries.</p>		
<b>Document review</b>		
<p>a. An optional procedure for participants.</p> <p>b. Women could choose to share their patient profile, hospital letters, brochures, posters or information sheets or messages.</p> <p>c. Women were asked for permission to access the documents that they held (No hospital charts were accessed).</p>	<ul style="list-style-type: none"> <li>• All documents that were reviewed were provided without me needing to request them and only two women provided me with their hospital letters.</li> </ul>	<ul style="list-style-type: none"> <li>• As the study was based on the perspectives of the women and their network members' perspectives. I preferred to review documents only if the women made independent decisions to provide them to me.</li> </ul> <p>For example, I mainly relied on the women's understandings about their stages of diagnosis of their breast cancer and its treatments rather than on the medical reports.</p>
<b>Mapping</b>		
<p>a. A required procedure.</p> <p>b. A large amount of information was needed before mapping of the social network could take place. Therefore I needed to assess the women's readiness to undertake this activity.</p>	<ul style="list-style-type: none"> <li>• Introduced the idea of mapping to participants in detailed when I assessed that the women had enough information related to their personal social networks to create their own networks.</li> <li>• Firstly, I tried to let the women create their own map through their own styles, but it was too difficult for them.</li> </ul>	<ul style="list-style-type: none"> <li>• Mapping was challenging not only for the participants but also for me. The challenge was how to assist the women to generate their network maps that reflected their experiences.</li> </ul>


Method protocols	Examples of applications	Challenges
<b>Mapping</b>		
<p>c. Informing the women about mapping included what a map is (something that can explain the interactions and/or relationships between the women and relevant persons during living with breast cancer), how to map (the women could create their own map alone or with assistance (including me). The most important factor was the map content had to be contributed by the women). Maps could be created in individual styles, in any form and with any materials.</p> <p>d. These maps could be modified many times depending on the women's preference.</p> <p>e. These maps were used as information themselves and as material to provoke discussion in in-depth interviews.</p> <p>f. The women's permission was requested for publishing these maps in the study report and other academic media. The identity of persons who were included in the maps was made anonymous.</p>	<ul style="list-style-type: none"> <li>As all participants requested my support to create the map templates first, I provided the women with the map template to help them created their own maps.</li> <li>Some women requested my support in mapping, some women did their map alone; and some created their maps with their spouse. The women's network maps were changed a number of times until the women thought their map represented their support network. (See examples of the women's network maps in Chapter 5)</li> <li>These maps then were used as a mediator in interviews and/or observations. Moving forwards and backwards between interviews and mapping occurred until the women perceived that their network content was saturated.</li> <li>All women gave permission for me to publish their network maps without names.</li> </ul>	<ul style="list-style-type: none"> <li>The layers within the properties of the networks could be observed from data gathered during fieldwork. When the women asked for a network map template, I adapted the simple network map from Price's article entitled 'How to map a patient's social support network' (2011) for use in this study.</li> </ul>  <ul style="list-style-type: none"> <li>I provided this network map template the women with the explanation that they could choose to use it or not, or they could modify it. The most important point was that the completed network map should align with the women's perspectives about what their personal social network looked like.</li> <li>In many cases the women requested my support in mapping. As linkages emerged between the network members during my fieldwork, I suggested to the women that they linking or relationship lines between their network members in their maps. (* My idea about lines or linkages was influenced by Price's article)</li> </ul>

Figure 3.1. A template of network map used in this study

In summary, the three main procedures of data collection in fieldwork were interviews, observations, and mapping and they were used with all cases. The other two procedures, photos and document reviews, were used in few cases, while no participants completed diaries. With regard to Table 3.5, the interplay between data collecting methods is obvious, as each method built on the data collected using other methods to achieve better outcomes. Particularly, observation was a natural activity that was integrated into all other methods providing opportunities to see the relationships among network members in action and evaluating the processes of data collection. The mapping was very helpful, as the map become a medium to display the blueprints of information that was gathered through other methods. Thus the process of mapping made information about the interactional properties became more concrete. However, the protocols for each data collection activity were

designed to be as simple as possible and to be flexible enough to accommodate individual differences, individual preferences and also participants' personal backgrounds. The most important factor was that the use of any of the selected methods was ethically sound for each woman and network.

## **Fieldwork**

An important consideration in this study was the dynamic nature of social networks over time. Therefore understanding the nature of cases and their significance could not be achieved successfully by any snapshot method. To develop an in-depth understanding of the cases it was anticipated that an extended period of data collection in the field would be required to gain longitudinal data. To gather the experience-based information from two main groups of informants, women with breast cancer and their network members, I initially planned fieldwork between October 2011 to June 2012 within three phases: i) getting to know the women's journeys of living with breast cancer, ii) learning the nature of personal social networks from the central women, and iii) puzzling-out the personal social networks through their referred network members. However, these phases overlapped, as each phase could not be completely separated from the others, and the data collection processes moved forwards and backwards depending on the flow of information, and the convenience and comfort of the participants. Furthermore, the processes of data collection and parallel analysis were planned to be conducted under the close supervision of my fieldwork supervisor in this setting. However, when doing fieldwork, many things are unable to be controlled and flexibility is definitely one characteristic that needs to be acknowledged and accepted.

### ***Two periods of fieldwork***

Initially, I had planned to conduct my fieldwork in one eight-month period. During the first seven months from October 2011 to April 2012, I obtained data from five cases, however, the data gathered was lacking depth and a larger sample size was required to meet the research aims, so the fieldwork was extended. From May to June 2012, I withdrew from the field for two months to enable me to have intensive discussions with my supervision team, to analyse preliminary findings, and develop a plan for further fieldwork. The data gathered was initially analysed with my supervisors in New Zealand to find preliminary themes and gaps. A sampling frame was developed to identify the characteristics of the first five cases and to identify others that that could be purposefully sampled to increase the diversity of cases. Then, I was ready to move forward to the second period of fieldwork.

I returned to the field and conducted data collection for four more months from July 2012 until October 2012. I accessed three more hospitals to seek access to potential participants, including women who attended a breast cancer club. Six more cases were added to the continuing five cases, meaning data collection occurred over these 11 cases over 11 months. During this time, one more phase of data analysis was developed: Depiction and description of networks as a whole.

## **Phases of fieldwork**

The focus of data collection differed with the phase of the fieldwork.

### *Phase of developing familiarity*

Even though I was a local person, I knew some hospital settings better than others. Therefore, I spent the first two weeks of fieldwork applying to each selected hospital for ethics approval, before engaging with any potential participants. I visited the hospital to develop my familiarity with the setting and also to start developing relationships with the staff, who would become the navigators between me and potential participants. During this period of time, I also observed the hospital environment and procedures, particularly those related to breast cancer care. I also practised creating field notes.

When hospital approval was gained, I contacted the charge nurse at the surgical clinic, and informed her about the project, gave her an information sheet, and then discussed with her about the process of recruiting the participants. I asked the nurses to screen the women's physical and emotional readiness based on their nursing knowledge of women over time before referring them to me.

During my first meeting with the first potential participant I identified an important challenge regarding my use of the term "personal social networks". When I introduced myself and the study project to the woman and used the term "personal social networks" as a direct Thai translation of 'เครือข่ายทางสังคม/*Krua-kai-tang-sang-khom*', the woman did not understand this term. This woman was a lay person (as was her relative who was at hospital with her at that time). I tried to explain the study topic in several ways but I thought she was still unclear. However, she decided to participate. I therefore discussed this problematic description with some other community members and none of them understood the direct-translated term in Thai. Finally, I decided to communicate the study issue with the participants by defining the personal social network as 'the persons who were in contact with

you (the women) or who you contacted since you were diagnosed with breast cancer (in Thai)' rather than its direct Thai translation terminology. With later cases, I used this meaning of social networks and did not use the terminology '*เครือข่ายทางสังคม/Krua-kai-tang- sang-khom*'.

The majority of activities in the first visit to each woman were about me introducing myself, introducing the study, the data collection procedures, and participant's rights. Later on, if the women decided to participate, a plan for further visits was discussed.

#### ***Four phases of data collection***

Four flexible phases of data collection were developed to help build relationships, trust and rapport.

- *Getting to know the women and their journeys of living with breast cancer*

Informal conversations were used to develop familiarity between the participants and me and also for me to get to know their daily living routine. Informal conversations are an unstructured interviewing technique which attempt to understand the complex behaviours of groups of people without imposing a pre-selected framework on the data or the flow of conversations (Fontana & Frey, 2000). I left it to the women as to when they were ready to talk about their breast cancer related issues, which I recognised as a sensitive experience. We had many conversations which were extended to in-depth interviews if the sub-issues needed further exploration.

After each conversation, I generated field-notes, including description of content and contexts (place, setting, environment, participant's characteristics and behaviours, and non-verbal language) (See examples of field notes in Appendix VII). Self-reflection on the process and outcomes of the conversation was a part of my field-notes and /or my researcher diary (See examples of researcher diary in Appendix VI). I re-read my field-notes in order to filter the essence of the data to guide sequential conversations and/or in-depth interviews. This phase was finished when I was able to capture the stories of the women's everyday lives and their breast cancer journeys and I had a picture of who may also form part of the social network

- *Learning the nature of personal social networks from the central women*

In this phase, I used a number of different data collection methods, customizing each depending on the participants' readiness, availability, situations and richness of the data

gathered. This phase was finished when I had an in-depth understanding of the woman as the central woman in her personal social network. Moving forwards to the next phase of data collection was also led by the readiness of the network members, identified as significant, to participate.

- *Puzzling-out the personal social networks through the women's network members*

Lists of referral participants were created to identify the people that the women mentioned during previous data collection activities. The balance of the representation between relatives and non-relatives was considered, however, the first priority was to identify those who the women labelled as significant for them, and who the women preferred to participate. Next, the women contacted these network members to ascertain their interest in participating and then arranged an appointment for data collection for me. Then, the first formal face-to-face conversation (via telephone or online in some cases) between the referred network members and me was conducted at a place convenient to them and where they felt comfortable.

To puzzle-out the personal social networks of the women through their referred participants, conversations and in-depth interviews were customised to relate to these people's network participants. Some women preferred to be part of my interactions with these participants, while others did not. The forward and backward movement between the previous phase and this phase occurred in many cases to puzzle-out the networks pictures as much as possible. Moving forward to the next phase of data collection depended on data richness.

- *Depiction of the whole networks*

When the data of the networks tended to be rich enough and their stories were stable I confirmed the data (and my interpretation) by retelling their stories to them, in particular, identifying the people who were mentioned in their stories and the relationships between those persons. So, the women and I could see the picture that the women had developed of their journey. I then asked the women to map their networks, based on their perceptions. I asked them to draw their significant supporters into a network diagram and also depict the relationships between them. Further, a network discussion in relation to the network maps created was conducted to gather each woman's description of their network and the relationships within it. Over that time, the drawing of the map unlocked further thoughts about their network and as they talked about these using their maps, some women made additions to the maps based on these emerging memories. Some central women did not make changes in their maps, while others developed their networks by editing.

***Phase of withdrawal from the field***

Before I withdrew from the field, I gave each woman (including some network members) my preliminary findings on their own networks. I used their network map with a verbal explanation to confirm my interpretation of their network experiences. Furthermore, I re-informed the women about the process of writing the dissertation and reconfirmed their permission to publish and disseminate the study findings. I expressed my appreciation and thankfulness to all participants, relevant persons and health professionals I met during fieldwork before leaving.

Data collection activities throughout all stages of fieldwork are described in Table 3.6. The numbers of visits per case varied, while periods of data collection ranged from three to ten months. Latter cases tended to be visited fewer times, and latter cases tended to be shorter than the early cases. These differences reflected the development of my fieldwork skills and different degrees of case complexity. Moreover, concurrent data analysis and data collection meant that the preliminary themes that evolved from the early cases guided data collection in the latter cases.

**Table 3.6**  
*Data Collection with 11 Cases in Fieldwork*

Case no.	1	2	3	4	5	6	7	8	9	10*	11*
Number of visits	20	10	18	18	10	7	9	8	5	7	6
Approximate periods of time (Months)	10	10	7	7	6	4	4	4	3	3	3
<b>Methods of data collection</b>											
Individual interviews	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Group interviews		✓			✓	✓					
Non face-to-face interviews			✓	✓				✓			
Observations	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Participatory observations	✓		✓	✓						✓	✓
Photos		✓									
Document review	✓			✓							
Mapping	✓	✓	✓	✓	✓	✓	✓	✓	✓		

\*The issue of interest of case no.11 and 12 was focused on the women’s experiences in breast cancer club participation; hence, mapping was not conducted in these cases.

During these data collecting activities, the interview transcripts, field notes, and maps related to the participants’ experiences of personal social networks and its context were gathered. The next step was the analysis of these materials. The goal was to find the key dimensions of

the personal social networks from perspectives of all the women with breast cancer that took part in the study.

## **Data analysis**

Data analysis was informed by the research purpose and methodology. Understanding the nature of women's social lives through a collective case study informed by a qualitative approach means that a holistic analysis of the complexity of each individual case was the first priority, while a synthesis of patterns among these networks was also a study objective. To reach these goals, the common processes of qualitative inquiry were required, that is overlapping phases of data collection and analysis. The analysis process began the first day I arrived in the setting and continued past the completion of data collection. Three strategies of qualitative data analysis were selected: i) Ongoing fine tuning by asking the key questions, ii) Individual case analysis, and iii) Collective case analysis.

### ***Ongoing fine tuning by asking the key questions***

In fieldwork, ongoing interactive processes between gathering data with richness and initial analysis of data is necessary to share construction of reality between these two procedures (Erlandson, Harris, Skipper, & Allen, 1993). As a result, research processes and questions were continuously refined throughout this study. I modified the key questions that Erlandson et al. proposed for naturalistic inquiry in order to adjust the process and/or shape further research questions. Following each data collection procedure and also the end of every day in fieldwork, I reflected on the following questions:

- *What did I learn from this respondent that will shape my questions for the next respondent?*
- *What additional questions do I have for this respondent now? (or for a follow-up interview).*
- *Do I need more respondents/cases?*
- *What are the major dominant points emerging from each data collection procedure?*
- *How can I modify my data collection techniques to amplify, extend, or shape my research questions?*
- *How can I be more efficient and effective in collecting and analysing data?*

For example, I wrote my researcher diary:

...After working on data collection for around 2 months, I could see a heap of data.

What themes and patterns came up from data gathered of case 1

- i. Her background and circumstances were gathered
- ii. Phases of her journey with breast cancer
  - Pre diagnosis
  - Diagnosis
  - During receive aggressive treatment
    - Mastectomy
    - Chemotherapy
- iii. Changes related living with breast cancer (what, why, how)
  - Physical
  - Emotion
  - Life style
  - Everyday living
  - Working life
  - Social life
  - Family roles and functions
- iv. The effects of Breast cancer to her family members (including her parents and siblings)
- v. Pattern of seeking information related to health
- vi. Pattern of her (and her family) decision/utilization of health care and influential factors
- vii. Significant supporters

### **Questions**

- i. Why and how/how much is those supporters important (based on her perception)?
- ii. What does she call “social networks” (groups of persons with whom she has been in contact since living with breast cancer).
- iii. What, why and how does she mean by “my cancer is cured”?
- iv. How does she perceive about the formal social networks and why?  
(Researcher diary: 25<sup>th</sup> November 2011)

### ***Individual case analysis***

The intensive study of individual cases is the approach which has the potential to give insight into the nature and complexity of the women’s social life experiences. To analyse four types

of data of each case—transcripts (verbatim), field notes, word documents, and network maps, content and thematic analysis were utilised as described by Thorne (2000) to generate the description and conceptualisation of the women's social networks.

As the personal social networks of the women in southern Thailand are unique and little is known about them, a data-driven code was chosen for theme development. Boyatzis (1998) proposed an inductively constructed coding procedure for the raw information. He provides three stages for generating the coding for both within and across (sub) samples/cases; i) sampling and design issues, ii) developing themes and a code, and iii) steps in validating a code. However, a data-driven code is highly sensitive to the contextual information, so inter-rater encoding with a supervisor was employed to validate the coding that I used in this part of analysis.

Further, thematic analysis was used to discover patterns of network characteristics and development. Thematic analysis is the way of seeing the pattern through the process of encoding the qualitative information (Boyatzis, 1998), while constant comparative analysis is the general approach that conceptualises the possible relations among various pieces of data (Thorne, 2000).

### *Cross case analysis*

Stake (1995) calls the process of searching for consistent patterns among multiple cases as “correspondence”. Patterns can be seen immediately during data collection, or emerge during the analytical processes such as coding or pattern synthesising. Nevertheless, within a single case consistent patterns can be seen from their repeated appearance. The analytical techniques which empower the search for correspondence in collective case analysis can be content, thematic and constant comparative analysis as patterns can emerge from both direct interpretation and codes. Notably, Stake says while we are trying to understand a particular case, a sense of correspondence should remain in the researcher's mind. I adopted Stake's cross-case procedure for multiple case analysis. He argues that “the main activity of cross-case analysis is reading the case reports and applying their findings of situated experience to the research questions of the Quintain [case]....” (Stake, 2006, p. 47).

## Research trustworthiness

Trustworthiness is a key term which is used to consider the quality of qualitative research findings. Lincoln and Guba (1985) identify four criteria for establishing the trustworthiness of a qualitative study i) credibility, ii) transferability, iii) dependability, and iv) confirmability. A comparison of conventional, naturalistic inquiry and the naturalistic techniques for establishing trustworthiness are summarised in Table 3.7.

**Table 3.7**

*Establishing Trustworthiness: A Comparison of Conventional and Naturalistic Inquiry*

Criterion	Conventional Terms	Naturalistic Terms	Naturalistic Techniques
Truth value	Internal validity	Credibility	<ul style="list-style-type: none"> <li>• Prolonged engagement</li> <li>• Persistent observation</li> <li>• Triangulation</li> <li>• Peer debriefing</li> <li>• Member checks</li> <li>• Reflexive journal</li> </ul>
Applicability	External validity	Transferability	<ul style="list-style-type: none"> <li>• Thick description</li> <li>• Purposive sampling</li> <li>• Reflexive journal</li> </ul>
Consistency	Reliability	Dependability	<ul style="list-style-type: none"> <li>• Dependability audit</li> <li>• Reflexive journal</li> </ul>
Neutrality	Objectivity	Confirmability	<ul style="list-style-type: none"> <li>• Confirmability audit</li> <li>• Reflexive journal</li> </ul>

(Source: Erlandson, Harris, Skipper, & Allen, 1993, p. 133)

With regard to the four criteria for establishing the trustworthiness of a qualitative study, I integrated its concepts and techniques to maintain the study quality. Table 3.8 shows the relationships between these techniques, results and demonstrations of trustworthiness in this study.

**Table 3.8***Trustworthiness Techniques, Results and the Study Demonstration*

<b>Technique</b>	<b>Results</b>	<b>Proposed Demonstrations</b>
<b>1. Prolonged engagement</b>	<ul style="list-style-type: none"> <li>• Build trust</li> <li>• Develop rapport</li> <li>• Build relationships</li> <li>• Obtain wide scope of data</li> <li>• Obtain accurate data</li> </ul>	<ul style="list-style-type: none"> <li>• 11 months in the field</li> <li>• Three to ten months each case</li> </ul>
<b>2. Continual observation</b>	<ul style="list-style-type: none"> <li>• Obtain in-depth data</li> <li>• Obtain accurate data</li> <li>• Sort relevancies from irrelevancies</li> </ul>	<ul style="list-style-type: none"> <li>• Purposeful, assertive investigation with (non) participatory observations from six to twenty times each case</li> </ul>
<b>3. Triangulation</b>	<ul style="list-style-type: none"> <li>• Verify data</li> </ul>	<ul style="list-style-type: none"> <li>• Using different or multiple methods of data collection</li> </ul>
<b>4. Referential adequacy</b>	<ul style="list-style-type: none"> <li>• Provide a “slice of life”</li> </ul>	<ul style="list-style-type: none"> <li>• Using different materials such as photos, documents, maps</li> </ul>
<b>5. Peer debriefing</b>	<ul style="list-style-type: none"> <li>• Test working hypothesis</li> <li>• Find alternative explanation</li> <li>• Explore emerging design and hypothesis</li> </ul>	<ul style="list-style-type: none"> <li>• Formal or informal discussions with a peer (and supervisors)</li> </ul>
<b>6. Reflexive journal</b>	<ul style="list-style-type: none"> <li>• Document researcher decisions</li> </ul>	<ul style="list-style-type: none"> <li>• Self-reflection records (in field notes and researcher diary)</li> </ul>
<b>7. Thick description</b>	<ul style="list-style-type: none"> <li>• Provide data base for transferability judgments</li> <li>• Provide a vicarious experience for the reader</li> </ul>	<ul style="list-style-type: none"> <li>• Transcripts, field notes, photos, maps, and documents</li> </ul>
<b>8. Purposive sampling</b>	<ul style="list-style-type: none"> <li>• Generate data for emergent design and emerging hypothesis</li> </ul>	<ul style="list-style-type: none"> <li>• Using purposive, theoretical, and snowball sampling techniques</li> </ul>
<b>9. Audit</b>	<ul style="list-style-type: none"> <li>• Allow auditor to determine trustworthiness of study</li> </ul>	<ul style="list-style-type: none"> <li>• Transcripts, field notes, diaries, photos maps, self-reflecting records</li> </ul>

## Conclusion

This collective case study was designed based on qualitative approach to develop the necessary in-depth understanding of the personal social networks of women living with breast cancer in the unique contexts of the lower southern region of Thailand. During the 11 months of the two periods of fieldwork, 11 central women and 30 significant members of their networks were involved in multiple methods of data collection. Longitudinal data were collected from these participants related to the shape of their networks and individual contexts. By using within and cross case analysis with these network data, the uniqueness of contexts, unique patterns of living with breast cancer and the characteristics and development of these participants’ support networks will be examined throughout the next chapters.

## CHAPTER 4

### The contextual findings

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#### **Introduction**

The focus of this study is how the networks of women living with breast cancer in the lower southern Thailand region were formulated and conducted in relation to their varied circumstances and within multiple contextual levels from nationwide to personal. This chapter will foreground the contextual findings based on a cross case analysis of the women's journey, while the three chapters that follow will provide detailed description and discussion about characteristics of the individual cases. Accordingly, Chapter 4 will introduce the macro and micro-level circumstances that interacted with the women's networks throughout their journey. These circumstances relate to living with breast cancer in the region within the levels of health system, community and family. Finally, two structural patterns of living with the breast cancer journey related to the disease and its treatment patterns will be introduced.

#### **Living with breast cancer in the lower southern region**

Several factors were identified from the data as having the greatest impact on the features of the central women's networks. These were the health system related to breast cancer care; the central women and their supporters' residences; careers; and family circumstances. The dominance of each of these factors, and the differences that created the uniqueness in both the structure and function of networks, are described in the following chapters.

#### **Health system related to breast cancer**

Two unique characteristics of health systems were observed as influential to network characteristics in this study. These characteristics were a unique pattern of health service organization and the traditional and alternative health services in this region.

### *Health service organization*

Once the central women began their involvement with health settings for breast cancer investigation, diagnosis, and therapies, the organisation and structure of the health service became one of the significant circumstances affecting their network. As outlined in Chapter 1, the Thai health system for breast cancer care is complex and service patterns differ in each setting; hence all of the women needed significant personal support to facilitate service accessibility. As previously discussed, women under different health financial support programmes had differing eligibility to access health settings for breast cancer care. However, because the breast cancer treatment courses are long-term and high cost, none of the central women used private health insurance or paid for their own private care.

All of the central women noted the complexity of interacting with the health system. For example, some central women had to initially access the district hospitals where they were registered for health care, even though these settings were unable to provide breast cancer investigations and/or treatments. Subsequently, these women were referred from their registered settings to a higher-level setting for mammography. Additionally, both the physical distance to services and unfamiliarity with the services of the settings the women were referred to were perceived as potential barriers to the access of care. Furthermore, the central women with an advanced stage of cancer on diagnosis required access to more advanced treatments that could only be provided at a few tertiary settings, as illustrated in Figure 1.2. The number of times that women were referred to higher level services to receive ongoing care created complexity for the networks supporting those central women (See case 5 in Chapter 5; cases 4 & 9 in Chapter 7).

The Thai health system provided the framework for breast cancer services in the region, however, the setting-based patterns of cancer services differed between hospitals. These differences impacted on the level of support required by the central women from their networks, in particular while undergoing investigations and treatments. The differences in service patterns are related to resource limitations and the high demand for breast cancer care. Staff shortage was one factor affecting service patterns. Two hospitals that provided treatment for central women each had two surgeons to deliver breast cancer investigations, surgeries and adjuvant therapies. These surgeons' responsibilities also covered other surgical patients. One of two tertiary hospitals did not have an oncologist, thus the surgeons managed the chemotherapy in that setting. Two provincial hospitals did not have an advanced practice nurse or nurse manager of breast cancer care. Furthermore, participants reported the impacts something I observed.

*APN “At the surgical clinic of my hospital [a regional hospital], two surgeons had to service approximately 120 cases a day, these included the breast cancer cases. On average, we had 30-40 cases a month coming for breast cancer screening and four to five cases were diagnosed with breast cancer. For the chemotherapy unit, last year we serviced around 1,000 visits with three nurses and two nurse assistants. Thus we have to have a good system and efficient coordination to flow patients from OPD to the chemotherapy unit as quickly as possible”.*  
(An advanced practice nurse of breast cancer, Int, p. 25)

The setting environment was observed to affect the patterns of service. For example, one hospital did not have a chemotherapy unit (although it was included in the hospital development plan). The central women, who received chemotherapy at this hospital, were therefore admitted as in-patients for treatment. In this hospital the bed occupancy was frequently over 100 percent and three nurses and two nurse assistants on a day shift and two nurses and two to three nurse assistants on a night shift provided care for 40 patients. The following excerpt describes a visit to a hospital ward to visit a participant admitted to receive chemotherapy and illustrates the expectation that those admitted would have family support in the hospital to assist with care.

I went to the surgical ward of a hospital to visit *I.a* [the central woman of case 1]. This admission was for her fourth cycle of chemotherapy. At around 6pm, I was in front of the ward and tried to find *I.a*. I saw the area inside the ward was full of beds with patients and some patients were on a respirator. Similarly, more than 10 beds with patients were placed in a walkway surrounding the ward and one of them had *I.a*. Before I headed to *I.a*, I heard somebody call my name - it was *I.c* (*I.a*'s sister) calling. She was helping another breast cancer patient walk back from a toilet to bed. She said as patient's husband had gone out for an hour then she helped her instead. She pointed me to where *I.a* was and said she was her sister's caregiver here and tonight she would sleep beside her sister's bed and showed me her sleeping accessories brought from home. (C1, Fn, 4<sup>th</sup> visit, hospital)

The need for family support to assist in providing care in the hospital was made more complex because of the different ways that the breast cancer services were provided. Through my fieldwork observations, I observed four differing patterns of breast cancer services at health settings attended by the study participants (See Appendix II). Differences in service patterns were found, particularly, in relation to investigation and chemotherapy management. Some hospitals managed breast mass biopsies as outpatient cases, while others admitted women requiring this procedure as in-patient cases. Participants reported two differing patterns of chemotherapy cycle management, a 21-day cycle (one hospital visit for each cycle) and a one-month cycle (two hospital visits for each cycle) (See Appendix II).

The differing patterns of service delivery contributed to differences in support needed by the central women while undergoing investigation and therapy. Participants reported many difficulties in service accessibility and management, including lack of confidence to use unfamiliar services, referral delays, expanded work leave, extra expenses required for travelling and daily living, and a high need for personal support. Formal breast cancer services were delivered without reference to traditional or alternative health services that the central women or their supporters might choose to access. However, for the women and their supporters, traditional and alternative health services were important part of their breast cancer journey.

### ***Traditional and alternative health services***

Traditional and alternative health services relevant to breast cancer are predominantly offered in informal health settings<sup>9</sup>. They comprise many levels of care from self-care to cure within both modern (western) and traditional approaches such as supplement consumption, homeopathy, bio-organic consumption, manipulative methods (such as massage, osteopathy), body and mind interventions (related and non-related to religion such as yoga, meditation), energy therapies (such as Reiki, therapeutic touch), folk medicine (such as herbal medication, supernatural performance, and integration of herbal medication and supernatural performance).

*4.a “While I was waiting for treatments, much information related to alternative remedies came to me. Many cancer friends gave me information about traditional therapeutic settings they had been to get alternative procedures. Some of them went to \_ [a village in her hometown]. Have you have heard about this? Many cancer patients went there but I don’t go there. All cancer friends asked me what things I use as an adjunct to the hospital treatment and I said ‘none’ as I don’t believe in this way. I rely only on treatments by the hospital doctors...//...Some of my cancer friends were absent from the hospital because they were not able to keep going with the hospital treatments which brought such long term suffering. They changed to undergo the traditional remedies instead”. (C4, central woman, Int, 8<sup>th</sup> visit, p. 11)*

Many central women used traditional and alternative therapies through informal settings. This seems a normal way of life for many local Thai people to seek hope, as illustrated in the field notes below. Some folk therapists deliver their treatments without licences and/or without requesting a fee.

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<sup>9</sup> **Informal health settings** in this study mean the places that deliver health care, therapies to clients without registration and with or without fees.

I went to one setting of alternative therapy that was attended by the central woman of case 1. This setting was a therapist's house which was located in a remote area of one province and treatments were provided by a man who claimed to be a therapist (without licence). The treatments provided included herbal remedies, blessed water, and sacred objects. I reached this setting at around 11am and at that time it was crowded. Many patients (with their caregivers) were there both by themselves and in groups. They were queued to receive remedies. I heard from dialogue between people who were waiting for treatments that some of them had cancer. All patients were from diverse living places, careers, and age. However, the similarity was they came to this setting because the treatments' reputation had spread widely by word of mouth... //

...One car drove to the setting; a man came to the therapist and told him that he had brought his father, but his father was in his car as he was not able to move to a shelter. Next, the therapist spoke to other waiting patients, asking for permission to treat that man first. Then the therapist headed to the car and treated the disabled man in the car for 10 minutes and then he came back to the shelter to treat other cases...//

...I conversed with one person who came from another province, approximately two and a half hours drive, for her chronic infection therapy. She said she was treated by a hospital doctor for a while but her wound didn't get better. Then it was suggested by a close person that she try the treatment here. After the first time she was treated by this therapist, she felt her wound healing was improved. Thus, this was her second visit... After delivering therapies, a set fee was not asked from clients, the fee payment and its amount depended on clients. However, I saw most of them put money-at least 20 baht - in a big bowl (NZ\$1.00 is around 26 ฿). (C1, Fn, alternative health setting used by the central woman, 17 January 2012)

In summary, the Thai health system was created for all Thais to achieve equity of health care including breast cancer care. However, many limitations in health resources and physical geography have to be overcome; the setting-based breast cancer services were complex and varied in delivery patterns. Furthermore, alternative and/or traditional therapies were offered as an adjunct to formal health services, predominantly delivered in informal settings. Another contextual difference for the central women and their network members related to those people's residency.

## **Residential contexts**

The central women resided in the lower southern region in differing urban, suburban, and rural locations; and in differing relationship-based and religious-based communities as summarised in Table 4.1. Around a half of them lived in agrarian villages, while others lived in town, a city suburb, or inner-city.

**Table 4.1***Residential Contexts of the Central Women*

Case no.	Geographic locations			Relationship-based communities		Religious-based communities		
	Rural	Suburban	urban	Village	City	Buddhist	Muslim	Mixed
1	✓			✓		✓		
2			✓		✓			✓
3	✓			✓		✓		
4	✓			✓		✓		
5	✓			✓			✓	
6		✓			✓			✓
7		✓			✓			✓
8		✓			✓		✓	
9	✓			✓				✓
10			✓		✓			✓
11			✓		✓			✓

***Travelling patterns of urban and rural community residents***

Their place of residence impacted on the structure and function of their networks. The women who lived in urban areas reported that they spent 10 - 20 minutes to travel to their main hospital, but reported longer travelling times to the hospitals they were referred to in provinces. The central women who lived in rural areas travelled for more than half an hour to their hospitals. Furthermore, living in a suburb or town or city meant travel was more comfortable on public transport than for those living in rural areas. City travel was also cheaper and could be done independently as illustrated in the following quotation:

[This central woman's home was in town]

*2.a "My home is at \_ [a living area's name], it is just 10 minutes from this hospital. Today after I get my medication, I will go back home by public motorcycle. I don't need to drive to the hospital, as then I have no trouble about car parking. In the morning, my husband drove me by motorcycle from home and dropped me at the hospital, but I will go back home by a public vehicle". (C2, central woman, Int, 1<sup>st</sup> visit, p. 12)*

In contrast, the travel requirements for the rurally located central woman in the following quotation were considerable more difficult.

[This central woman's home was in her farmland in a rural area.]

*1.a* "For the next hospital visit, I think I will go there on my own [previously, her sons or her sister took her from home to hospital and brought her back home.] I will go there by the first minibus for students in the early morning. This bus will be crowded with school children [laughing]. After finishing the doctor's visit, I will go back home by this bus again and will walk from the main road to home, no problem it is not too far [laughing]". (C1, central woman, Int, 20<sup>th</sup> visit, p. 21)

Referral from their local hospital to higher-level hospitals in other areas for advanced investigations and/or treatments put an additional travel burden on rurally based participants.

[This central woman's home was in a rural area.]

*4.a* "I had to take off from home not later than 5am. I travel from home to town by a public motorcycle and then took the first taxi of a day to the university hospital (situated in another province). Sometimes, my sister drove me from home to the taxi station in town. A taxi driver dropped me at the hospital before 7am. Taking blood tests before 7am meant I could see my doctor at around 9 to 10 am and then my chemotherapy could start not later than 1pm. Around 20 minutes before my chemotherapy finished, I rang my taxi driver and he came to pick me up at the hospital at around 4.30pm. Then I would arrive in town before dark and got back home by public vehicle or with my sister". (C4, central woman, Int, 7<sup>th</sup> visit, p. 25-26)

In addition to the distance from health services, the type of community in which the central women lived also impacted on their network.

### ***Living patterns of village and city community residents<sup>10</sup>***

Many participants emphasised the social aspects of the communities in which they resided; in particular the relationships among community members. The central women who lived in agrarian villages were located in their birthplaces. This means the interactions and relationships among community members, including with the central women and their families, developed over generations. Hence, the rural-based central women more frequently reported feelings of closeness and support, both tangible and non-tangible, being voluntarily given by neighbours, than the women in city communities.

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<sup>10</sup> The term '**Village community**' is used to identify the characteristics of Thai village communities based on the concept of human relationships (Kemp, 1991). This term is used for Thai village communities in which members live together in traditional Thai life style with kinship, friendship, and neighbourhood as communal folk. In contrast, in a '**City community**', members live a more independent life style with few interactions and / or sharing in daily living with other members.

The other half of the central women lived in towns and inner-city areas, and a city housing estate. A feeling of closeness with community members was rarely mentioned in network conversations and a trend of placing the lowest degree of reliance on these community members was observed. The urban way of life had weaker ties within communities as evidenced in the following field notes.

[*2.a*, the central women of case 2 lived with her family in a rented house in town].

I had many visits to *2.a* at her home and I have not seen or heard her interacting with her neighbours. Today's visit was similar to previous visits. When I reached her home and parked my motorcycle in front of her house. I saw one neighbour was in the next-door house but she did not have any reaction at my arrival. (C2, Fn, 5<sup>th</sup> visit, home)

In other cases the central women and/or their families, who lived in village communities, had frequent interactions and close relationships with neighbours.

[At a grocery shop of *5.a*; a central women of case 5, in a village of rubber tree farmers]

I was sitting on a bench in front of the shop waiting for *5.a* to be free from her customers so I could conduct an interview with her. One elderly woman came to a shop and she asked who I was and why I came to her neighbour's (*5.a*) shop. Next, she told me that during *5.a*'s hospitalisation, she visited *5.a* at a hospital in town for two or three times depending on vehicle availability, as many neighbours wanted to visit *5.a* to encourage her... //

...When *5.a* was free from other customers, she started talking with this woman about the wedding ceremony of the woman's son that would be held the next week. *5.a* said she really wanted to participate in it but she still was not well enough, however, her husband and children would join in it... After the woman had gone, *5.a* told me that this neighbour seemed like a relative ... (C5, Fn, 4<sup>th</sup> visit, home)

However, length of residence in a place was a factor, as one woman who lived in a city suburb revealed different experiences with her neighbours. She had lived in this community for more than 20 years. Her neighbours were providing emotional and information support to her and her family, particularly those neighbours who had lived in the community as long as her family (See case 8 in Chapter 6).

### *Living patterns of Buddhist, Muslim, and mixed community residents*

The 11 central women lived in differing religious-based communities. Three women lived in traditional Buddhist villages, one lived in a traditional Muslim village, one Muslim woman lived in a traditional mixed religious village; however, only Muslim residents lived in her

zone of the village. One Muslim woman lived in a city suburb of a Muslim community. Two women lived in a city suburb, however they came from a traditional Buddhist village, and most of their relatives still lived in that village with its traditional Thai Buddhist lifestyle. Four women lived in a city centre or city suburbs in mixed religious communities, where religious-related values do not predominantly influence members' social behaviours.

#### *Patterns of residential distance of significant supporters*

The residential locations of significant supporters of the central women also impacted on network characteristics. Four patterns of distribution of supporters' locations were observed. **The first pattern** was that most significant supporters lived close to the central women. The central women's family, most siblings (and their families), some relatives and close friends lived close to the central women (See cases 2 & 5 in Chapter 5; case 8 in Chapter 6).

**The second pattern** was that some significant supporters lived far from the central women. The physical distance, especially between the central women and their main supporters, was associated with difficulties in providing support by networks. This was more obvious when urgent support was requested. This living pattern was observed in many cases (See cases 1 & 6 in Chapter 5; case 3 in Chapter 6; case 4 in Chapter 7).

**The third pattern** was that all significant supporters lived far away, but were in the lower southern region. In case 9, the central woman, who was single, had five siblings, but none of them lived close to her. Their living places were scattered around the lower southern area. Difficulty in support management by family members was observed. (See case 9 in Chapter 7).

**The fourth pattern** was that most significant supporters lived far away in another region. This residential characteristic was observed in case 7 where the central woman's birth town was not in the lower southern region. All of her relatives and some close friends lived at least 1,000 kilometres away. This distance created significant difficulties for the relatives trying to provide tangible support, particularly during the early phases of her journey (See case 7 in Chapter 6).

In summary, the networks in this study were formulated and developed in regional contexts that had four unique characteristics based on residential environments. There were i) three differing geographical types (rural, suburban, and urban areas), ii) two types of relationship-based communities (village and city communities), iii) three types of religion-based communities (Buddhist, Muslim, and mixed religious communities) and iv) four patterns for

the residential distribution of supporters. The occupations of central women and their supporters also influenced the development and functioning of networks.

## Occupational contexts

Many central women and their network members were of working age. Network members who were workplace members were identified as a significant supporter group for the central women. However, differences in job characteristics, resources and support can be discerned. Some of the central women were not in paid work. They were either elderly and/or housewives. These women tended to have a smaller group of potential supporters. Those working could be grouped into those self-employed and those employed by institutes. The employees of institutes include employees of private or civil organisations, staff of industrial companies, teachers, and nurses. The self-employed include small shop owners, farmers, fishermen, and market women. The key difference between these two sub-groups is the institute workers have formal support systems that belong to their workplaces and the ranking of their job, whereas personal support for the self-employed came from among their working friends and family.

[2.a, a teacher at a primary school]

*2.a “My school has a support system, like my class level has two classrooms and they are under the responsibility of two teachers like a partner of each other in working and \_ [name] is my teaching partner. If she or I have to leave from work, the other one will cover two classrooms at the same time... During receiving chemotherapy, I had difficulty working on a computer and ...\_ [her close friend’s name] helped with typing, such as doing annual reporting”. (C2, central woman, Int, 6<sup>th</sup> visit: p. 5)*

As illustrated in the quotation above, the institute workers tended to have support by systems and by personal relationships. In addition, the health professional and health-related workers had an even higher potential of support related to their career-related resources (See case 3, Chapter 6). In contrast, the self-employed central woman in case 8 discussed below was dependent on family and friends or customers for support.

[8.c, a mother of the central woman who was a market woman]

*8.c “Yes, I sold my daughter’s seafood instead of her. After her husband finished fishing, he carried his products to the market and I sold them beside my goods. ... Many friends and customers at the market asked me about her sickness and told me about remedies [alternative therapies] for cancer patients that they had heard of or they had experienced ...” (C8, mother, Int, 1<sup>st</sup> visit, p. 25)*

Accordingly, occupational context was one factor that influenced the quality and quantity of a resource segment of networks for living with breast cancer, and one that influenced the characteristics of networks.

## **Family contexts**

The family is a significant part of networks in normal life. Information about families can give an indication of the potential human resources the central women have, and the normal roles they carry out in their everyday living. As well, potential persons who may be able to perform supporter roles and what facilities and barriers exist for the provision of support can be identified. In all cases, family groups were identified as the most significant group of supporters and participants always included family members with relationships both by blood and marriage. Accordingly, the size of the central women's families and living patterns will be discussed in this section to reflect the family-related resources and capability in networks. Family-related responsibilities have a significant effect on the degrees of complexity of daily living.

In half the cases, the central women lived in families of two members and in two of these cases the sixty-year-old central women lived with older spouses. In two cases the families comprised three or four members. A family of seven belonged to the two central women who were siblings and lived together in an extended family. This family included the two women, their parents and the younger sister's family (See case 3 in Chapter 6; case 4 in Chapter 7). Other families lived separately from their parents in a nuclear family situation. This arrangement is a change from the traditional Thai way of life where large and extended families were dominant.

Most central women came from quite big families of five to ten children, with the exception of one woman who had only two siblings. Additionally, three central women identified relatives who were so close in relationships that they felt them to be their quasi-family. Prominently, all participants claimed good relationships and connections among their families related by blood and these good relationships continued during their journey with cancer. However, some siblings in families had passed away or lived far away from the central women. So the potential for more support from a larger family could not always be realised. Furthermore, in one case a significant supporter lived away periodically for work (See case 6 in Chapter 5).

#### *Four living patterns based on family responsibilities*

Differences in family types influence family responsibilities, roles, affecting resources and difficulties in support. The central women's families can be categorised into four types based on family responsibilities.

**First**, there is a category of families without children; this category includes a family of a married woman living with her husband (See case 7 in Chapter 5) and a family of an unmarried woman living with her unmarried sister (See case 11 in Chapter 7). These families had fewer responsibilities in the family compared to other patterns but also had more limited family support resources as well. **Second**, a category of families with children was common. If the children were young, they were still dependent on their parents and had lesser abilities to provide tangible support to other members. (See case 8 in Chapter 6). The teenage children were less dependent on parents in their everyday living; however, they still needed some support for other issues such as their study (See cases 2 & 6 in Chapter 5; case 3 in Chapter 6). However, they were able to provide some support to others. In contrast, adult children were less dependent on their parents and had the highest ability to provide support to them. (See cases 1 & 5 in Chapter 5). **Third** is a category of family with elderly parent(s); a higher dependence on adult children was observed if the parents were elderly and /or sick. (See case 9 in Chapter 7). **Lastly**, there is a category of families with elderly parents and more than one member with cancer. The family members had to perform supporter roles parallel with the patient role over a long period of time (See cases 3 in Chapter 6; case 4 in Chapter 7).

In summary, most central women lived in a small family but came from a large family with good connections. These characteristics of family contexts reflected that most central women had a small number of resources in their family related by marriage; however, they had a larger number of resources in their family related by blood. The responsibilities in each family varied, in relation to differing family structures and living patterns. Another factor that influenced the networks related to the features of the central women's breast cancer journeys.

#### **Structural patterns of the breast cancer journey**

Two structural living patterns related to breast cancer treatments and management were observed associated with the network lifecycle (further described in Chapter 8). The two patterns of living with breast cancer can be described as a cyclical process (loop) of living

with the first diagnosis and a loop of living with a recurrence diagnosis as shown in Fig. 4.1 (This recurrence pattern was developed from the experience of only one woman and her network members).

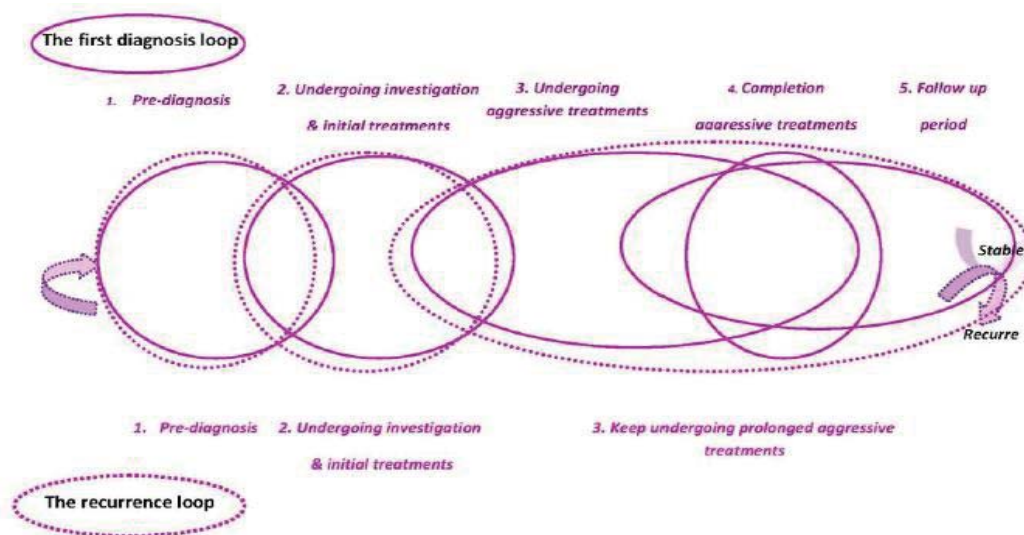


Figure 4.1. The two patterns of living with breast cancer.

The loop of living with the first diagnosis of breast cancer consists of five phases (See the pink solid line of Fig. 4.1). First, the pre diagnosis phase is the beginning phase of the breast cancer journey, when the central women first identified signs or symptoms which could be related to cancer. During this period of time, these women were living with their potential cancer and the end of this phase is when they and/or their supporters had decided to move further to investigate their lump. **The phase of undergoing investigations +/- initial treatments** is the second phase of this loop. During this phase, the central women and their network members started engaging with the health sector for investigations and then waited for the results of those investigations. It includes first diagnosis of breast cancer, and for some women, initial treatments such as lump excision, chemotherapy, and/or radiation therapies (before surgery). These initial treatments were delivered to prepare the women for future aggressive treatments.

**Undergoing aggressive treatments** is the third phase of living with the first breast cancer diagnosis. The length of the third phase depended on the course of aggressive treatments designed for each woman and how well the women were able to keep going with their aggressive treatments. Aggressive treatments could be breast surgeries, chemotherapy and/or radiation therapy, individually or in combination. During this phase, the women and their

network members focused on the preparation of both body and mind for aggressive treatments, getting aggressive treatments, recovering from the aggressive treatments and their side effects and then preparing the body and mind again to be ready to get the next aggressive treatments. However, in general the doctor had planned and told the women how many kinds and doses or cycles of treatments they would be given. The phase of undergoing aggressive treatments thus was the period of keeping going and counting down.

The fourth phase of the journey of living with the first breast cancer diagnosis was labelled as **the phase of completion of aggressive treatments**. It was not a long period of time but it was a precious one. The women and their network members were living with the moment of the end of the hardest period (aggressive treatment), a time when they realised one treatment routine was over and they had thoughts about what to do next. Some women intended to keep going with the mainstream therapeutic approach, while others were thinking and/or seeking and / or using for alternative / traditional treatments as an adjunct to the mainstream therapies.

Finally, if the disease remained under control, the women had to keep going with up to five years of follow up, with or without hormonal therapy. Therefore, the women and their network members were living in **the phase of follow up** in their everyday lives. Nobody knows whether the signs and symptoms will recur during this period of time. Some women, unfortunately, do get a recurrence diagnosis. Experiences of the recurrence case had a different pattern compared to the first breast cancer diagnosis loop.

Three phases in the **Loop of living with recurrence of breast cancer** were identified. As there was only one woman with a recurrence, this limits the inferences that can be made. The beginning phase for the breast cancer recurrence loop is a **(re) pre-diagnosis phase**. When the woman re-recognised symptoms related to her breast, the woman and her network members spent a period of time living with the anomaly until the woman decided to engage with the process of re investigating her disease.

Next, the woman and her network members' experiences moved to **the phase of (re) undergoing investigations +/- initial treatments**. The woman who developed breast cancer-related symptoms during her follow up period had to undergo investigative procedures and then she and the network members waited for the results. After the woman was diagnosed with a recurrence, living with the initial treatments to prepare for the further aggressive treatments restarted again.

Further, to control metastases, the woman and her network members were living with

prolonged aggressive treatments. **The phase of undergoing prolonged aggressive treatments**, thus, was a specific phase of this loop as the woman and her network members did not know when this phase would finish. The circle of getting aggressive treatments; particularly cycles of chemotherapy, and recovering from the treatments and side effects was replicated again and again to protect the woman from further metastasis. Accordingly, living with cycles of aggressive treatments became a part of the woman's everyday life.

During the study, all of the central women had passed through the phases of i) pre-diagnosis, ii) undergoing investigation +/- initial treatments and iii) undergoing aggressive treatments. Two women were in the phase of completion of aggressive treatments and at the end of my fieldwork, more than half women were in the post treatment phase. Only the woman with recurrence was undergoing prolonged chemotherapy. Additionally, two central women were permanent members of the breast cancer club with regular attendance for around five years. Their club engagement was to support both themselves and others.

## **Conclusion**

In this chapter, the contextual circumstances in the study setting that range from family, community, and system levels had been described as the complexities impacted positively and negatively on personal support provision and needs and therefore the shape and function of the network. The next two chapters, then, will detail eleven networks within four categories regarded to the uniqueness of networks and/or their circumstances through each network vignette. Further, cross-case analysis of dynamic development of personal social networks will be discussed in Chapter 8.



## CHAPTER 5

### Living with mature support networks

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#### Introduction

The journey of living with breast cancer is more complicated than that of daily life. This journey comprises a series of critical periods, such as getting the diagnosis of a threatening disease and undergoing long-term aggressive treatments such as chemotherapy. It also includes times when living became disrupted because of hospital visits and hospitalisation. The central women and their network members had to balance the activities of normal living, family and work, in parallel with extra activities related to the central women's breast cancer journey. The networks mostly evolved naturally to support the central women and their significant caregivers and continued functioning throughout the experiences of living with breast cancer in varied circumstances (as revealed in Chapter 4). These expanded networks later became integrated into the networks that existed prior to the women's breast cancer illness.

However, each case has its own story. When analysing individual cases, the longitudinal network data provided the unique qualities of the inter-linkages among the multiple levels of each network's circumstances and the interplay between the unique features of networks as a whole and their circumstances. In Chapter 5, 6 and 7, I aim to convey the intense and holistic life experiences of the unique cases to bring deeper comprehension about these networks. Networks that were rich in support resources, both tangible and non-tangible, and well functioning to encompass diverse and dynamic needs of support of the woman and their relevant persons in any situations through the journey can be observed from many cases. These networks were categorised as '**mature support networks**'. In this chapter, four cases, presented as vignettes, were selected to elaborate on the core characteristics of living with mature support networks and the unique network characteristics of contextual interactions are described and discussed.

## Case 1: An older adult farmer from a family with a traditional Thai living style

**Table 5.1**

*Information of Case 1's Participants and Data Collection*

<b>Key participant</b> <sup>11</sup>	<i>I.a</i> : A farmer in her sixties living with her older farmer husband in a traditional Thai village
<b>Cancer and therapies</b> <sup>12</sup>	Second stage breast cancer, diagnosed three months prior to study participation  Total mastectomy with partial lymph node removal; eight cycles of chemotherapy, and followed by five years of oral hormones
<b>Financial support programme</b> <sup>13</sup>	The programme of civil service welfare
<b>The referral participants</b> <sup>14</sup>	<i>I.b</i> : the central woman's husband <i>I.c</i> : the central woman's younger sister <i>I.d</i> : the central woman's sister in law
<b>Data collection period and numbers of visits</b>	October 2011 to April 2012 and July to September 2012 Total = 20 At <i>I.a</i> 's hospital X 4; at <i>I.a</i> home X 11; at the parents' (and <i>I.c</i> 's) home X 3; at a neighbour's home X 1; and at <i>I.a</i> 's alternative care setting X 1
<b>Data collection methods</b>	Conversations, (in-depth) interviews, observations, participatory observations, and mapping

The central woman of this case was a farmer who developed breast cancer in late adulthood and lived with her older husband. She had a higher level of dependency on her family members, compared to other cases, because of their age, life experiences, their residential location in a rural village, and the residential distance of their two adult sons. However, the support provided by her family (related both by blood and by marriage), very much reflected the traditional Thai lifestyle. Considerable support was provided by this mature support family during her breast cancer journey.

*I.a* and her husband (*I.b*) lived in their farmhouse in a village, where they had spent most of their lives. Since they were born, both had lived in the traditional Thai way of life in big agricultural families with close relationships and sharing among family members. *I.a* was the eldest of seven children and her husband, the youngest of seven children. *I.a* had to leave school to look after her younger siblings as her parents had to work, thus, *I.a* spent only four

<sup>11</sup> The central women

<sup>12</sup> From the central woman's perspective

<sup>13</sup> See details of all Thai health financial support programmes in Chapter 1

<sup>14</sup> The network members who participated in the study with the central woman's permission

years at school, while her husband had five to six years in school and was a monk for seven months.<sup>15</sup>

When growing up, *I.a* and her husband were rice and rubber tree farmers, the same as their parents. Outside harvest seasons, *I.a* sometimes worked part time as a construction worker. When *I.a* married *I.b* they separated from their parents' families to build their own nuclear family on arable land in their village with a lot of support from her husband's two sisters. This couple had two adult children; however, the children lived in other regions. The elder, unmarried son worked in a city government office, one and a half hour's drive from his parents' home. The younger, married son, a farmer, lived an hour's drive away, closer to his wife's parents in a remote village.

As a common pattern of Thai family living, *I.a*'s parents, in their eighties, were living in their own home under the close care of *I.a*'s two younger single sisters. The parents and these two sisters had regular support and visits from other siblings (particularly, a younger sister, younger brother, and *I.a* and also their families) who, since marriage, lived with their own families. A brother has higher education compared to many siblings. Although, he had worked in another province, he and his family had better connections with *I.a* (and other siblings) because his family was still in this province and he and his wife (*I.d*) regularly visited the parents and also *I.a*.

Moreover, this sister in law—*I.d* was a hospital staff member for many years and one of her sisters and her niece were nurses at the provincial hospital. *I.a* explained to me about the important role of *I.d* for her (and other family members) as a health service navigator, consultant, and also facilitator when family used health services.

*I.a* "...Having *I.d*'s support, yep; helped me to use the health services of the hospital better than not having her. For example, she knows the doctors so she can talk or ask the doctors any questions. Moreover, I haven't needed to go to hospital in the early morning to book service queues because *I.d* will pick a queue card up for me, so I can go to hospital after 8am. If I didn't have her, I would have to go to the hospital around 5 to 6am to pick up a queue card, even though the doctor doesn't start his work until after 9am". (C1, central woman, Int, 6<sup>th</sup> visit, p. 5- 6)

Once *I.a* was diagnosed with breast cancer, even though it was not advanced and she was treated by only one doctor at a hospital in her hometown, this couple and their family realised that they would be unable to look after her alone.

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<sup>15</sup> In Thailand in the past, to be a monk was a path of erudition / education for Buddhist boys.

*I.a* “My husband can’t be my caregiver at hospital. He has never gone out from our village because he has severe car sickness. I know if he is with me at hospital, he can’t provide care for me. He will get high stress as he can’t do anything”. (C1, central woman, Int, 3<sup>rd</sup> visit, p. 10)

Accordingly, others (either their members or their family members’ networks) were either asked for more support or spontaneously provided it. The support needed for dealing with the breast cancer and its treatment included information, consultation, decision-making, health service accessibility and facilitation, and also personal care both during hospitalisation and at home. For example, when the woman wanted to access the breast cancer specialist, her brother provided the connection through his wife who was able to facilitate her access to the appropriate health professional because of her greater knowledge from working at the provincial hospital. Furthermore, to visit the doctor the central woman needed close family members to drive her and accompany her to the appointment and to help with communication, as with her level of schooling, she was not confident about talking to the specialist and fully understanding the information they expected him to provide.

*I.d* “When \_ [central woman] wanted to see the doctor I usually knew this because my husband [*I.a*’s brother] asked me via phone (as he was in other city) what *I.a* should do. Then, I suggested through my husband that she could go to see the doctor who was my hospital’s surgeon at his private clinic. ... I didn’t go with them. I just made the appointment for her and then she went to the doctor with her son”. (C1, sister in law, Int, 18<sup>th</sup> visit, p. 1)

*I.d* “When my husband consulted me about *I.a*’s sickness and the subjects were her disease and treatment, because I have no medical knowledge, I consulted my sister or my niece as they are both nurses. Then sometimes they gave support directly to *I.a*, or told me what I should do for *I.a*, or I passed their suggestions through my husband to *I.a* and/or her family ...” (C1, sister in law, Int, 18<sup>th</sup> visit, p. 7)

The two quotes above also illustrate that some of the support provided to the central woman was provided or facilitated by having other family members and the family members’ networks behind them. Occasionally, when her husband, who was her caregiver at home, was sick, additional support was required from her network members. More often, *I.a*’s siblings had to provide support to *I.a*’s husband because her two sons were living far away.

*I.c* “Two days ago, *I.a*’s husband was not well. She said he had a headache and was vomiting during the night and then was not able to work on the farm the next morning. That night, *I.a* rang her eldest son as she wondered if her husband might need to go to hospital. Her son suggested that she keep observing his symptoms first and if he does not improve her son will come back home. Fortunately, her husband got better and slept for a while. ... I think his food

*habit is not good enough so I will tell his son to buy some healthy food for him and I think he should go to the health centre in the village to check if anything is wrong with him....”*

*(C1, sister, Int, 14<sup>th</sup> visit, p. 5)*

Support provided by family was cover, as well, for the work that the woman and her husband would usually undertake on the farm that still needed to be done by the youngest son or occasionally by hired extra labour. Furthermore, involvement in normal social activities continued as much as possible. The woman's younger sister kept good connections between the relatives and undertook social activities that the central woman would have normally done, particularly those related to the group who had close relationships with the family. Other community activities were undertaken by the husband.

Additionally, community members with long-term relationships as quasi-kinships were also good assistants through her journey. One neighbour was identified by the woman as her closest friend, a relationship explained as kinship and also one of her significant supporters.

*I.a “I and \_ [name] are quite close, closer than other neighbours. Before getting this disease, I often went to her home because sometimes she had to leave her mother alone at home. Then I walked to there to look after her mother who had dementia. If she was away from home, she rang me to let me know ... Now, I am not well. Thus I don't feel able to go there. However, she still often rang me and asked about my sickness and what things I wanted her to buy for me from town...//...If we have any urgency, particularly if we are not well in the night-time and my sons would not come to us, I will ring or call this family first as I know they frequently said to us just call them if we need any help. They are so kind for us and for others too”. (C1, Int, 6<sup>th</sup> visit, p. 20)*

Similar to other cases, network members reported feelings of uncertainty related to the many issues that they needed to manage, particularly related to therapy outcomes. This uncertainty was intermittent for both the woman and some of her network members throughout all phases of the breast cancer journey, even when the cancer was, from health professionals' perspectives, treated. These feelings resulted from many factors including her doubt about the success of the therapies, the reactions of others and the unpredictability of the cancer itself. The quote below illustrates this woman's doubt and uncertainty, and the woman's lack of confidence in her ability to communicate with the doctor about her fears.

*[One month after the completion of her chemotherapy]*

*I.a “I wonder how successful the outcome of my treatment will be. My doctor told me that everything is fine now and I just have to take the hormone pills for five years. However, I doubt how he knows this at this time. There was no investigation procedure, like the investigation I*

*underwent before I was diagnosed with breast cancer. [But she had never discussed her doubts with her doctor]” (C1, central woman, Int, 16<sup>th</sup> visit, p20)*

Feelings of uncertainty were common in all cases and often led to the central women and/or their network members to seek information and/or resources related to alternative therapies. These therapeutic approaches were then used in some cases. In this case, the pattern of coping with the feelings of uncertainty was unique as the central woman had frequent access to, but irregular involvement with alternative health therapies. During our conversations, the woman and her sister disclosed that they, some of their family members and their neighbours, particularly the close and/or knowledgeable family members believed in the use of alternative therapies. They also used these therapies themselves or knew of others who did. Therefore, some network members provided information and advice about alternative therapies as part of their supporting role, in part to help manage the uncertainty about the outcomes of the breast cancer therapies. A clear pattern existed whereby use of alternative therapies was driven by the strength of feelings of uncertainty of both the woman and her network members.

*[During the period of receiving chemotherapy]*

*I.a “...last week I went to a traditional therapist in a remote area with my neighbour. My sister’s step-daughter told me about this therapist and that his treatment was not harmful and my sister had already been there to observe this therapy first. The therapist just uses incantation and a piece of vine to make the sick people get better. ... I asked my neighbour to go with me as he has a car [her sister does not have a car]. I don’t think this way can be the main treatment for me, I just hope for something to be able to assist the doctor’s treatments [hospital treatments]”. (C1, central woman, Int, 4<sup>th</sup> visit, p. 15-16)*

Around one month later this alternative therapy was discontinued as she thought it was not a treatment she could trust. Next, the woman tried herbal medication and homeopathy, again following recommendations of her brother who she regarded as more knowledgeable than her and he had friends and/or colleagues with the experiences of living with cancer and used alternative approaches. The feelings of uncertainty about the treatment outcomes recurred after her aggressive treatments were completed. The woman and her family members restarted seeking for information and resources of alternative therapies again.

*I.a “I have heard from many people about the traditional therapy ... and my youngest son’s mother in law went there for her sickness. The way the therapist treats the sick people is ... My son told me now his mother in law is very much better. This therapist is now very popular ... I asked my eldest son to take me there. He laughed and said I still want to go there next month*

*he will take me...". (C1, central woman, Int, 20<sup>th</sup> visit, p. 7)*

The access to and/or use of alternative therapies as an adjunct to the mainstream therapy was not only influenced by personal beliefs and direct and indirect experiences of the women, but also followed the recommendations of others who were close in relationships and seemed more knowledgeable and experienced than her.

*I.a* kept going through her breast cancer journey with good support from this long-lasting and mature network, which was able to encompass the woman's and her significant supporters' needs related to both the disease and normal living. Finally, *I.a* identified her personal social network during living with breast cancer as Figure 5.1. This map demonstrates the network which is family relationship based. Specifically, her doctor (**H1** in Fig. 5.1) was included as her network member, based on *I.a*'s perception that this doctor exceeded her expectations in the care he provided. Otherwise, even though, frequent access to alternative therapists existed in this case, none of them was counted as her network member.

Case 1

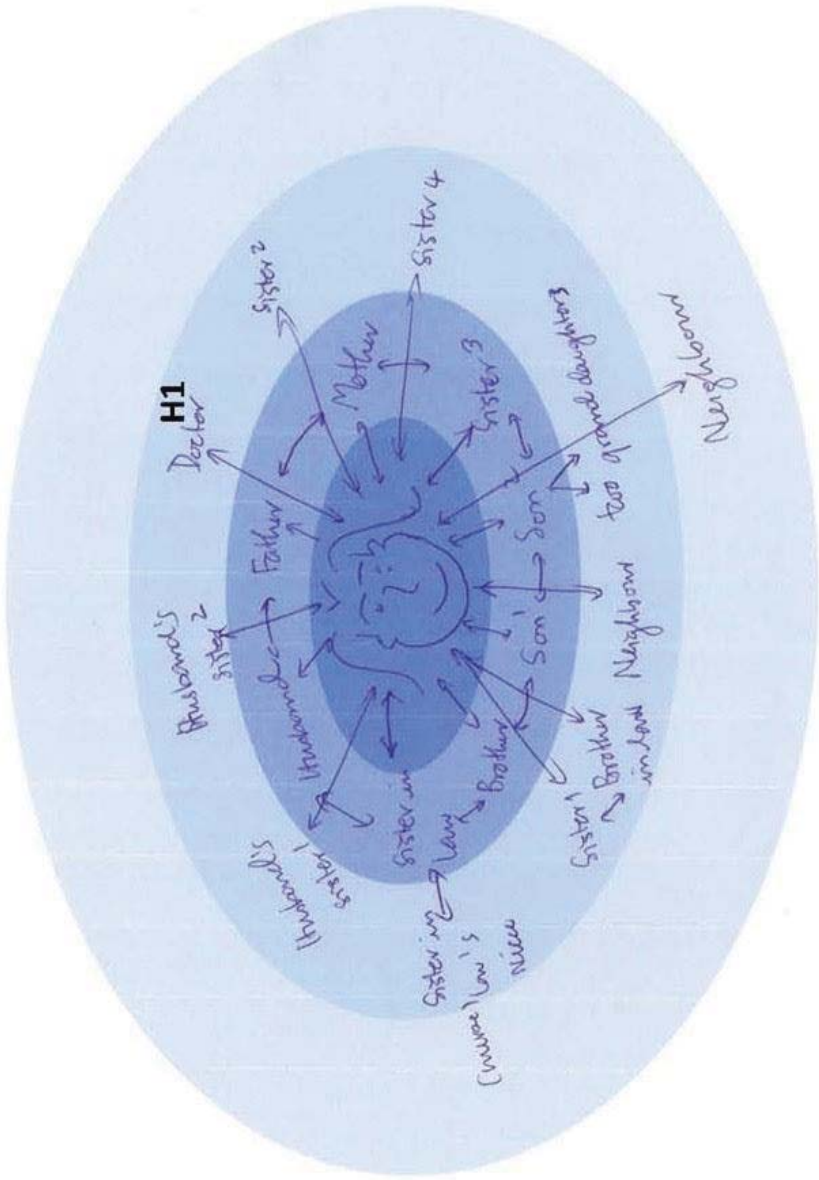


Figure 5.1. The network map of case 1.

## Case 2: A teacher from a quasi-extended family with cancer experiences

**Table 5.2**

*Information of Case 2's Participants and Data Collection*

<b>Key participant</b>	<i>2.a</i> : A forty-year-old married teacher in a family with a history of cancer
<b>Cancer and therapies</b>	First stage breast cancer without metastasis, diagnosed six months prior to study participation  Total mastectomy and four cycles of chemotherapy
<b>Financial support programme</b>	The programme of civil service welfare
<b>The referral participants</b>	<i>2.b</i> : the central woman's eldest sister <i>2.c</i> : the central woman's cousin <i>2.d</i> : the central woman's cousin <i>2.e</i> : the central woman's closest friend
<b>Time and number of visits</b>	October 2011 to April 2012 and July to September 2012 Total= 10 At <i>2.a</i> 's hospital X1; at <i>2.a</i> 's home X 6; at <i>2.a</i> 's school X 2; and at <i>2.b</i> 's home X 1
<b>Data collection methods</b>	Conversations, (in-depth) interviews, group interview, observations, and mapping

This woman's family had initial experiences with cancer twice before she was diagnosed with breast cancer. Even though she and her husband lived away from parts of her family, when she developed her breast cancer, her eldest sister and cousins (and their families) took over as her main caregivers and supporters in hospital and at home until treatment completion. Furthermore, as described in chapter 4 a group of her teacher friends were her significant supporters as part of her school support system, especially related to her job responsibilities. After her treatment was completed, her network members with close relationships were still supporting the woman and helping her to re-settle into normal life. Later, the woman developed her supporter role for another cancer patient.

The woman—*2.a*, grew up in a big farming family with five older siblings in a traditional Thai village. *2.a*'s mother died of cancer when *2.a* was ten years old. After that, her eldest sister—*2.b*—who was 20 years older than her, nurtured *2.a* and another sister as her own children. *2.a* and her sister told me that their family and her aunt's family (*2.c* and *2.d*'s family) had a very close relationship like an extended family. They lived physically close to each other and shared their everyday lives as the traditional Thai lifestyle. The sharing lifestyle continued through several generations to now. In adulthood, three of her siblings were married and lived away with their families on their farmland in remote areas. *2.b*—the eldest sister who was an unmarried farmer still lived at home as a caregiver for her father who had heart disease. *2.a*'s family had many experiences with cancer. After the mother's

cancer diagnosis, the second case was her sister, two years older than her. **2.b** again took over the main caregiver role for this sister until she died.

*2.b “I don’t want to think about it again as it has already passed...2.a was a high school student when her sister was diagnosed with cancer. The elder sister lived with her cancer around one year. She was so brave and never complained about her suffering. Her doctor first diagnosed her with cancer of the cervix and this was successfully treated. Then she got cancer of the hip. The doctor said her cancer originated in her hip but he didn’t find it that first time. She went back to work for several months after completing the treatment of cervical cancer. Then, she passed away not long after her second diagnosis. ...My mother was diagnosed with cancer of the liver (crying). You see, I’m an experienced caregiver for cancer cases”. (C2, sister, Gr. Int, 8<sup>th</sup> visit, p. 3)*

After graduation, **2.a** started work as a public school teacher in another province. She lived there for many years before moving to a job in her hometown. This meant that she was not close to her family’s relatives and their neighbours, unlike her siblings. Five years before **2.a**’s cancer diagnosis, she married a widower from a small family who had one teenage daughter. Next, **2.a** left her family to live with her husband and his daughter in their rented house in town.

**2.a**, in her late thirties, found a breast lump. She had initial investigations at a private clinic in town and then was referred to a provincial hospital for further investigations and treatment. She completed treatment and follow up with only one doctor at one hospital. A difference from case 1 is that initially **2.a** did not identify any need of support from family and friends to access to health care. This might be because she had previous experience with the doctor and breast conditions, however in the past it had been benign.

*2.a “When I found my breast lump, I went to my doctor’s clinic in town alone. I didn’t need any companion with me ... Why I chose to go there first? Several years ago, I used to visit this clinic as I found a lump in another breast. At that time, I was diagnosed with a breast cyst and the doctor treated me by a cyst excision”. (C2, central woman, Int, 2<sup>nd</sup> visit, p. 3)*

Accordingly, she was not expecting a cancer diagnosis. **2.a** said between finding her breast lump and getting her breast cancer diagnosis, she did not think about the possibility of cancer at all and she was able to access to the doctor for the lump investigation alone. Once diagnosed with breast cancer, she was shocked.

*2.a “When หมอ/Mor/ [the doctor] told me พี่/Pee/ [elder sister], you got เนื้องอก/Neau-raay/ [carcinoma]’, I felt numbness in my whole body. My brain immediately shut down as I was*

*shocked. ... I had never thought I would get cancer... At that time, I needed someone with me but I didn't ask a nurse to tell my husband to come to me..... I felt ใจแห้ง /Jai-hang/ [a heart was getting dried] for two weeks. I mean I had mental distress. I was so SAD. At that time, my heart had no moisture at all". (C2, central woman, Int, 2<sup>nd</sup> visit, p. 4-5)*

Accordingly, while undergoing treatments, **2.a** seemed highly dependent on her network, especially her family and friends for about six months. As this family, in particular the eldest sister, had experiences with taking care of cancer patients, her eldest sister—**2.b** (who was like **2.a**'s mother) took the position of main caregiver for **2.a** both in hospital and at home, throughout her cancer journey.

***2.b** "I never left her alone, I was with her every night at hospital and at home. I knew she needed me... .. How I knew that she needed me? When she woke up and didn't see me, she called me ' \_ [2.b's name] where are you?'... My brother in law [2.a's husband] was so poor, if I could know my sister will get cancer I won't allow them to get married. [R—I thought as his ex-wife passed away]. After surgery and after each cycle of chemotherapy I took her back to my home to look after her by myself. I planted chemical free vegetables to cook food for her. I looked after her until she recovered and then let her go back home living with her husband for a week and then prepared herself for the next cycle of chemotherapy". (C2, sister, Gr Int, 7<sup>th</sup> visit, p. 8-9)*

**2.a**'s network made adjustments in their normal lifestyles and maintained support within the family to help **2.a** accomplished her treatments. For example, a sister resigned from her part time job and altered her work schedule on her farm and rearranged her routine activities with her father. A lot of support was provided for the main caregiver by **2.a**'s husband, other siblings and their families, and their cousin—**2.c** and **2.d** (and their families) who identified as pseudo-family and also were living physically close. Significantly, this support was provided without any request.

***2.c** "If 2.b was with 2.a at hospital, I came to this house every morning to check their father's condition and asked him anything he wanted me to help such as food or other things. I came again in the evening to help him about dinner... What other things I did... encouraged 2.a to keep going with her treatment, didn't give up receiving it". (C2, cousin, Gr Int, 7<sup>th</sup> visit, p. 10)*

***2.b** "Some days, my nephew accompanied 2.a and me at hospital and he took me back home to prepare things for my father. ... When 2.a finished each cycle of her chemotherapy and she wanted to go home even though in the night time, I just rang to 2.d's husband at anytime and then he drove to hospital to collect us to home. He was such a kind person, he always ready to be our driver... yes without asking". (C2, sister, Gr Int, 7<sup>th</sup> visit, p. 13)*

**2.a**'s family, especially her eldest sister, seemed to provide resources and energy that **2.a** needed to carry on her breast cancer journey, particularly when undergoing aggressive treatments. This was also influenced by feelings of uncertainty related to the family's previous experiences with cancer.

*2.b "Since I have known about 2.a's breast cancer until the completion of her treatment, I didn't have a good sleep in any night. You see, cancer again happened in my family... I got difficulty in sleeping because of high stress. Every night, I kept thinking about her illness. I did chanting and praying for her...Nothing at all for myself. ...It was hard to sleep before midnight and then just two to three hours later I had to get up for my routine job on a rubber tree farm. Finally, I went to see a doctor and the doctor told me that my insomnia was because of my high stress... ('Why you don't tell me about this' -2.a said and cried)... ... At that time, I lost weight, around 8 kilograms. [laughing] Don't worry now I have gained back three to four kilograms already. I look very much better [laughing]". (C2, sister, Gr Int, 7<sup>th</sup> visit, p. 17)*

Furthermore, because **2.a** was an employee of an institute, support in relation to her job was mainly provided by her teacher friends at school both under the school support system and personal relationships. This is different from case 1 where only network members with personal relationships helped the central woman in her jobs because the central woman of case 1 was self-employed. However, in this case colleagues with close relationships tended to have a higher contribution in the network more than other colleagues.

*2.a "I told everything to my teacher friends [a group of teachers who had taught at the same building], I had no secrets from them as we work and live together as a family. The day that I went to visit a doctor for the investigation report, all of them were waiting to hear the report at school... During undergoing treatment, they supported me as best as they could such as giving me healthy food, information related to my illness, and also helping in job...// ...For 2.e [2.a's closest friend at school], she helped me with everything, being my companion for outside school activities, carrying things for me, helped me do the report, and seeking things which I wanted. You see, one day I just complained with her that I wanted a jacket because during chemotherapy my skin was more sensitive with sun light. Then, she drove to a city [in other province] to buy a jacket for me"*

*2.e "My husband drove a car, not me"*

*2.a "During my hospitalisation, she often rang me".*

*2.e "I didn't visit her everyday but I talked to her via phone about her students. I know who are her favourites and their stories would make her happy".*

*(C2, central woman and close friend, Gr Int, 6<sup>th</sup> visit, 1-2)*

On completion of her treatments, **2.a** began to re-settle into her normal life and work, with her family and friends' support at this time more as mentors rather than caregivers. During this period, **2.a** still kept in contact with a breast cancer friend with whom she shared hospitalisation experiences. **2.a** also developed a new role as a supporter for a friend (who she had previously lost contact with) who had been diagnosed with cancer one year after her diagnosis.

*2.a "My friend who is a teacher in \_ [one province of insurgency] was diagnosed with lung cancer. She rang to consult me about her illness. I'm very sympathetic as her husband is a soldier and works in another part of Thailand. She lives with her elder sister in \_ [the province's name] and had to hire a driver to drive her car to hospital...//...Now she is undergoing chemotherapy, she is suffering greatly with the side effects. During every phone conversation I always encouraged her to keep going with the treatments and told her she would be better soon. I also advised her to have a healthy lifestyle ... ..I try to be her mentor as best as I can." (C2, Int, 7<sup>th</sup> visit, p.29-30)*

Through mapping, **2.a** identified her network while living with breast cancer as shown in Fig. 5.2 which was family and friend based. People with (breast) cancer experiences (**CA1-5** in Fig. 5.2) who were involved with her journey were identified as her network members. Note that the cancer-related members comprised those who were hospital-based (**CA1** in Fig 5.2) and normal life-based (**CA 2-5** in Fig. 5.2). They were her breast cancer friend who shared hospitalisation experiences and her relatives and a colleague who were diagnosed with cancer before her. The relationships between some of these network members were perceived as becoming closer after a number of sharing of cancer-related experiences (**CA2- 4\*** in Fig. 5.2). Additionally, **2.a** disclosed that she had made connection with an online community of breast cancer patients because she was seeking information and wanted to know other patients' experiences. Although she wanted to be involved in the breast cancer club which was located in another province, it was too hard for her to manage the travel, her work and the family commitments. **2.a**'s network map differs from those of other networks in that **2.a** included some information resources in her network map, the online community of breast cancer patients (**I2** in Fig. 5.2) and magazines she read to find out about breast cancer (**I1** in Fig. 5.2). Similar to case 1, health professionals who provided services she really appreciated were identified as her network members (**H1-2** in Fig. 5.2).

Case no. 2

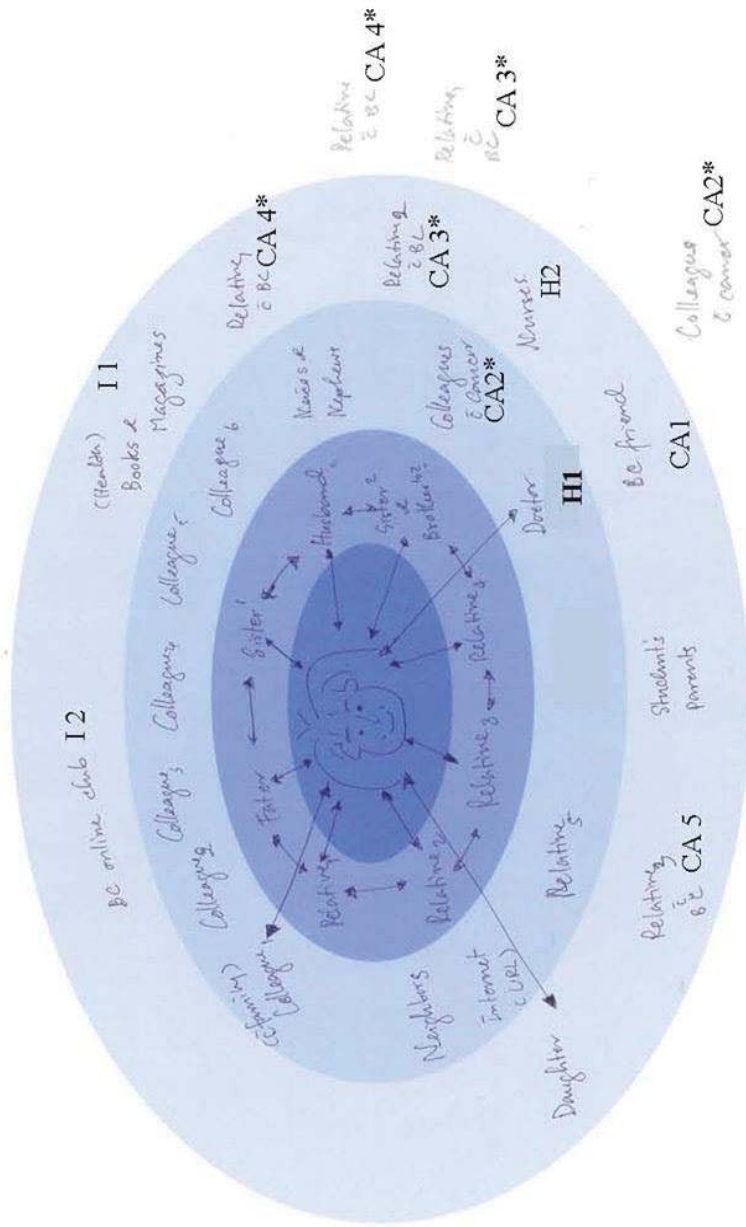


Figure 5.2. The network map of case 2.

## Case 5: A woman surrounded by adult children in a traditional Muslim village

**Table 5.3**

*Information of Case 5's Participants and Data Collection*

<b>Key participant</b>	<i>5.a</i> : a sixty-year-old Muslim woman living with her older husband in a traditional Muslim village, surrounded by four adult children
<b>Cancer and therapies</b>	First stage breast cancer, diagnosed six months prior to study participation  Total mastectomy with partial lymph node removal and four cycles of chemotherapy
<b>Financial support programme</b>	The programme of the universal coverage scheme
<b>The referral participants</b>	<i>5.b</i> : the central woman's husband <i>5.c</i> : the central woman's older daughter <i>5.d</i> : the central woman's younger daughter <i>5.e</i> : the central woman's younger son
<b>Time and numbers of visits</b>	February to April 2012 and July to August 2012 Total = 10 At <i>5.a</i> 's home (and shop) X 9; and at <i>5.e</i> 's home X 1
<b>Data collection methods</b>	Conversations, (in-depth) interviews, group interviews, observations, and mapping

The woman of this case (*5.a*) was an older adult Muslim who was a grocery shop owner in a traditional Muslim village of rubber tree and rice farmers. She lived with her older husband. Even though their four adult children lived with their own families, they still lived close to their parents in the same village. Throughout *5.a*'s breast cancer journey, some difficulties related to breast cancer management and residential location, were mentioned. The woman and her family could overcome these difficulties because of their mature family network which continuously functioned to meet the woman's needs related to illness and daily living and also maintained her business. Moreover, as *5.a* and her family had lived a traditional Muslim lifestyle in a homeland village for a long period of time, plenty of tangible and non tangible support was provided by relatives and neighbours. This case reveals the significant benefits of a mature support network of family members living close together and community cohesion.

*5.a* was the first child of a family with nine children. Her mother, now in her late eighties, lived with one daughter and her family, while her father died many years ago. When *5.a* was 19 years old, she married a Muslim man (*5.b*) who came from an agricultural family with nine children. *5.a* and *5.b* had a few experienced years of formal education. *5.b* also undertook ongoing learning in relation to his religion and was acknowledged as one of leaders of the village mosque. This couple had lived a traditional Muslim lifestyle in an

agricultural village all of their lives. **5.a** worked at home, which was one of two shops in the village, while **5.b**, was a rubber farmer and also his wife's assistant in the shop. Their shop (home) was surrounded by the homes of **5.a**'s mother, siblings, and relatives. All of **5.a**'s children graduated from high school and diploma level study and all were married. They and their spouses lived and worked in the village and their homes were close to their parents' home. These residential circumstances of living in a stable, traditional, religious-based community with long-term kinship relationships, and close proximity, were resources for the woman and her network during her cancer journey.

More than ten years ago, **5.a** was diagnosed with diabetes and received therapies at the district hospital—her local registered setting. When **5.b**, (husband), was diagnosed with a chronic infection, the local setting (his registered setting) referred him to the university hospital (under the system at that time, he could be directly referred from the registered setting to the tertiary level setting). He underwent treatment for many years and was now only having an annual doctor's visit. Accordingly, this couple and the family members were more familiar with the services of their local setting and the university hospital than the provincial hospital in town. **5.a** said normally she and/or her husband preferred to look after themselves, but if they did not have enough ability to manage, they would ask for help from their children. Thus, they intended to try to access the local services independently.

*5.a "I went to the local hospital for my diabetes treatments and other health problems, I went there with my husband with a motorcycle. Its distance from home is around 20 kilometres. It is not a problem as we drive on a local road, not on the highway. We went there in the early morning and the process would be finished around 10am and then I could come back to run my shop just before lunch ... My husband's [disease] had been treated at \_ [the university hospital]. To go there, my children had to drive for him. Before I got it [breast cancer], I often went there with him. During the school break, our grandchildren would love to go there with their grandpa as well. ..."* (C5, central woman, Int, 3<sup>rd</sup> visit, p. 6)

Around six months before **5.a**'s study participation, she found a tiny lump in her left breast. Next, she told her daughters about the lump and as usual she went to see a doctor at her local hospital with her husband. The doctor told her that she had to be referred to the higher level setting because an advanced investigation was needed. **5.a** and her family wanted her to be referred to the university hospital, the same as **5.b**. As the system had changed, she had to be referred to the provincial hospital in town instead. Even though its distance from her home was around one hour by car, similar to the distance of the preferred setting, **5.a**'s family was not familiar with the provincial service. However, because of financial issues, **5.a** and her

family decided to undergo the investigation and treatments at the provincial hospital. When the doctor of the provincial hospital diagnosed her with breast cancer and suggested that she should be treated by a total mastectomy; she said she was shocked and started crying:

*5.a “I was with my older daughter in my doctor’s room. The doctor told me I got ไข่น้ำ/Ai-nan/ [means something; she meant she got breast cancer] and my breast should be cut off as it was the best way to treat it. I felt fear. I don’t know what things I felt fear of, it might be the operation, and ‘cutting my breast off’ made me scared. When I was crying, my doctor told my daughter to let me talk to other family members and other patients. My daughter rang my husband and other children. Everybody told me to follow the doctor’s suggestion...” (C5, central woman, Int, 3<sup>rd</sup> visit, p. 21-22)*

Accordingly, the disease itself, its treatments, and complexity of the health system interacted with individual limitations and resulted in a need for more personal support. However, **5.a** was well supported by her husband, children and their families through six months of investigation and treatments. Her family was always involved with all activities including any decision-making related to her breast cancer treatments.

*5.b “When 5.a was admitted in hospital, I was her main caregiver in hospital. All the children assigned me this job [laughing]. They said they would do everything for us, including the shop, just so I was with their mother. Thus, one of them looked after the shop, one did housework and cooking food for us and the two sons were drivers for others and also bought goods to sell at the shop. They kept doing things like this until now.”. (C5, husband, Gr. Int, 9<sup>th</sup> visit, p. 18-19)*

*5.a “I felt fear about getting breast surgery because I heard that one of my relatives, after she had breast surgery, she got worse and then passed away. Moreover, my mother suggested I change the treatment to traditional methods such as traditional herbal medication. At that time, I was very confused about what I should do... However, all of my family members said in the same way that they wanted me to use the modern medication, rather than the traditional way. They said ‘Ma [mother] you should follow the doctor’s suggestion, getting surgery and then you will be well’ ... Yes, I followed my family because they were my caregivers, so I should listen to them”. (C5, central woman, Int, 3<sup>rd</sup> visit, p. 7-8)*

While undergoing surgery and chemotherapy, **5.a** had a lot of visitors both at hospital and at home, including her mother, siblings and relatives (and their families) who either lived close or far away from her, other patients and friends, neighbours (also her customers), her goods suppliers and the health personnel in village.

*5.a “Many people came to visit me, particularly during my admission for the breast surgery.*

*Other patients said to me 'you had such a lot of visitors, the most that I have ever seen. How nice they are'. [Laughing], somebody I had not met before"*

**5.b** *"They were my children's friends."*

**5.a** *"For my relatives and neighbours, as I got ไข้หนัก/Ai-nan/ [she means her cancer] they might think I got severe sickness. So, many came to me. I got a lot of money<sup>16</sup> and stuff from them."*

**5.b** *"When I was discharged from hospital, we used this money paid to pay the hospital for the extra charges. We gave much stuff, in particular food, to the cleaning workers. Do you [5.a] remember this?"*

**5.a** *"I am not of the young generation [laughing]. I have lived here for a long time and also have behaved well to other people... When I got sick the reason I had a lot of visitors might be because when they were sick we went to support them. When I was sick, they wanted to do the same thing for me. I think".*

**5.b** *"Allah said 'do good things to others without expectation of its outcome, just do it' Because everything is decided by Allah already. Without expectation, you will get a lot of merit".*

*(C5, central woman and husband, Gr Int, 9<sup>th</sup> visit, p. 2-3)*

Due to the long period of breast cancer treatment, as time passed the family members needed to make a number of adjustments to their ways of providing support. For example, during her chemotherapy, one of her daughters was admitted to hospital for surgery. The four children adjusted their support roles to maintain the support flow to their parents. Once therapies were completed **5.a** returned to her normal life as a shop keeper. Nevertheless, she needed a period of recovery from her illness, and the four children kept supporting her everyday living and the jobs at her shop, while support from others was lighter.

I reached **5.a**'s shop at around 11 am; **5.a** was selling goods for one customer. I didn't see her husband at the shop as usual. While I was waiting for **5.a** to be free from her job, **5.b** came home on his motorcycle. He told me that he came back from working on his rubber tree farm. He did not go there for several months and this morning he went there after he finished helping his wife in the shop... // ... During my interview with **5.a** at the front of the shop, a car arrived

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<sup>16</sup>Giving a little money to sick people is one of living cultural behaviours among Muslim people in southern Thailand. This is a way to share with others who is suffering as Allah has taught.

and parked in front of the shop. **5.a** said it was her son's pickup. She said to me, this son (**5.e**) was the younger, and the father of a girl who I had met with her mother here last week was the elder son. **5.e** had called in at his mother's as he was going to the district centre and he wanted to know if his mother wanted him to buy anything for the shop... **5.a** said her son would take responsibility for buying goods that were big or heavy, such as a sack of rice or a bottle of oil. Her older daughter (**5.c**) managed little things such as shampoo or soups. The younger daughter (**5.d**) liked to do the housework and sometimes their children came to her at her shop too.

(C5, Fn, 7<sup>th</sup> visit, home and shop)

A unique characteristic for Muslim cases was demonstrated in this case. **5.a** revealed that one of her most important sources of support was having a spiritual connection with **Allah**. This connection was maintained through living following **Al-Quran**, including performing religious activities such as prayers five times a day, fasting during Ramadan, and attending special prayers at the village mosque. Her husband (**5.b**) explained that as **Allah** is a higher being and cannot be compared with people his name could not be included on the network map.

Finally, **5.a** depicted her personal social network as shown in Fig. 5.3, representing the family based network similar to the characteristics of case 1. For this case, health professionals (**H1** in Fig 5.3) were indicated on the map as network members related to **5.a**'s appreciation of the proactive services they delivered at home. Similarly, **5.a**'s breast cancer friend and her husband (**C1** in Fig. 5.3) were named on the map because after her treatment was completed they came to visit her at home. As these two situations seemed to reflect unexpected support, and resulted in these members being awarded a higher degree of significance. Moreover, through mapping, **5.a** identified supporters' significance that differed related to their residential distance from her as she identified her relatives who lived in her village as more significant than those who lived outside the village, even though she perceived that both were concerned about her illness (**R1-2** in Fig 5.3). The closer the living places, the more chance for people to visit and provide support to her and then the higher significance identification followed.

*5.a "All siblings and relatives are concerned about my illness. When they knew I got cancer they came to visit me, someone gave me money. However, for those living far way, they are not able to frequently visit me; it is different from whom living close such as living here [her village] as they can come frequently. I understand them". (C5, central woman, Int, 9<sup>th</sup> visit, p. 11)*

Additionally, although this woman and her husband were self-employees, similar to the woman and her husband of case 1, differences between these two cases can be observed. A

network member with a career-related relationship does not appear in case 1’s map, on the other hand, some appear in the map of case 5 (J1-2 in Fig 5.3). The characteristics of different occupational groups resulted in differences of opportunity for career-related contribution to networks. For example, farming is more solitary than working in a market trading.

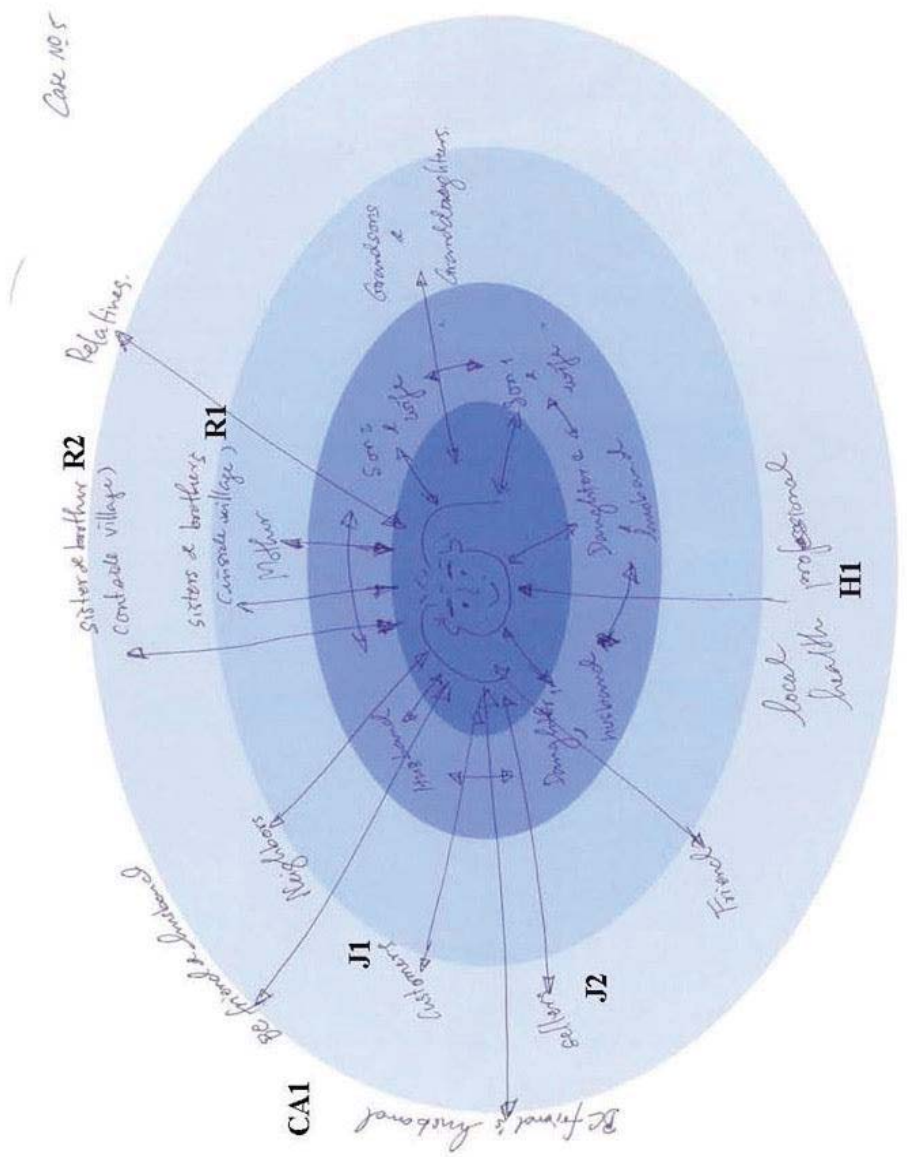


Figure 5.3. The network map of case 5.

## Case 6: A housewife from family with good connections and living close together

**Table 5.4**

*Information of Case 6's Participants and Data Collection*

<b>Key participant</b>	<b>6.a:</b> a housewife whose husband worked away from home
<b>Cancer and therapies</b>	Second stage breast cancer, diagnosed seven months prior to study participation  Total mastectomy with partial lymph node removal, 6 cycles of chemotherapy
<b>Financial support programme</b>	The programme of the universal coverage scheme
<b>The referral participants</b>	<b>6.b:</b> the central woman's husband <b>6.c:</b> the central woman's daughter <b>6.d:</b> the central woman's sister
<b>Time and numbers of visits</b>	July to October 2012 Total = 7 At <b>6.a's</b> home X 4; and at <b>6.a's</b> hospital X 3
<b>Data collection methods</b>	Conversations, (in-depth) interviews, group interviews, observations, and mapping

The woman of this case was a housewife who came from a big family with close relationships and most of them lived close together in their hometown. The woman was diagnosed with breast cancer and then underwent long-term treatment, while her husband worked away from home periodically. The rotation of providing support between her husband and her siblings (and their families) as a mature family network helped the woman to complete her treatments and also maintain her normal life responsibilities. Specifically, in this case, differences in perceptions of the significance of members of the network were identified in the mapping exercise.

The woman, **6.a**, was the youngest of her five siblings. **6.a's** father had died many years ago, while her mother now was in her eighties, living with one daughter's family. **6.a** and one sister graduated from higher education, the other four siblings completed a few years of formal education; one brother had died. All her parents' children were married. Most lived with or close to their parents' home but only one sister who had higher education lived far away from the others in other regions. After **6.a's** graduation, she never worked outside the home. **6.a** reported that she had a very small number of close friends. **6.a** married her high school friend (**6.b**), who came from a big family with 13 children. He was a shift worker, working away from home on a cycle of 25 working days and 25 days off. In contrast to **6.a**, her husband (**6.b**) was a social person, with a big group of close friends with good connections.

After they were married, **6.a**, her husband and their son and daughter had lived with **6.a**'s parents and one sister's family for many years. **6.a** revealed that she and family related both by marriage and by blood had close relationships with every member including a sister who lived far away. When **6.a** lived in an extended family, sharing in everyday living was common. As she didn't work outside the home, she helped nurture their children and also provided some financial support for her nephew's education.

Four years before **6.a**'s cancer diagnosis, she and her family moved from their parents' place to live at their new house in a new community in a suburb of her hometown. For **6.a**, living in this new community seemed lonelier compared to living in her hometown community. However, their new house was around 15 minutes drive from their parents' place and their good connections were maintained.

*6.a "We lived with my parents for a long time until our children had grown up. We decided to move out from my parents' place to live at our new house because our children became teenagers...// ...Living at the new house, I only know a few neighbours because we just moved to live here a few years ago and I don't like to go out. I love to stay at home. If I go out, I only go to my parents' place or go out shopping or meeting with friends with my husband during his days off..."(C6, central woman, Int, 2<sup>nd</sup> visit, p. 3-4)*

When **6.a** was nearly forty, she found a lump in her breast. At that time, as her husband was away for work, she went to see a doctor with her sister. The breast cancer diagnosed by the doctor shocked her. However, when she thought about her beloved children, she said she had only one choice; 'being alive for them'. Hence, she underwent breast cancer therapies. Her treatment took around ten months and her husband and her siblings (sometimes including her mother) took turns to be her caregiver in hospital and at home. If her husband was off work, he was her main caregiver. If he was away from home, **6.a**'s sister (**6.d**) was her companion at the hospital and her caregiver at home during the weekend (as she had to work weekdays). Other siblings and their families also provided support to **6.a** and her children as much as they could.

*6.d "If 6.a's husband was away, I requested a day off to be 6.a's companion at hospital. No problem, my boss knew about this and my co-workers knew as well. This year, my days off are saved for being her companion if necessary... //...After each cycle of chemotherapy, my mother was with her at home for a few days until she got better. My eldest sister cooked food for her because she preferred to eat only some kinds of food that she believed were good for cancer patients such as ... In the first week after receiving chemotherapy, after work my husband sent me to her home and I helped her with housework and also during weekends*

*too. ...When her children finished their study late, they would go to my place and then my husband would take them home later... //...Today my son will pick us up from the hospital and take us home as he is coming back home from his study. We will go to my place first; stay with my mother for a while, and in evening 6.a will go home with her children after dinner.”*  
(C6, sister, Int, 4<sup>th</sup> visit, p. 12-14)

The quotation above reveals a high contribution of **6.a**'s family in her network. It reflects the sharing lifestyle of their family. Furthermore, it might result from the previous support that **6.a** provided to other siblings related to the Thai values about respect and gratitude to benefactors and the need to provide reciprocal help (as mentioned in Chapter 1).

In addition, her sister (and her husband) who lived at a distance from **6.a**, helped her in terms of being consultants and seeking resources about alternative therapies. **6.a** said she had read many books about alternative treatments/procedures for cancer patients, choosing to consume only one kind of herbal remedy suggested by her sister as an adjunct for her main-stream treatment. This confirms that significant supporters who had high education and were close in relationships seemed influential in decisions about using alternative therapies. **6.b** said that while working away from home, he rang her every day after finishing his work. Many friends (or friends of friends) provided support to him or through him to his wife, particularly information and emotional support, through electronic-based communication (Facebook).

*6.b “Since my friends had known about my wife’s breast cancer, when I met them or had online conversation with them, a topic of our conversation was about my wife’s illness issues rather than my issues”. (C6, husband, Gr Int, 6<sup>th</sup> visit, p. 5)*

However, the support provided by the group of friends, especially those that were electronic-based, was not mentioned as significant by **6.a**. (as she did not join the Facebook community). After completion of treatment, **6.a** returned to her normal life, looking after her children and house, taking care of mother and mother-in-law and having social activities with her husband. After medical treatment, they sought another alternative therapy to use as an adjunct treatment, following the suggestion of her husband's sister.

The network map of case 6 is shown in Fig 5.4. In contrast to other cases, this network map was created by two participants, **6.a** and her husband. Firstly, they depicted the map together and many names were included in the map, mainly based on her husband's interpretation. Next, **6.a** preferred to review and edit her personal social network map alone and she drew arrows between the names she identified as her network members. From the woman's

perspective, many friends were excluded from her network map. As a result, this woman's personal social network was family-based. Relying on her husband's perspective, the network would have been family and friend-based.

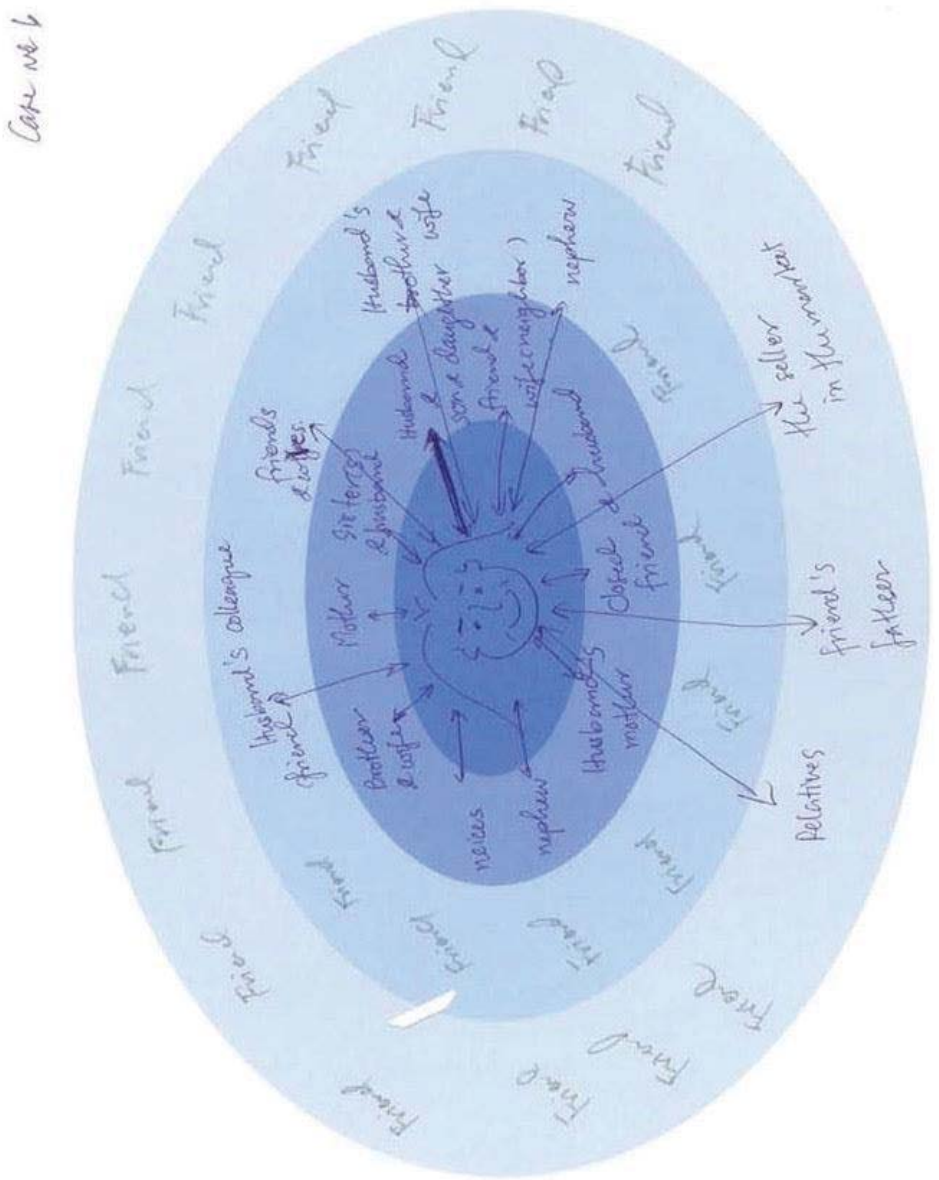


Figure 5.4. The network map of case 6.

## **Conclusion**

The women's mature support networks were either family or family and friend-based, however, the majority of members were family members. Network members with close and long-term relationships tended to have a higher contribution for a longer period of time in the networks. Many contextual factors were revealed that influenced the patterns of support of each mature support network, more than the disease itself including residential, occupational, and family contexts. However, as each case had their own contextual characteristics, hence, they had their own pattern of support, in particular among their family members. Importantly, the significant features of mature support networks of each case are (quasi) family living in the traditional Thai style, (quasi) family cohesion and the adjustment capacity of family members.



## CHAPTER 6

# Living with complexities in family circumstances

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### Introduction

With regard to the previous chapter, explicitly, **'family'** was a crucial part of these networks. However, family is not simple, it is a complex system. This chapter will illustrate the complexities in family-related situations that then resulted in specific network characteristics. **'Complexities in family circumstances'**, in relation to family responsibilities of the woman with breast cancer and/or their family members, and family living patterns can be observed in many cases. Three cases were selected that chronicle the specific characteristics of family complexities related to members' illnesses, family and relatives' living patterns and its changes and family incomes. Regarding their family complexities, these three cases developed their own patterns of support networks to maintain the necessary support flow within the family throughout the journey, with varying degrees of success. In this section these three cases will be described and discussed.

## Case 3: A nurse from an extended family with three cancer patients

**Table 6.1**

*Information of Case 3's Participants and Data Collection*

<b>Key participant</b>	<b>3.a:</b> a nurse from an extended family with three cancer patients
<b>Cancer and therapies</b>	Second to third stage of breast cancer with lymphatic invasion, diagnosed around five years prior to study participation  Total mastectomy and total lymph node removal; eight cycles of chemotherapy and 30 doses of radiation therapy
<b>Financial support programme</b>	The programme of civil service welfare
<b>The referral participants</b>	<b>4.a.:</b> the central woman's older sister with breast cancer ( <i>and the central woman of case 4</i> ) <b>3.b:</b> the central woman's son (and was <b>4.a's</b> nephew) <b>3.c:</b> the central woman's mother (and <b>4.a's</b> mother) <b>3.d:</b> the central woman's co-worker
<b>Time and numbers of visits</b>	January to April 2012 and July to September 2012 Total= 18 At <b>3.a's</b> office X 9; at <b>3.a's</b> parents' (and <b>4.a's</b> ) home X 7; and at <b>3.a's</b> and <b>4.a's</b> health setting X 2
<b>Data collection methods</b>	Conversations, (in-depth) interviews, electronic interviews (e-mails), observations, participatory observation and mapping

(\***3.a** and **4.a** (presented in chapter 7) were siblings and lived together in their extended family. Accordingly, information belonging to this case and case 4 was often integrated when delivered by the two central women and their referral participants who shared experiences with these two cases, in particular their family members.)

**3.a** was a married woman with two teenage sons. She and her family lived with her parents and an unmarried older sister as an extended family in a traditional Thai village, while other siblings lived far away from them in other regions. Sharing in everyday life was this family lifestyle. The woman and her older sister (**4.a**, case 4) were diagnosed with breast cancer at around the same time, one year after her father's cancer diagnosis. To sustain the family throughout the cancer journeys of three members with multiple and complicated burdens, 'sharing networks' was observed as a significant characteristic of this case. Furthermore, as the central woman was a health professional, a larger number of health professional members were also network members, and this was a special feature of this case.

**3.a** was a nurse who had worked at the hospital in her hometown for more than 20 years. She grew up in a big family with five siblings. Her parents now were in their eighties. Her two elder sisters attended formal education for a few years and then worked on the rice farm similar to their mother. The other three siblings graduated from higher education, had jobs and families in other regions, and lived over 1,000 kilometres from their hometown. Her eldest sister lived with her own family in another village. Her second sister, **4.a**, was an unmarried farmer who took over the role of their parents' caregiver at their home. **3.a**

perceived all her family members were close and had good connections, including the siblings who lived far away.

**3.a** married and had two teenage sons. After marriage, **3.a** lived close to her parents' place, around ten minutes walk away. The proximity allowed them all to continue to live as an extended family. However, individual family members had different responsibilities. The older sister, **4.a**, took charge of home activities such as looking after family members, and managing their participation in village activities.

*3.a "My sister [4.a] loves to help me, not only for me but also for my husband and absolutely my sons. I have no need to worry about my housework, cooking food, and also participation in social activities in the community as she and my parents always do these jobs for us. You see every day after I and my husband left home for work or when I went away to other provinces, she or sometimes my mother went to my home to check my house for anything we forget to do such as switching off the electric equipment or shutting windows and doors. ... If they went to social events in the village and gave money to the host<sup>17</sup>, they always did it for me and / or my husband too". (C3 & 4, central woman and sister, Int, 12<sup>th</sup> visit, p. 4)*

**3.a** mainly took responsibility for the family activities with organisations or kin groups. Particularly, as she was a health professional, she took over the role of health-related manager for all family members (and sometimes for her husband's family as well):

*4.a "Previously, when we [4.a and other family members] went to hospital we didn't have to do anything. 3.a prepared and managed everything for us such as making the doctor's appointments, taking us to hospital on the appointment date and also talking to the doctor instead of us. If she was not available to see the doctor with us, her friends at the hospital would facilitate for us instead of her. After finishing the doctor's visit, we had to do nothing - just went back home as 3.a and/or her friends would manage the follow up appointment and/or medication for us". (C3 & 4, sister and central woman, Int, 8<sup>th</sup> visit, p. 19)*

The quote above also illustrates how **3.a** undertook this role with the support of her workplace friends. The differences in families' ability to access health service is shown in the ways that families (or networks) with health professional members were able to navigate the health services easier than the families without any health professionals.

Around six years before **3.a** joined this study, her father was diagnosed with cancer and

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<sup>17</sup> In Thai culture, one of the social rules to demonstrate respectfulness at auspicious / misfortune ceremonies is the giving of some money to the hosts.

underwent a year of treatment while being looked after by his children, in particular, these two daughters—**3.a** and **4.a**. The older sister was the father's caregiver in hospital and at home, and also looked after her mother at home. Concurrently, **3.a** mainly worked on health-related activities, information seeking, decision-making, resource management, and also coordination and facilitation of her father's investigations and therapies.

*4.a "During my father's period of receiving investigations and treatments, my sister managed everything such as contacting the doctor, discussion about his treatments with the doctor and the management of [health service] accessibility. She hired a part-time driver for us. She gave her car and hired the part-time driver to take us to the university hospital for radiation for 30 days. I always was with my father when he visited the expert at the private clinic, stayed with him at the provincial hospital and the university hospital. If anything needed a decision I rang my sister and asked her what we should do." (C3 & 4, sister and central woman, Int, 5<sup>th</sup> visit, p. 7)*

Soon after the father's cancer treatments were completed, and while he still required some monitoring, **3.a** and her sister were both diagnosed with breast cancer and started their treatment together. Having two new breast cancer patients (and both were the key family caregivers) and one unwell elderly cancer patient was really challenging for this family to overcome together.

*3.a "My mother said several times, ... could she get cancer instead of us. ... Why she said that? I think because she thought that I, and my sister, can look after and/or provide support to other family members and siblings. For herself, she is not able to look after others; instead, she is dependent on others". (C3 & 4, central woman and sister, Int, 3<sup>rd</sup> visit, p. 10)*

At that time, **3.a** had just finished the first year of her part-time postgraduate study, which she suspended while she underwent cancer treatment. During hospitalisation, personal supporters were needed to provide personal care, social contact and company to **3.a** and **4.a**, while their parents still needed ongoing care and support, especially when they were unwell or during an emergency. Although **3.a**'s two sons were high school boarders and were relatively independent, they needed support to transition from high school to university level study. Fortunately, this family reported that they experienced no financial difficulties. Even though their networks were long-lasting and resourceful, particularly in relation to health support the number of burdens occurring in the family around the same time created a major challenge for this family.

Significantly, the lifestyle of sharing everything together as a family continued during the cancer journey of all three family members. It is hard to separate one personal network from

the other as the overlapping sector forms the majority of these two networks, while the individual part of each is small. ‘**Sharing**’ was the strategy used within networks of both sisters to provide support among family members. Accordingly, several ways of sharing within the networks of **3.a** and **4.a** can be observed within either the dimensions of the network structure or the ways it functioned.

Sharing characteristics within the structures of these two networks related to the network members and their relationships. Most members were identified in the networks of both women. The family group, not surprisingly, was the same for both the sisters’ networks. Similarly, relatives and neighbours were a part of the non-family group of these shared networks as they had similar relationships to the two sisters and other family members because of kinship and/or being community members. These relationships had developed from generation to generation. Most network members had general supporter roles and some occasionally took over supporter roles instead of family members.

*4.a “People living round us are as our relatives. We lived here [the village] together for a long time. They often told me that any help I want them to do for me and my parents, just let them know. Sometimes I asked to buy something for me from the local market. Someone offered me, like they can accompany me to the hospital if I want”. (C3 & 4, sister and central woman, Int, 8<sup>th</sup> visit, p. 9)*

Furthermore, **3.a** had friends and colleagues and these relationships were long-term and individual-based and so many of her friends had interacted with her family. Accordingly, familiarity and relationships extended to the other family members. These friends and colleagues had involved themselves with the older sister’s journey.

*4.a “Many of 3.a’s friends were familiar with me. Some of them used to come to our place such as \_ and \_ [names]. For her friends (and colleagues) who were working at 3.a’s hospital, when we [she and other family members] visited a doctor there, they often came to take care of us. During our hospitalisation, many came to visit us and some of them came to visit me at home too.” (C3 & 4, sister and central woman, Int, 9<sup>th</sup> visit, p. 10)*

This quote also shows how the close relationships, formed with **3.a** and her friends and colleagues, were shared with **4.a** and other family members. The shared relationships between the sisters’ networks were also observed within the family group. The relationship between **4.a** and **3.a**’s husband was like a blood-related relationship rather than the relationship between sister and brother-in-law, as they looked after each other as siblings. **4.a** had looked after the two boys as if they were her children and their relationships were as close and deep as a parent-child bond.

**4.a** *“I love them very much, they are my darlings as I looked after them since they was born. ... When they were young, they slept with me in the night time too here [a room at her home] and they didn’t like to go to sleep at their parent’s home [laughing]... I can remember, the day when the older one was going to move to another province for his study. I was not able to see him go away from home as I was crying... If they are away from home either for a short or long period of time they ring me twice a day, same as they do to their mother. Now when they come back home, they will sleep with me at least one night, especially the older boy.”* (C 3 & 4, sister & central woman, Int, 9<sup>th</sup> visit., p. 5)

As well as the sharing of relationships, these networks also showed similar sharing of resources and support, both tangible and intangible.

**4.a** *“As we [3.a and 4.a] undertook the surgery on the same day, after our operations the head nurse decided to put us into the same room and then we didn’t need others to be our personal caregivers at hospital. We were the caregiver and the patient of each other [laughing]. Then, my brother-in-law was able to be my parents’ company at the night time”.* (C3 & 4, sister and central woman, Int, 3<sup>rd</sup> visit, p. 9)

**3.a** *“I know my sister loves my sons very much. So, I told them like they have to be concerned about their aunt’s sickness and ring her regularly to emotionally support her. Ringing me is not as important as ringing her...”* (C3 & 4, central woman and sister, Int, 10<sup>th</sup> visit, p. 8)

The two quotes above also reveal that both the supporters and recipients performed the sharing. Much of the evidence reflecting the network discussions shows that the supporters provided their support with awareness that they were sharing their support to both women. For example, **3.a**’s son stated that he was always careful to take care of three sick persons in his family equally and he managed his time and support shared to all of them.

**3.b** *“I tried to support both of them as best as I can as they are my beloved. I sometimes took care of my aunty at home or at hospital when I was at home during my study break times. I took her to hospital to visit the doctor and accompanied her. During my study semester I was not able to be with them. Normally, I ring my aunty and mom twice a day and make extra calls after the aunt’s doctor visits and after receiving investigation and/or treatments. For mom, she was the workaholic, so I sometimes helped mom about her job and being a good boy for her... Moreover, when I was home I often took my grandpa to his working site as I know he really loves to go there”* [The women’s father still works.] (C3 & 4, son and nephew, E Int, p. 3)

Sharing was also a way to distribute the resources and support within the two networks. The thoughtfulness in the support use was illustrated by both sisters because of their consideration about each other (and their father). In the quote below, the older sister was

reluctant to firstly receive emotional support from her nephews because at the same time, these boys' support was needed for the younger sister (their mother).

*4.a "The two boys came to the hospital to visit me on the operation date. As we didn't tell them about their mother's sickness yet, they headed to my bed which was on the first floor. So, I decided to tell them that their mom was on the second floor and they should go to see her first..." (C3 & 4, sister and central woman, Int, 5<sup>th</sup> visit, p. 12)*

*4.a "My first chemotherapy got started first and 3.a was my caregiver. Then, when her first cycle of chemotherapy started, I was her caregiver at hospital. We took turns like that until we finished our treatments. At that time I had few side effects from chemotherapy. I was almost well. In contrast, 3.a had severe nausea and vomiting in every cycle. I looked after her on Friday night and her husband would take us back home on Saturday morning. That was our life cycle at that period of time". (C3 & 4, sister and central woman, Int, 4<sup>th</sup> visit, p. 11)*

3.a's long-term therapies took around eight months and were completed around three months after her older sister's therapies (for the first diagnosis). With no evidence of disease, 3.a returned to her normal family, study and work responsibilities, graduating one and a half years later. After graduation, she said she was happy to work hard to achieve career success. In addition, 3.a shared her personal experiences gained from living with breast cancer in her job with her patients and their families. She also developed a personal supporter role for others outside the family by participating in a workplace club. (It was not a breast cancer club.)

*3.a "I started to engage in the voluntary club of my hospital for a year. I'm really happy with the club activities as I can help others in an independent way. It is different from my job. As a voluntary club member, I am an experienced person in breast cancer, not a nurse. Sharing within club, I don't do it because of my responsibility to work; I do it because I love to do... Tomorrow if you have time, you can come to observe the club activity here [her hospital]. In tomorrow's activity, I will be the moderator and also present the story that I have written to share experiences". (C3 & 4, central woman and sister, Int, 1<sup>st</sup> visit, p. 15)*

During her follow up period, her father had symptoms related to his cancer that resulted in regular medical review and admissions to hospital. As well, 3.a developed symptoms four years after her initial diagnosis, including low back pain and small spot was found on her lung on the magnetic resonance imaging (MRI) chest scan. Two months before I left from field work, she was referred to the specialist at the university hospital for further investigations.

Through network mapping, **3.a** identified her network during her cancer journey as shown in Fig 6.1, which overlapped with her sister's network map (see names with \* in Fig. 6.1 and Fig. 7.1). Even though this network was family and friend-based it contained many health professionals with several types of relationships including professional relationships only (**H1** in Fig 6.1), health professional relationships with other relationships of career, and kinship (**H2** in Fig. 6.1), or health professionals without health professional relationships with the central woman (**H3** in Fig. 6.1). This characteristic is unique reflecting the influence of occupation on the network. Another difference is that no other breast cancer patients were included in this network. **3.a**'s explanation was that during her hospitalisation and/or hospital visits, she had less chance to share experiences with other patients because of time limitations and sometimes she used services through personal contact after office-hours.

Case 3

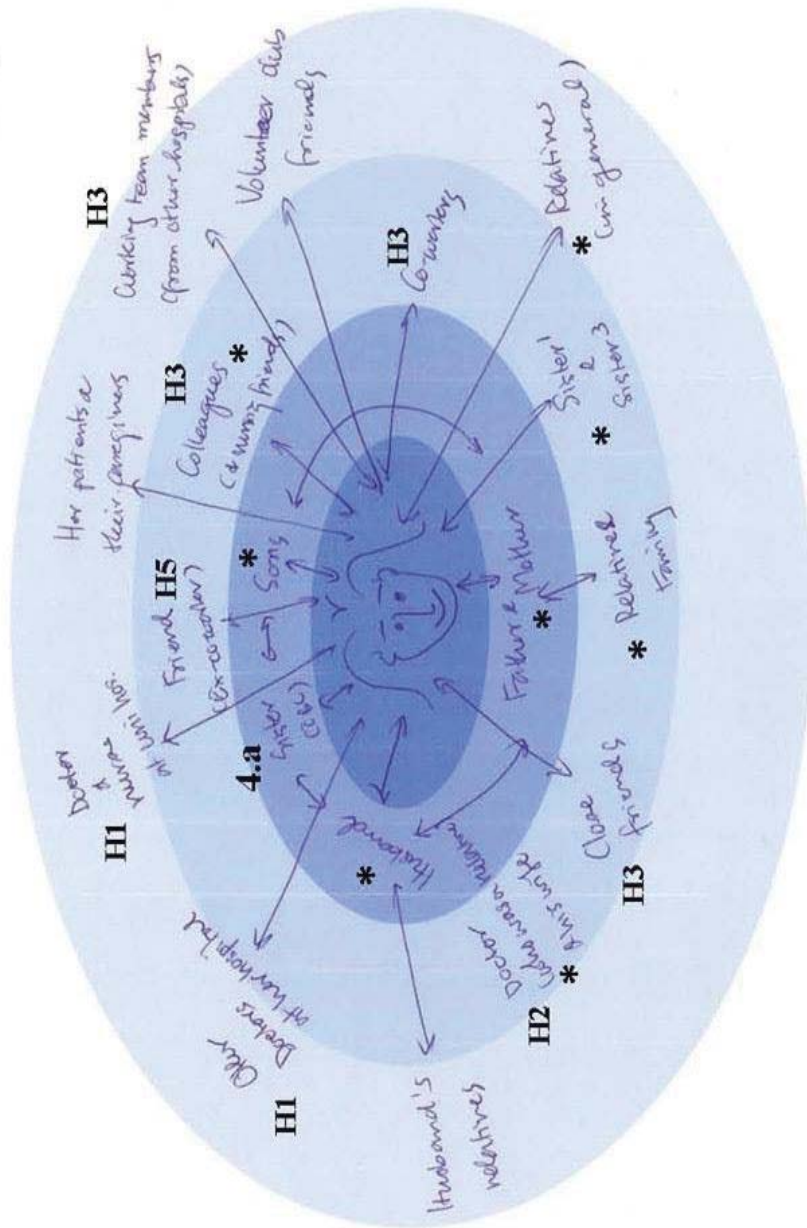


Figure 6.1. The network map of case 3.

## Case 7: A married woman living far away from relatives in a city

**Table 6.2**

*Information of Case 7's Participants and Data Collection*

<b>Key participant</b>	<i>7.a</i> : a married woman with no children living far away from relatives
<b>Cancer and therapies</b>	(Unknown stage) breast cancer, diagnosed three months prior to study participation  Total mastectomy with total lymph node removal and followed with eight cycles of chemotherapy (three cycles were completed)
<b>Financial support programme</b>	The programme of the universal coverage scheme
<b>The referral participants</b>	<i>7.b</i> : the central woman's aunt <i>7.c</i> : the central woman's friend
<b>Time and numbers of visits</b>	July to October 2012 Total = 9 At <i>7.a</i> 's home X 6; and at <i>7.a</i> 's hospital X 3
<b>Data collection methods</b>	Conversations, (in-depth) interviews, telephone interview, observations, and mapping

*7.a* came from another region to the lower southern region for work. She married a local man but had no children. When she was diagnosed with breast cancer, she was living with her husband in a new community of a city suburb. She came from an extended family with good connections and support but all her relatives and some close friends lived more than 1,000 kilometres away. For this case, the residential context, family living pattern, and an unexpected change in normal life circumstances led to a perceived gap in the support provided at times. This complex family situation resulted in specific network characteristics including more involvement of friends and health professionals.

*7.a* came from an agricultural family of a traditional Thai village. She was the oldest child, with a younger brother and sister, and she had more education than other family members. When she was young, she lived in an extended family. She and her mother's siblings were in close relationships as family members. Her parents' home was one of the grocery shops in their village and her father had been the village leader. Accordingly, her home was like the informal village centre. She frequently mentioned to me how the long lasting relationships with neighbours (as kinship) continued even though she lived far from them for many years.

After graduation from university, *7.a* worked in her hometown for a few years and moved for work to a city more than ten years ago. Seven years before her breast cancer diagnosis, she married a local man, who came from a farming family living in a remote area of this region. After marriage, *7.a* started selling clothes at a local market where she had many friends because she had worked there for so long.

7.a found a lump in her breast and went to see a doctor at the regional hospital with her husband. She was diagnosed with breast cancer but did not know the stage of the disease.

*7.a "... My husband, my sister, my brother-in-law and I were together in my doctor's room. My doctor hesitated to tell us about my diagnosis. Finally, my sister said to the doctor 'could you tell us her diagnosis, is it cancer?' Then, my doctor told us 'do not worry it can be treated. Let's get the surgery'. Then my sister and I were immediately crying. And my sister rang my parents to tell them about this... // ...So, I haven't known yet what my cancer stage is, it might be the second or third stage. Uh but I think the stage I got, is not significant for me. Any stage I was diagnosed, I still have to keep going with the treatment until it was completed. So, until now I didn't ask my doctor about this". (C7, central woman, Int, 1<sup>st</sup> visit, p. 3)*

Since her breast lump was found and during the period of breast cancer investigation and surgery, continuous support was provided by her husband, friends and particularly her family even though they lived far away.

*7.a "Since my family have known about my lump, they rang me every day and then they sent my sister and her family to be with me while I was undergoing investigation... My husband said he wanted me to stop working and he was able to look after me... ...My mother, her sisters and brother-in-law, and a relative came to be with me during my surgery and three days after... Further, my sister and her family (a husband and a baby) decided to live with me here and they were trying to take over my business. If they can't, I will sell my business to others. Let them try first...// While I was in hospital, I had many visitors visiting me, such as my market friends, my customers, and my close friends. Some of them came to see me at the hospital, some came to my house and some rang me as they were busy with their shops..." (C7, central woman, Int, 1<sup>st</sup> visit, p. 9-10)*

When 7.a moved to the southern region she had not renewed her health setting registration. Therefore, while undergoing cancer investigations and treatment, she was faced with a problem about accessing financial support. This problem was solved when the hospital staff intervened. Furthermore, 7.a often mentioned her appreciation of the all of the hospital staff who provided services that exceeded her expectations:

*7.a "I can remember the day that I got a mass biopsy. Normally, I am scared of needles... very much. When I was on a trolley in front of a theatre, a nurse, may be, came to me asking about my feelings. I said to her that I was frightened as during surgery I would be still awake [because the procedure would be under a local anaesthesia]. She told me that I would not be worried as during surgery she would be with me. So, I asked her that during surgery, could she hold my hand. When I was undergoing surgery ... as I was very frightened, sometimes I squeezed her hand very strong. I think she might be hurting. However, we handled it together*

*until the procedure was finished. She was so kind to me and others too including a porter; he also encouraged me many times". (C7, central woman, Int, 1<sup>st</sup> visit, p. 3)*

**7.a** joined this study at the beginning of her first chemotherapy cycle. Once the first cycle was finished, unexpectedly, her brother-in-law's mother became sick and her sister and family had to move back to their hometown to look after the mother and run her business. This unpredicted change of her family's circumstances led to a big change in this network. At that time, **7.a**'s life was focused on the cycles of chemotherapy and recovering from the side effects. She and her husband needed others to help them during this critical period. Even though **7.a**'s relatives were aware of this and worried that her husband might struggle to provide the necessary care they were unable to manage their own everyday responsibilities to come to **7.a** and look after her.

***7.a** "My mother said she and some relatives will come to see me during the school break. She said one of my uncles-in-law will drive for them and they will stay with me for many days. When they are here I will let you know and you can come to interview them. My aunt \_ [**7.b**] who was my closest said she wants to look after me by herself but she can't leave her business. I know they want to look after me but they are not able to. My husband said when my sister goes back home, we have to adjust our daily living and be more independent ..." (C7, central woman, Int, 4<sup>th</sup> visit, p. 4)*

During the second chemotherapy cycle, **7.a** felt very unwell and struggled with daily life. Her husband was unable to meet all her care needs at this time. **7.a**'s relatives were unable to provide these missing supports, even if they knew her needs and they really wanted to support her.

***7.b** "I knew, she [**7.a**] was not well, even if she told me that she was fine and she had no problem. I could notice from her voice as she was not well... We [the woman's family and cousins] are ready to look after her but she lives very far from us. I used to tell her like if she changes her health setting to one close to our living places then we can provide the best care to her. However, she doesn't want to change her setting. So sad, we can't go to see her soon because of our job and many things in families to take responsibility for. Such as me, I have to look after my shop and it opens everyday..." (C7, aunt, Tel Int, p.2)*

This support network took time to adjust itself and maintain the support flow, helping **7.a** to continue with her next cycles of chemotherapy. Fortunately, there were friends who could help her. **7.a** and her closest friend(s), especially **7.c**, made many adjustments within their network to provide support needed to **7.a** to help her during each recovery time. As **7.c** was her closest friend and lived in the same town, he became more involved in providing

resources such as food and things she wanted. **7.a** also assigned the role of ‘consultant’ to this friend (and some other friends) because of the close relationships between them, and because she did not want to share her personal problems with her family when they were far away.

*7.a “I know my family is very worried about my sickness, one thing because they are not able to look after me by themselves. They can’t see what things are happening with me as I am here. Thus, I won’t tell them about my problems as I know my telling will make them get higher stress than usual. So, as I can’t tell my family, I told him [7.c—her close friend]. I rang him to tell or consult about my problem. I know he is a friend that I can rely on, as we were a friend of each other for a long time with close friendship...” (C7, central woman, Gr Int, 7th visit, p. 15)*

The quote demonstrates **7.a**’s intention to protect her family from additional stress due to their lesser involvement in her network. Her friend (**7.c**) explained that his increased network contribution during her cancer journey resulted from his concerns not only about the disease, but also because of the limited support available with her extended family far away.

*7.c “When I have heard from her [7.a] as she got this disease, it made me shocked. I thought it was unbelievable as she was such a health-concerned person. ... I provided her a lot of encouragement and sought related information such as from books and asking my co-worker who has a family member with breast cancer... ... I’m really concerned about the personal support provided to her as she is not a local person like us. I sympathise with her as she is living separately from her family while getting this disease. It is definitely different from the southern local people as they have their family to support them. So, I have attempted to help her as much as I can... // I know the best support was from her family but they live so far from her by physical distance. When she got the surgery and her family was with her, I was not here. Now she does not have them. That’s why I am here with her”. (C7, close friend, Gr Int, 7th visit, p. 2-3, 13)*

Additionally, **7.a** and her family members identified some health professionals as supporters who could take over some activities instead of her family group. This was different from other networks.

*7.a “Now I am okay, I can manage my daily living. I also have planned forwards like if some things happen what I should do. Thus I already told my friend [7.c] if I go what things and how he could help my relatives manage... ...If any emergency happens, I think I will ring \_ [nurse] first or you [researcher], if you still are here. [Laughing] Why? I think\_ [nurse] has health-related knowledge and she is helpful. She preferred to help me as she used to tell me”. (C7, central woman, Int, 9th visit, p. 28)*

*7.b “[7.a] often told me about the good support she received from her doctor and nurses. She told me about you as well. She very appreciated your visits and helping her... // ...Even though we [7.b and other family members] are worried about 7.a’s sickness, I feel better when I know that she has good supporters there. Thank you to you and also to her doctor and nurses who have looked after her instead of us”. (C7, aunt, Tel. Int, p. 15)*

7.a provided very little information about the everyday and cancer-related support given by her neighbours. She did not identify any neighbours as her network members. Through my observations when I visited her at home several times, I did not recognise any socialising behaviours between the woman and her neighbours. However, many of her parents’ neighbours who lived in her hometown were mentioned as providing emotional support to her through her parents and sister.

*7.a “My mother told me via our everyday calling that many neighbours came to my parents’ place asking about my illness. For example, **ໂປ່ງ/ປາ/** [name]<sup>18</sup> who lives behind my parents’ home, she went to ask my mother that how my treatment is going and how well I am. This aunt, she lives alone and when I visited home I often gave her something such as food and went to her place and spent time a while with her... Another neighbour, **ໂປ່ງ/ປາ/** [name], she was diagnosed with breast cancer too and she is waiting for surgery. She came to my parents frequently to ask about my illness. ... I know they came to support my parents as well”. (C7, central woman, Int, 2<sup>nd</sup> vist, p. 5)*

The descriptions reflect the differences in support patterns between village and city communities as mentioned earlier.

Through mapping, 7.a identified her network members as shown in Fig 6.2, which was a family and friend-based network. Explicitly, family was the most significant members and their significance was not related to the quantity and/or quality of tangible support they provided. This network map had a large number of friends and some were located in core supporter group close to family members (**F1-3** in Fig 6.2). Similarly, three health professionals (including me) were counted as network members, as part of the significant supporters (**H1-3** in Fig 6.2). This number is quite large compared to other cases in which no

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<sup>18</sup> Thai people use specific prefixes to identify gender, age, relationship, and as well to present respect to others. For example, **ໂປ່ງ/ປາ/** means aunt, however, this word is also placed before a female name of people who are not relatives but seem older than parents. In the same way, **ອາ/ລູງ/** means uncle. It is also placed before the name of a male who is not a relative but seems older than parents.

members of the women's family were health professionals. The higher involvement of non-family members, including health professionals, was possibly a sign of a perceived lack of available support from family members. Furthermore, 7.a distinguished her friends into subgroups of significance, with different physical distances between her and her friends' names on the map; this might relate to the different network involvement of these friends (F1-3 in Fig. 6.2).

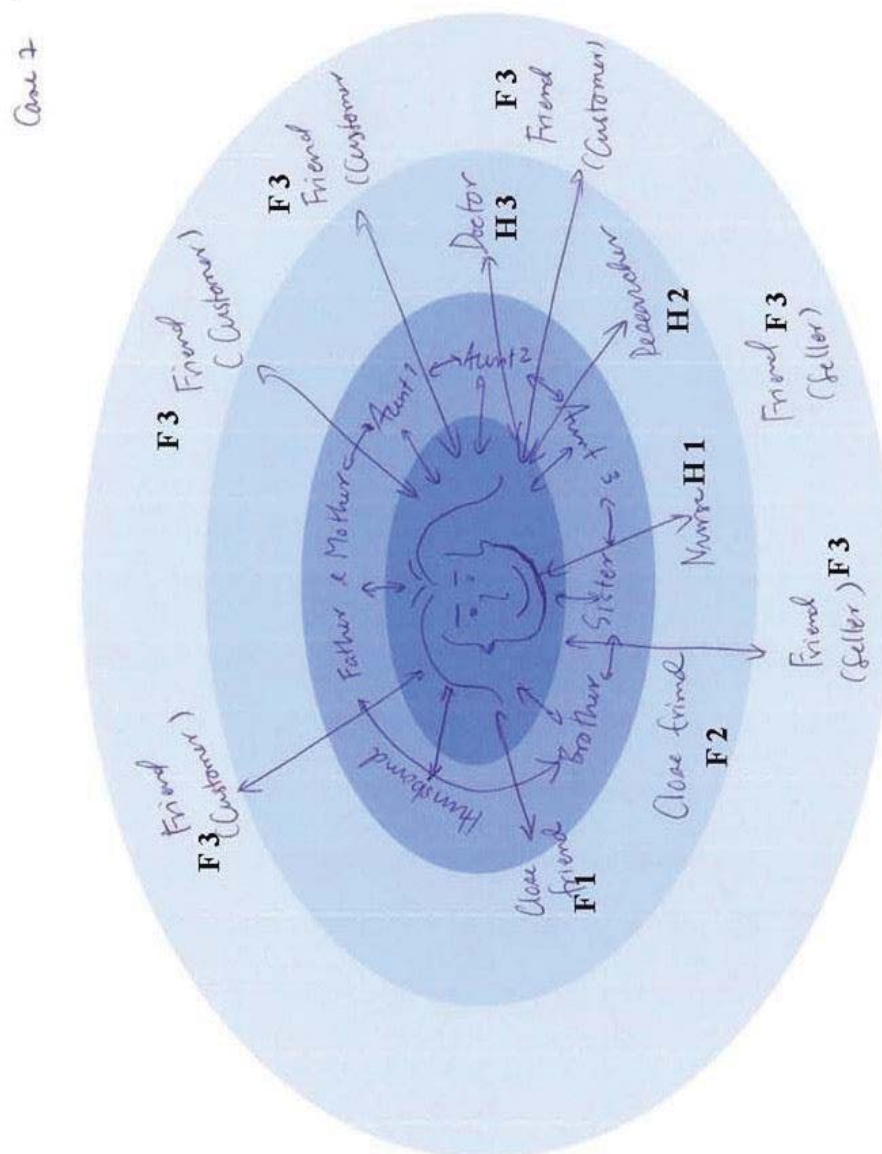


Figure 6.2. The network map of case 7.

## Case 8: A Muslim woman with two young children and an irregular income

**Table 6.3**

*Information of Case 8's Participants and Data Collection*

<b>Key participant</b>	<b>8.a:</b> a Muslim market woman who had two young children
<b>Cancer and therapies</b>	(Unknown stage ) breast cancer, diagnosed four months prior to study participation  Total mastectomy with partial lymph node removal and four + cycles of chemotherapy
<b>Financial support programme</b>	The programme of the universal coverage scheme
<b>The referral participants:</b>	<b>8.b:</b> the central woman's husband <b>8.c:</b> the central woman's mother
<b>Time and numbers of visits</b>	July to October 2012 Total = 8 At <b>8.a's</b> home X 5; at <b>8.c's</b> home X 1; at <b>8.a's</b> hospital X 1; and at <b>8.a's</b> market X 1
<b>Data collection methods</b>	Conversations, (in-depth) interviews, observations, and mapping

**8.a** was a Muslim market woman who married a fisherman husband and had two young children. The family income was irregular as it depended on selling seafood at a market. When the woman was diagnosed with breast cancer and then underwent prolonged treatment with many days stay in hospital, her husband took over as a main caregiver for her both in hospital and at home. The woman's illness and a treatment pattern led to more complexity in her family because these factors affected the family income and their children who were still dependent on their parents. They lived close to the woman's relatives, and her mother and siblings provided support to cover their job, children and also financial support. **8.a** felt uncomfortable relying on her relatives, especially for financial help, and therefore she returned to her normal life activities as soon as possible. As a result, a unique characteristic of this network was an early transition of family roles from being supporters to being facilitators and/or mentors for the woman and her family instead.

**8.a** was the second child of a Muslim family with nine children. Almost all her parents' children were married and some lived far away from their parents. Her father died one year before **8.a's** breast cancer diagnosis. When **8.a** was young, her family moved to live in a new community in a Muslim city suburb. Some community members had lived in this community for a long time, similar to her family. **8.a** and her other siblings had a few years of formal education. After school graduation, **8.a** was a factory worker for many years while still living from this job and she disconnected from those friends. **8.a** said her family had close relationships and connections and she was able to tell her parents about any issue in her life

and always received good advice.

Around 13 years ago, she married an older Muslim widower fisherman (**8.b**). Her husband came from a fishing family with seven children. He attended school for a few years and had one adult child with his first wife. When **8.a** got married; she lived with her husband and two young children in her house just next door to her parents' home. Her mother, now in her sixties, lived with two daughters and continued selling seafood at the market every day. One year before **8.a**'s cancer diagnosis, her father died; however, **8.a** felt an ongoing connection with him. She said when faced with any difficulties, thinking of her father could encourage her. After marriage, **8.a** began selling her husband's seafood at a local market (where her mother had worked for many years).

**8.a**'s registered health setting was a provincial hospital, just ten minutes by motorcycle from home. Four months before **8.a**'s participation this study, she found a painful lump in her breast. She twice went with her husband to see a doctor at her registered setting before being diagnosed with breast cancer.

*8.a "He [her doctor] said that my lump was possibly cancer and I should undergo micro surgery to check the lump cell first. If its cells were proved as cancer he would treat me with a mastectomy soon... At that time, I suppose that he did not tell me the stage of diagnosis and I didn't ask him as well... I don't know how to ask him about this..." (C8, central woman, Int, 1<sup>st</sup> visit, p.4)*

When **8.a** was diagnosed with the breast cancer, she was admitted to hospital for almost a month to undergo the breast cancer investigations and surgery. During her hospitalisation, a caregiver was needed and her husband took this role. This resulted in the disruption of the family income and changes in the ways to look after their children.

*8.a "when my doctor told me that I had to be admitted on that day for a surgery I had no chance to go back home to prepare things. Thus, when I was at the ward already, my husband went back home and took my kids to my mom's place [next to her home]... During my hospitalisation, my husband was with me every day and night, and then my kids stayed with **Ma** [mother] and my sister until I was discharged from the hospital. My kids came to me at the hospital every day after school and slept with my mom every night... At that time, my husband didn't go to the sea for fishing, thus my mom gave me the money. ... When I was undergoing the chemotherapy as the OPD case, my husband was able to go to work and my mother sold his seafood instead of me. Thus my mom didn't give me money then. ..." (C8, central woman, Int, 5<sup>th</sup> visit, p. 8-10)*

The quote describes the sudden effects the pattern of breast cancer care had on the whole

family's daily life. These effects included the short-term suspension of the woman's daily work and in her caregiver role for their dependent children. This family then was reliant on the support from **8.a**'s relatives, particularly those who lived close to them for a period of time for both financial support and childcare. These children had temporary changes in their living environment and the people who looked after them.

The study engagement started with **8.a** after she finished the third cycle of chemotherapy. However, **8.a** was unable to look after her children after her chemotherapy as she had before getting breast cancer. Thus these children became more independent.

*8.a "Both of them are such a good boy and girl. When I had vomiting, my girl said 'Don't worry **Ma** [mother] you will get better soon' and she used her hands to rub on my back like an adult's behaviour...[laughing] ...my boy didn't do like this as he is a male... For the boy, his **Pa** [father] has trained him to do simple cooking and washing the socks for his younger sister and himself, such a good boy. ... Both of them now can go to school and come back home by themselves, they ride a bicycle..." (C8, central woman, Int, 6<sup>th</sup> visit, p. 5-6)*

Uniquely, the early shifting of roles of **8.a** and her network members with the intent to reset patterns of normal life can be observed.

[Half way through the chemotherapy cycles]

*8.a "Next week I will go back to the market to sell my seafood. I think I can do it as I am better now".*

*8.c "The last two or three days ago, she asked me if can she come back to the market. Thus, I told her that she'll start with going out to relax first. Then yesterday she and her children went out to participate with the festival on the beach. ..."*

*8.a "Yes, I went there with my family and I was fine".*

*(C8, central woman, Int, 5<sup>th</sup> visit, p. 12)*

[One month later, at the hospital]

... I met **8.a** at the chemotherapy unit. She told me that in the morning she came to the hospital by a public motorcycle as her husband had gone to the sea for fishing in the early morning. After finishing her chemotherapy today, it will be afternoon; her husband will come to the hospital to take her back home. After the hospital she will go to the market to sell the seafood. She said '**I have no choice** but if today I am not well enough, I will go there tomorrow'...  
*(Fn, hospital observation, 20 September 2012)*

The two excerpts above reveal how **8.a** intended to re establish her normal life even when she was still unwell. Regarding the woman's statement '**I have no choice**', the feeling of discomfort (and *เกรงใจ/Kreng-jai*) about the dependency on relatives' support, particularly the financial burden, forced the woman to attempt on early return to her family responsibilities. When **8.a** attempted to go back to her market job to sell her husband's seafood by herself, her mother (and her siblings) still kept an eye on her and her family, and if necessary, support was provided by them. Specifically, her mother took over the roles of consultant and mentor instead.

*8.c "I told my daughter[8.a] like she should do exercise too. She could not only stay inside her house. In the morning she should go out for walking around here. This will help her get better, recovered from the chemotherapy side effects... // ...Many friends and acquaintances suggested she use other kinds of medicine or supplements, particularly those who used to be cancer patients... One is my customer. She said to me ... But I told her [8.a] doesn't use it. I think she should wait until the hospital treatments are finished. It is okay to use some supplements as an adjunct to the hospital medication. Now she is having \_ [a supplement's name] every day, I bought it for her ..." (C8, int, 2<sup>nd</sup> visit, p. 20)*

I went to the local outdoor market where **8.a** and her mother were selling their seafood at around 4pm. **8.a** with Hijab was sitting beside her mother. Both of them had their own products to sell for their customers. I saw **8.a** was selling her seafood to one customer. When I walked close to her, she was looking at me and smiling. She said her husband just brought her and his seafood to the market around 30 minutes ago with his motorcycle trailer. And he will come back with her children at around 5 to 6 pm to pick **8.a** up to take home. It depended when she finished her job... When her mother was free from her customers, I went to talk to her. She described her market friends to me, who was close to her and had a long- term relationship and she pointed out a friend who had a daughter with cancer diagnosis and had suggested a herbal medication for **8.a**... (C8, Fn, 2<sup>nd</sup> visit, market)

The two quotations above also demonstrate that support provided by non-family members both direct and indirect to her, however, these supporters tended to have long relationships with her or her family members.

Specific features unique to the Muslim cases were also demonstrated in this case, **8.a** said when she and her family had known about her cancer, her husband guided her to keep thinking about their children and then she just focused on completing the therapies. Her mother reminded her '*As everything happens in order of Allah, so we just accept it and then keep going with it as best as we can.*' These were efficient ways to empower her to continue

with therapies. Similar to case 5, having a spiritual connection with **Allah** through religious practices was a significant support for **8.a** and her family. Again, **Allah** did not appear on the network map.

The family-based network map was depicted by **8.a** as shown in Fig. 6.3. Interestingly **8.a** included her deceased father as a network member and put his name in her network map (\* in Fig. 6.3). The network contains a combination of cancer-related members split between hospital-based and normal-life, similar to case 2 (**CA1-3** in Fig 6.3). Furthermore, no health professionals were identified as network members, possibly as a result of the way **8.a** perceived the quality of services she had received. Different from other cases, in the network map the woman identified the significance of her family by marriage (**Fm circle** in Fig. 6.3) as more than her family by blood (**Fb circle** in Fig. 6.3). This was confirmed by her explanation through our network discussions:

*8.a “ How they are significant for me? For my children and my husband, they are the most significant. If I compare them with my organs, they are as my heart, it is the vital organ. For my father, mother and my siblings, they are significant for me as well. However, they are as my eyes, arms or legs something like that. For others who are not my family, they are as other organs which are not significant for me much... You know, sometime felt like I love my children and my husband more than I love myself”. (C8, central woman, Int, 6<sup>th</sup> visit, p. 1)*

Case no. 8

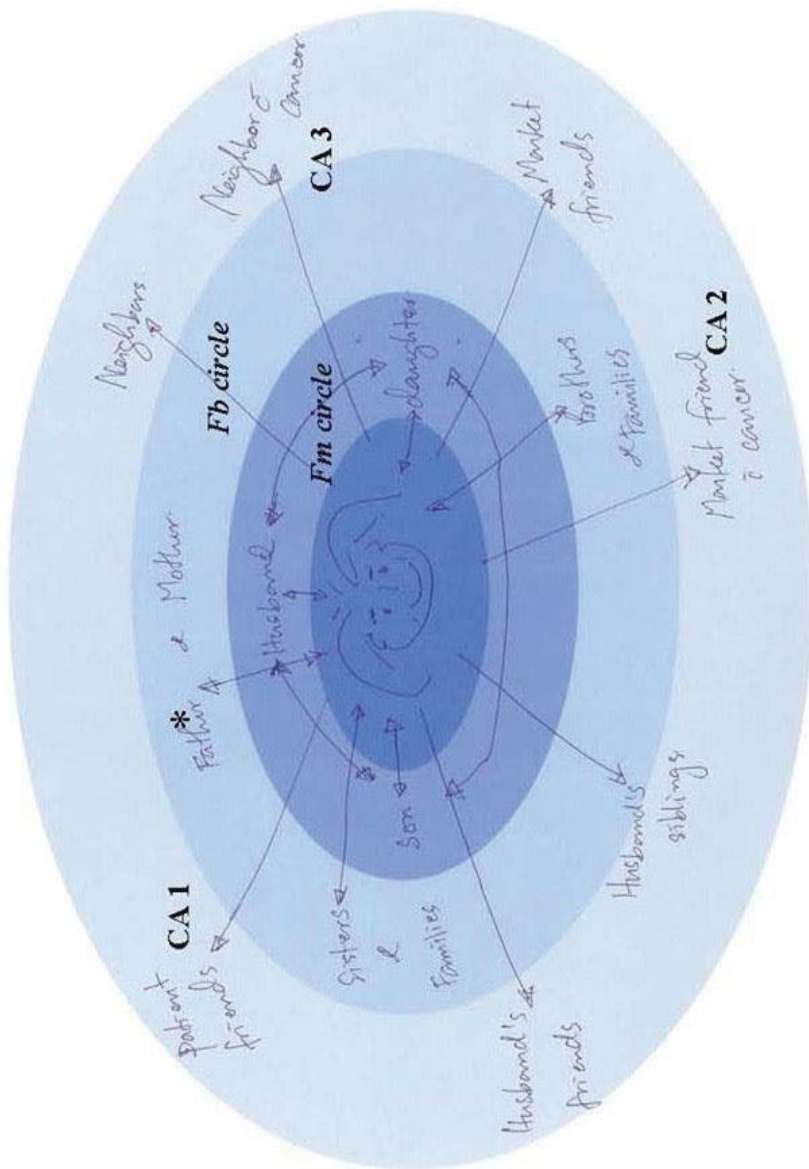


Figure 6.3. The network map of case 8.

## Conclusion

In the previous chapter ‘**family**’ was identified as the most significant part of networks. This section revealed how ‘**family**’ influenced support needs and the ability to provide support among network members related to complex family circumstances. Consequently, networks adjusted to maintain the flow of support. Undeniably, family was always the first group to adjust their activities to counter the family complexities. Further, adjustment within the non-family group occurred to support family members and/or provide the support perceived as lacking. Additionally, at times there were examples of where supporter roles transitioned in response to the family complexities. This occurrence of (early) network transition could be influenced by illness-related situations, normal life-related situations, relationships or socio-cultural values.

The seven cases presented in this and the previous chapters provide examples of the significance of ‘**Family**’ in networks. Families provided major support resources for the central women’s networks, while living with breast cancer in many situations. At the same time, family complexities could coexist that resulted in additional support demands and influenced members’ ability to provide support in networks. Accordingly, family-related circumstances had a great impact on the network characteristics. Due to ongoing interactions between situations related to breast cancer, the health system, and normal living circumstances of individuals (including family-related situations) family adjustments occurred throughout the journey to maintain support flow in networks. Adjustments within the family always occurred before those of non-family members. Within the non-family group, people with closer personal relationships seemed have more chances to contribute in a network, when there was a perceived imbalance in the support provided. The next chapter will present the other four cases. The characteristics of these networks relate to the interplay between family and health service circumstances.

## CHAPTER 7

# Living with complexities in health services and family circumstances

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### Introduction

This chapter continues with an in-depth exploration of the holistic life experiences of selected cases to enable deeper comprehension about these networks. Four cases were chosen that reflect the interplay between complexity of the health service and family circumstances, and how these factors result in the specific patterns of individual networks. In this chapter, the first category relates to the complexities in breast cancer management and family circumstances, and the second category focuses on a breast cancer club as a specific type of support for women with breast cancer.

### Living with breast cancer management and family complexities

‘Complexities in breast cancer management’ can be caused by the disease itself and / or the health system at both national and setting levels. Divergent patterns of breast cancer management were observed in some cases where women had more complicated investigations and therapies than others. As mentioned previously, the interplay between three situations related to disease, health system and normal living always occurred throughout the journey. The following two cases illustrate how breast cancer management interacted with individual family circumstances and then resulted in the unique characteristics of each network.

## Case 4: A single woman with cancer recurrence from an extended family with three cancer patients

**Table 7.1**

*Information of Case 4's Participants and Data Collection*

Key participant	<b>4.a:</b> a caregiver of eighty-year-old parents in a family with three cancer cases
Cancer and therapies	<p><b>1<sup>st</sup> time</b> First stage of breast cancer without lymphatic invasion, diagnosed around five years prior to study participation</p> <p>Total mastectomy and six cycles of chemotherapy</p> <p><b>2<sup>nd</sup> time (Doc)</b> Recurrent invasive ductal carcinoma of right breast, sternum and rib metastasis, diagnosed around one and a half years prior to study participation</p> <p>Six cycles of chemotherapy; 30 doses of radiation therapy; wide excision of tumour with resection of sternum and ribs and followed with prolonged chemotherapy (25 cycles +)</p>
Financial support programme	<p>1.The programme of the universal coverage scheme</p> <p>2.The breast cancer drug trial project</p>
The referral participants	<p><b>3.a:</b> the central woman's nurse sister with breast cancer</p> <p><b>3.b:</b> the central woman's nephew (and <b>3.a</b>'s son)</p> <p><b>3.c:</b> the central woman's mother (and <b>3.a</b>'s mother)</p> <p><b>3.d:</b> <b>3.a</b>'s co-worker</p>
Time and numbers of visits	<p>January to April 2012 and July to September 2012</p> <p>Total= 18</p> <p>At <b>4.a</b>'s (and her parents') home X7; at <b>4.a</b>'s hospital X 2; and at <b>3.a</b>'s office X 9</p>
Data collection methods	Conversations, (in-depth) interviews, electronic interviews (e-mails), observations, participatory observation and mapping

(\*See case 3 in Chapter 6)

**4.a** was a single farmer who was first diagnosed with breast cancer at the same time as her younger sister (**3.a**). The characteristics of this network during the first diagnosis were integrated into case 3 as shared networks of two sisters in the previous chapter. Around two years after her first diagnosis, **4.a** was diagnosed with a recurrence of her breast cancer with metastasis to her chest wall. She underwent complicated therapies to control the metastatic progress for more than two years and was still receiving chemotherapy at the end of my data collection. The complexities in her journey resulted from the advanced diagnosis with recurrence of her breast cancer including the complicated situation in the family with three cancer patients. Once the woman was diagnosed with a cancer recurrence, her support network quickly re-formed and made diverse adjustments for maintenance of the network function to continue the support flow to enable **4.a** to live as normal a life as possible with breast cancer. These network characteristics were underpinned by the family's previous experiences of living with cancer, their degree of family cohesion, and an increased family capacity to adjust the support they provided.

**4.a** lived with her parents and **3.a**'s family as an extended family and was a caregiver at home for her parents with chronic illnesses (as discussed in Case 3 in the previous chapter). Around five years ago, **4.a** was diagnosed with a first stage breast cancer and during living with her first cancer diagnosis; **4.a**'s support network was created and functioned as 'sharing networks' with **3.a**'s network.

After completing treatments following her first diagnosis, she was able to return to all her responsibilities she fulfilled before her illness. Later, one and a half years before the study engagement, she found a solid and painful node on her sternum. She again told her sister (**3.a**) and they went together to see a doctor who worked at **3.a**'s workplace the next day. The doctor referred her to the university hospital, which was around two hours away by public transport, for more investigations and treatment. After investigation, the doctor said that her breast cancer had metastasised to her sternum and ribs. Before her second surgery, the first therapeutic set included 30 doses of radiation and six cycles of chemotherapy. Afterwards, her second surgery was conducted by three specialists, a general surgeon, orthopaedic surgeon, and cardiologist.

*4.a "I was in the theatre for many hours and this made my family members very worried about my condition. When they were with me at the ward after the operation, they told me that they wondered if I would not come back [laughing]. My eldest sister cried a lot when she saw I was on my bed after operation because she was in empathy with me... //...My doctor told me that he had to take some of my muscle from my right chest wall off with two rib pieces. So, I have to be careful about this as my chest is not complete as previously. Have to be careful about any stamping. Thus, my mother suggested that I modify my bras.. I added supporting materials into my bras to make them thicker than usual to protect my chest wall. Have a look,..." (C4 & 3, central woman and sister, Int, 5<sup>th</sup> visit, p.4)*

The diagnosis of **4.a**'s recurrence re-focused the network attention on providing support to encounter this family challenge. This might be influenced by previous experiences with cancer of this family. At that time the father was still living with the intermittent symptoms related to his cancer (and/or its treatments), while **3.a** also developed symptoms during her follow up period and had to keep monitoring them. The pattern of family support when **4.a** was living with the recurrence differed from the support pattern when she was living with her first diagnosis.

**4.a** decided to participate in a breast cancer drug trial because this project provided her with free access to further investigations and therapies related to her breast cancer and also support for travel costs.

*4.a* "...When I visited my doctor after my operation, he said I needed prolonged chemotherapy to control the metastasis and he would send me to the project about the breast cancer drugs experiment if I wanted. At that time I went to the hospital with my eldest sister and this situation was so complicated for us to make decisions. Hence I rang *3.a* to have a phone discussion with my doctor. Further, *3.a* suggested I participate with this programme as I could get good treatments, including financial support from the programme. Accordingly, I have been involved in this programme since after my surgery until now". (C4 & 3, central woman and sister, Int, 5<sup>th</sup>visit, p.4-5)

This decision, although it benefited the woman, also led her breast cancer management to become more complicated. She had to frequently attend the hospital and each chemotherapy cycle was 21 days. In addition, between every two cycles of chemotherapy, her cardiac, liver and lung functions were monitored through electrocardiography (ECG) and Computerized Tomography (CT scan). At one of her doctor visits when I was with her, her doctor told her that even though the 24 cycles of post-operative chemotherapy were done, her chemotherapy had to be continued to control the metastatic progress. It means *4.a* had to continue with chemotherapy as long as she could.

During living with *4.a*'s cancer recurrence her network members, especially family members made many adjustments to the support they provided. *3.a* (the nurse sister) seemed to reduce her support level to be a 'consultant' rather than a 'caregiver'. *3.a* told me that because of the recurrence of her sister's cancer and the intermittent occurrence of her own symptoms, she recognised the unpredictability of life. She decided to change her method of supporting other family members to encourage her sister to depend on herself more than relying on her support, in particular, related to the processes of using health services and also making simple decisions about her health. *4.a* told me that during her second time of undergoing long term treatments, she tried to depend on herself as much as she could. This intention underpinned her concerns about the burdens on her supporters, such as her younger sister breast cancer patient, the main supporter in the family, and the mother of her beloved boys (the two sons of *3.a*). *4.a* commented:

*4.a* "My second turn of undergoing investigation and treatments, I mainly went to the hospital alone by public transportation. ... In case any complicated decision was needed, consulting my sister via phone was used. Sometimes, I let my doctor and/or the nurses have direct conversation with my sister via phone because I had low education and less skill of literacy and something the doctor or the nurse explained to me was very hard to understand..." (C4 & 3, central woman and sister, 10<sup>th</sup>visit, p. 22-23)

The quotes above and below also illustrate that **4.a** developed a lot in her capacity to manage facilities and processes to access to her health services by her own.

*4.a “At the hospital, if I could not understand information given by health professionals, I rang my sister to discuss with them instead of me or I asked for a written form from them. Then I could take the written one home to ask my sister to explain about it to me later. ...// In case I was asked to fill in any document, as I have just a few years in school, so I have limitation in writing. So, I asked help from any officer at a unit to write it for me. Previously, I was embarrassed to do this. Now, it is not a problem [laughing].” (C4 & 3, central woman and sister, Int, 13<sup>th</sup> visit: p.15)*

*4.a “When I went to see the doctor in the morning and then received the chemotherapy in afternoon. I had everything in my handbag such as a packet of biscuits, a milk box, a bottle of water, and some cash. If visiting doctor took longer time than usual and made me have not enough time to have lunch before getting the chemotherapy, I will eat some biscuits instead. I also had a cell phone number of the public transportation driver, I rang him before time a bit and then he would take me from the hospital to home. ...” (C4 & 3, central woman and sister, Int, 10<sup>th</sup> visit, p. 24)*

The other family members, such as the eldest sister and her daughter (and her family), had to increase their contribution levels in the networks not only to support **4.a** but also to lighten the load of other supporters.

*4.a “Sometimes I had to ask my eldest sister to accompany me to the hospital in case I needed a caregiver with me and others were not available. ... This sister was not well because of her chronic pain in her knees and I was concerned about her pain. So I seemed to take care of her instead [laughing]. Another thing, we didn’t know how to use an elevator. At the hospital together it was so funny that we had to wait for somebody to come to use an elevator and asked them to help us...// ... At that time as I went to the hospital for the blood transfusion, so I just need someone with me if anything unexpected happens. ...Fortunately, at that time I had allergic symptoms during the blood transfusion that after the blood transfusion started for a while I felt itchy all over the body and she told a nurse to observe my symptom and a nurse gave me the anti-allergic drug injection. ... //...Later, my niece who is this sister’s daughter came to the hospital and trained me how to use an elevator. Now it is not my problem. The niece also stood by to help me as she and her family lived there. After each time of receiving the treatment if I need her support such as for taking me to a bus terminal or if I am not well enough to go back home and want to stay overnight there, easily, I just ring her and then she and her husband will come to pick me up from the hospital after work ...”(C4 & 3, central woman and sister, Int, 13<sup>th</sup> visit, p. 2-3, 6)*

The quote above reveals that **4.a** had developed many new skills such as her management skills and also how to use an elevator, so she could look after herself during hospital visits with complicated medical procedures. The lesser dependency on other family members meant more opportunities for the family members to look after her parents and her beloved boys and also her sister had more time to look after herself.

The family members who lived far away also had adjustment in their support roles for **4.a**. Since **4.a** was diagnosed with the recurrence, they regularly delivered emotional support to **4.a** to encourage her continue with her prolonged treatments. **4.a** said the calls from her two boys twice a day, from her youngest sister who lived far away every day, and occasionally from other siblings were encouraging to her. Especially, she waited for her beloved boys' calling every day:

I was with **4.a** at the hospital to observe her experience and her social life. She went to hospital for her routine scans and check up. Normally, her visit would be finished at around six pm. Unfortunately, on that day one of scanning machines was dysfunctional, so **4.a** spent a longer time than usual at the hospital. While waiting for the scan, I saw she answered phone calls several times...//

...After finishing her scanning, she was with me as we drove back to home. **4.a** told me that at hospital **3.a**, her nephews (**3.b** and his brother), and her brother rang her to ask about her check up and then they knew that **4.a** was with me. She said for today her nephews made special calls to her as they knew the dates she had to go to hospital and they wanted to know the check up results...//

...Today her brother surprised her with his call because this brother did not ring her frequently and she also had a phone talk with the brother's daughter too. Even though it was such a short conversation with a few sentences, it could make her happy...//

...On the way to home, **3.a** rang **4.a** again. **4.a** told me that **3.a** would collect her from my home to go back home and their mother had cooked dinner for **4.a** and was waiting for her go home to eat it. Finally, we reached my place at around ten pm. and **3.a** was already waiting for us in her car in front of my home. (C 4& 3, Fn, 12<sup>th</sup> visit, hospital)

Furthermore, **4.a** mentioned the support she received from her relative's family who lived close in a village, a group of friends in normal life, and some patient friends who shared experiences of hospitalisation and their connections were always remembered and impressive.

During her cancer journey she carried on her responsibilities in the family, particularly the

caregiver role for her parents, as much as she was able.

*4.a* “I don’t want to live longer, I don’t mind if I will go soon. However, I just want to go after my parents because I want to look after them until they go...// All of my siblings have their families to look after. Thus I am the suitable person to take this role for them”. (C4 & 3, central woman and sister, Int, 17<sup>th</sup> visit, p. 15)

One week before I completed my fieldwork, her mother was admitted in hospital to receive treatments for an infection. While *3.a* managed the mother’s treatments, *4.a* was the mother’s caregiver at the provincial hospital, the same roles and responsibilities they used to carry in the family before having breast cancer.

Finally, *4.a* depicted her network map as shown in Fig. 6.1 which was family based. Her network map had a large overlapping area with her younger sister’s network map (See names with \* in Fig 7.1 and Fig 6.1 in Chapter 6). Health professionals counted in case 4 were a smaller number than case 3 and these health professionals had personal relationships with *3.a* (H1-2 in Fig. 7.1). The presence of all non-family members who were counted in networks was underpinned by the woman’s feelings of gratitude for their support provided to her, reflecting the Thai values.

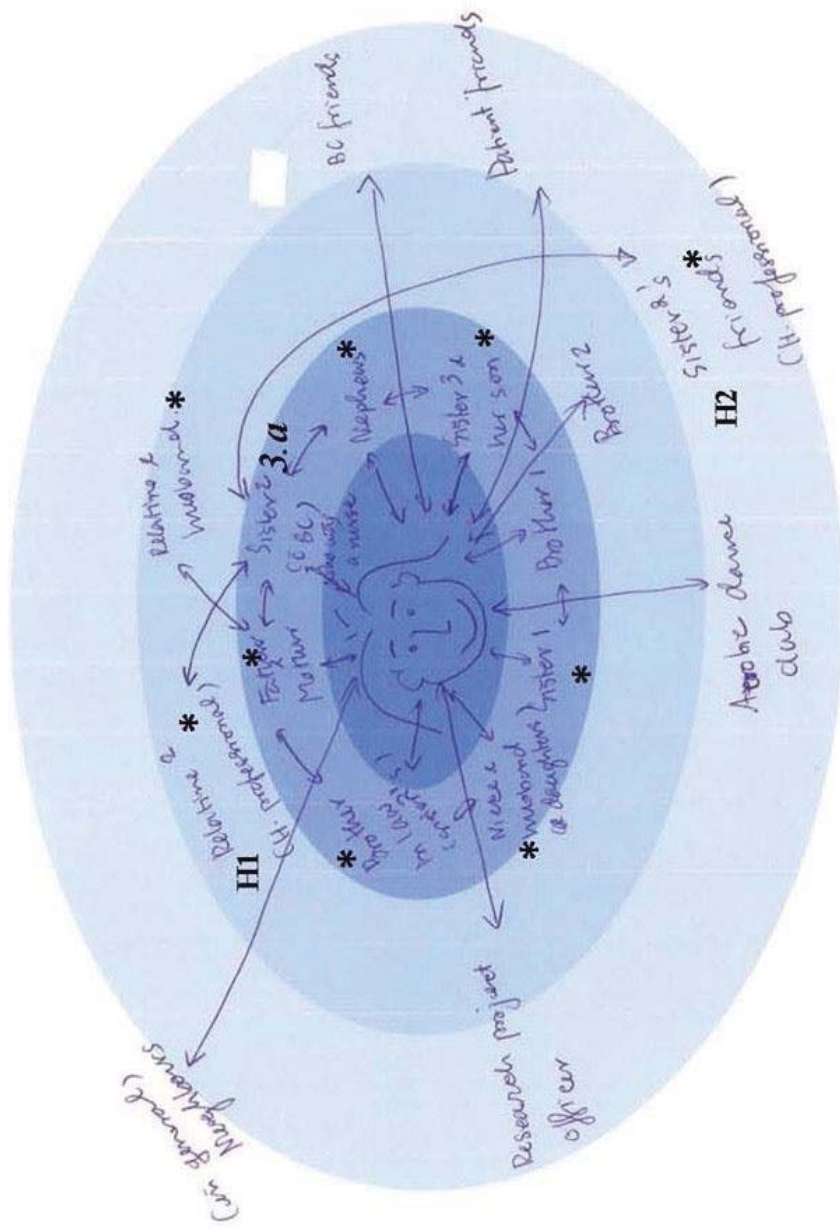


Figure 7.1. The network map of case 4.

## Case 9: A single Muslim woman living with a bedridden mother and involvement with several settings for treatments

**Table 7.2**

*Information of Case 9's Participants and Data Collection*

<b>Key participant</b>	<i>9.a</i> : a single female Muslim living with her bedridden mother in a remote area
<b>Cancer and therapies:</b>	First or second stage breast cancer, diagnosed nine months prior to study participation  Breast conservation surgery without lymph node removal; eight cycles of chemotherapy, and 30 doses of radiation therapy
<b>Financial support programme</b>	The programme of the universal coverage scheme
<b>The referral participants:</b>	<i>9.b</i> : the central woman's niece
<b>Time and numbers of visits</b>	August to October 2012 Total = 5 At <i>9.a</i> 's home X 3; at <i>9.b</i> 's accommodation X 1; and at <i>9.a</i> 's hospital X 1
<b>Data collection methods</b>	Conversations, (in-depth) interviews, observations, and mapping

*9.a* was an unmarried Muslim woman living with her bedridden mother alone in a remote area. When the woman was diagnosed with breast cancer and involved with a number of settings to treat her disease, each setting provided care within different patterns (as mentioned in chapter 1), therefore different knowledge to access and utilise services was required. Many difficulties in access to care and continuing with long-term breast cancer treatment were perceived. When these difficulties interacted with the family complexities of the family living pattern and the residential environment a gap occurred between the support provided and needed. Support was needed related to the illness, daily living, and family responsibilities. As a result, there was a high level of involvement in the network of non-family members. However, for this case, neighbours (with kinship relationships) were reported as having more contribution to the network than, for example, friends and this resulted in a pattern of support underpinned by the religious collective identity.

*9.a* was the youngest child of a Muslim farming family with six children. Her parents were rubber tree farmers who lived in a village of mixed Buddhist and Muslim members in a remote area. All children, except the eldest, graduated from tertiary education and worked as employees of (non) government institutions. All of *9.a*'s siblings were married and lived with their families scattered through the lower southern region of Thailand. When *9.a* graduated from high school, she moved to live with one brother's family (*9.b*'s family) in a city for her university study. After graduation with a bachelor's degree, she worked as a teacher for a private school for five years while still living with this brother's family. *9.a* claimed that living close to family was important. One of her family's routine activities was

a daily phone conversation. Many years ago, her father died and her mother then lived alone. Around two years before **9.a** was diagnosed with breast cancer, her eighty-year-old mother fell and then was bedridden. After this accident, her mother could not live alone and although she tried to live with many children, she was not happy living in unfamiliar environments. Finally, one year before her breast cancer diagnosis **9.a** decided to resign from her job and moved to take over as her mother's caregiver at her mother's home. This move affected **9.a**'s social life as she left her familiar environment and network in the city to live in an agricultural environment at her hometown. This change also made her lose contact with previous friends.

One year before **9.a**'s breast cancer diagnosis, one of her sisters was diagnosed with breast cancer and was treated in the university hospital. During her treatment, she was well supported by her siblings including **9.a**. Later, nine months before her participation in this study, **9.a** found her breast lump and was diagnosed with cancer. After that, unlike her sister, she engaged with **five** different health **settings** for breast cancer investigations and treatments. **9.a**'s initial access was with a specialist's private clinic as she wanted to be referred to the university hospital with which she and her family were familiar. However, as **9.a**'s health-related costs were covered under the universal coverage scheme, she had to be referred by her registered setting (a district hospital at her hometown) to the provincial hospital in town. Unfamiliarity with the provincial hospital services and the physical distance between this setting and her siblings' homes were perceived as barriers by **9.a** and her family. Therefore, this network was expanded in its non-family sector to include a facilitator, someone with the specific skills that were missing. **9.a** reconnected with her high school friend, who was now a provincial hospital staff member, to ask her to facilitate access to the hospital services:

*9.a "My sister was treated by the university hospital but I had to be treated by the hospital in town because I was under บัตรทอง/Bahd-dhong/ programme [the financial programme of the universal coverage scheme]. Previously, my family had never used this hospital's services and its location was far from my siblings' living places too. Thus I had to reconnect to my high school friend who is a nurse and works there. \_ [friend's name] helped me to make an appointment with the surgeon and managed my admission".(C9, central woman, Int, 3<sup>rd</sup>visit, p. 7)*

After surgery, **9.a** requested to be referred from the provincial hospital to the university hospital for further treatments, because this hospital was the tertiary level hospital and was closer to her brother's home and this brother and his family would be better able

to provide support to **9.a**. This family was familiar with the university hospital and its services. However following health system rules, she was referred to the regional hospital for chemotherapy. Later, she was referred to the university hospital for radiation therapy, the only setting in the region that could deliver this treatment. Furthermore, differing doctors diagnosed different cancer stages leaving her unclear about her diagnosis.

*9.a "I thought I was told by the doctor at the first setting that I was diagnosed with first stage of breast cancer. At the second hospital where I underwent chemotherapy, the doctor said to me it is the second stage of breast cancer, then after chemotherapy I should undergo radiation therapy and he referred me to the university hospital for radiation therapy. These made me unclear about my diagnosis. I think I will ask my doctor when I visit him next time to make me clearer about this". (C9, central woman, Int, 5<sup>th</sup> visit, p.20-21)*

While undergoing the course of 24 weeks of chemotherapy at this regional hospital, the central woman lived with her mother at home, around one and half hours drive away. Therefore, during this time the woman needed a range of support including assistance with travel, physical and emotional support during the chemotherapy in the hospital and travelling back home and also daily support during the recovery period at home. Additionally, a caregiver was needed to take over her duties in caring for her bedridden mother. As a result, her family members and her relatives who lived close to her house were involved in taking turns with these support roles when possible.

*9.a "...During undergoing the chemotherapy, firstly my nephew was with me and mom, but he was not able to look after us. ... Sometimes, if my brother got the days off he was with us for two or three days each time. During my nieces' semester break, they stayed with us and looked after me and mom. ... However, at many times that I had no family members with me at home. ... Around one week after receiving the chemotherapy, I felt discomforted inside my body as I felt sick, hot, nauseated and edgy. Then sometimes, I was not able to dress as the good female Muslim should do, so I didn't go out, just stayed in my room and sat in front of a fan. ...Fortunately, our place was surrounding by my parents' relatives. The male relatives could not come inside our place if none of my male family were at home. Thus, they just came to the outside area and asked me if there was anything I wanted, or they visited me and mom when my brother was home. Three of my female relatives who live close to me, kept observing us, especially if mom and I had nobody with us at home. They came to prepare food and things for me and mom... They came when we had nobody to support us; I knew they kept observing us to see when we would need support from them ..."* (C9, central woman, Int, 4th visit, p. 8 &10)

In the quote above the influence of religion and social culture on the performing of support roles is evident. However, **9.a** and the network members worked out ways to keep the

support flowing in the network by ‘**watching out**’. With the complexity within living patterns of **9.a** and her family members, there were a number of times that **9.a** hesitated to ask for any support from her family and / or non-family members because she was concerned to put a burden on her supporters.

*9.a “Sometimes, I didn’t tell my brother when I went to hospital. I used a public minibus to the village centre and then transited to a public van to my hospital... Why didn’t I ask help from them? If they reluctantly replied to my asking for help, I felt discomforted about this. However, when my brother knew that I went to hospital by myself, he felt unhappy. I know they were concerned about me.” (C9, central woman, Int, 2<sup>nd</sup> visit, p. 5)*

Focusing on the group of friends, **9.a** had moved from the city, where she had lived for many years, to live with her mother in her hometown about one year before she was diagnosed with breast cancer. This situation caused not only the changes in her daily living, but also changes in her social life. Living for a short time in new environment meant that she did not feel unified with the community. Moreover, it disconnected her from her previous social life and social support and as a result there was less involvement of friends in her network.

*9.a “As I just moved to living here for a few years, I had few friends here. Before getting this disease, I frequently went to the hair salon at the village’s centre and participated with the exercise group of the health centre, so I had some friends here but they were not close friends. ... but sometimes you know we had differences in the interesting things... ... Since I got this disease, I disconnected from these friends such for a period of time... ...For my old friends, either my university or working friends, we still have connection as they or I ring to each other occasionally. These friends know about my illness as they rang me by accident when I was not well after receiving my chemotherapy”. (C9, central woman, Int, 3<sup>rd</sup> visit, p. 9 & 10)*

Lastly, **9.a** also required radiation therapy after the chemotherapy. This required involvement in the fourth setting—the university hospital. During the six-week course of radiation therapy, she had to travel to the hospital five days per week. To reduce the burden of travel, during the week she stayed with her niece who was a university student in the dormitory near the university hospital. She then went back home during the weekends to look after her mother. During this time, her brother stayed with her mother at home as much as he could. However, sometimes he was unable to get time off work and then he could only visit his mother in the evening for a short while. This network, however, continued finding the way to maintain support flow in the network; including through ‘**the open window**’.

I met **9.a** [the central woman of case 9] at the hospital canteen on the last day of her radiation therapy and we went to her home together in my car. On the way to her home, her brother rang

*9.a* twice at least to check where she was and if everything was okay for her... // ...We reached her home at around 2pm, I saw the house window was open but the door was locked. She unlocked the door and called ‘**Ma**, have a look who comes with me’. And she led me to her mom’s room to say hello to mom. The mom was on her bed and beside her bed was a little table with things such as food and water and **Al-Quran** book... // ...*9.a* told me that when she is away and nobody is at home with her mother, she will leave her mother’s window open like this ‘as our relatives can come to deliver food (and things) for mom through this window and they also could observe or check mom’s condition through this window as well’... // ...before our interview started, she asked me for time to change her mother’s clothes first. (C9, Fn, 2<sup>nd</sup> visit, hospital and home)

Through network mapping, *9.a* identified her family and kin-based network during living with her breast cancer as shown in Fig 7.2. Importantly, *9.a* identified non-family members as core supporters. In this case, the three female relatives (**R** in Fig. 7.2) were counted at a similar level of significance as the significant family members such as her siblings and their family. This might result from the tangible, daily support they provided to the woman and her mother without request. This is similar to the findings in case 7. For this case (*9.a*), network members with direct experiences of cancer comprised only family-based members, they were her older sister (**CA1** in Fig 7.2), and relatives with cancer diagnosed before and after her diagnosis (**CA2-3** in Fig 6.2). This demonstrates that the sharing of experiences occurred through participation with breast cancer club activities, and also through personal contacts or informal activities. Even though many friends (and their families) were named in the network map of this case (**F1-5** in Fig. 7.2), *9.a* mentioned that their involvement was less significant and a lesser contribution when we talked after the mapping exercise. The exception was her nurse friend who helped her navigate through the health system (**F1** in Fig. 7.2). This affirms that a discussion about the network after a mapping exercise is a significant step to help understand the reality of network experiences.

Case 9

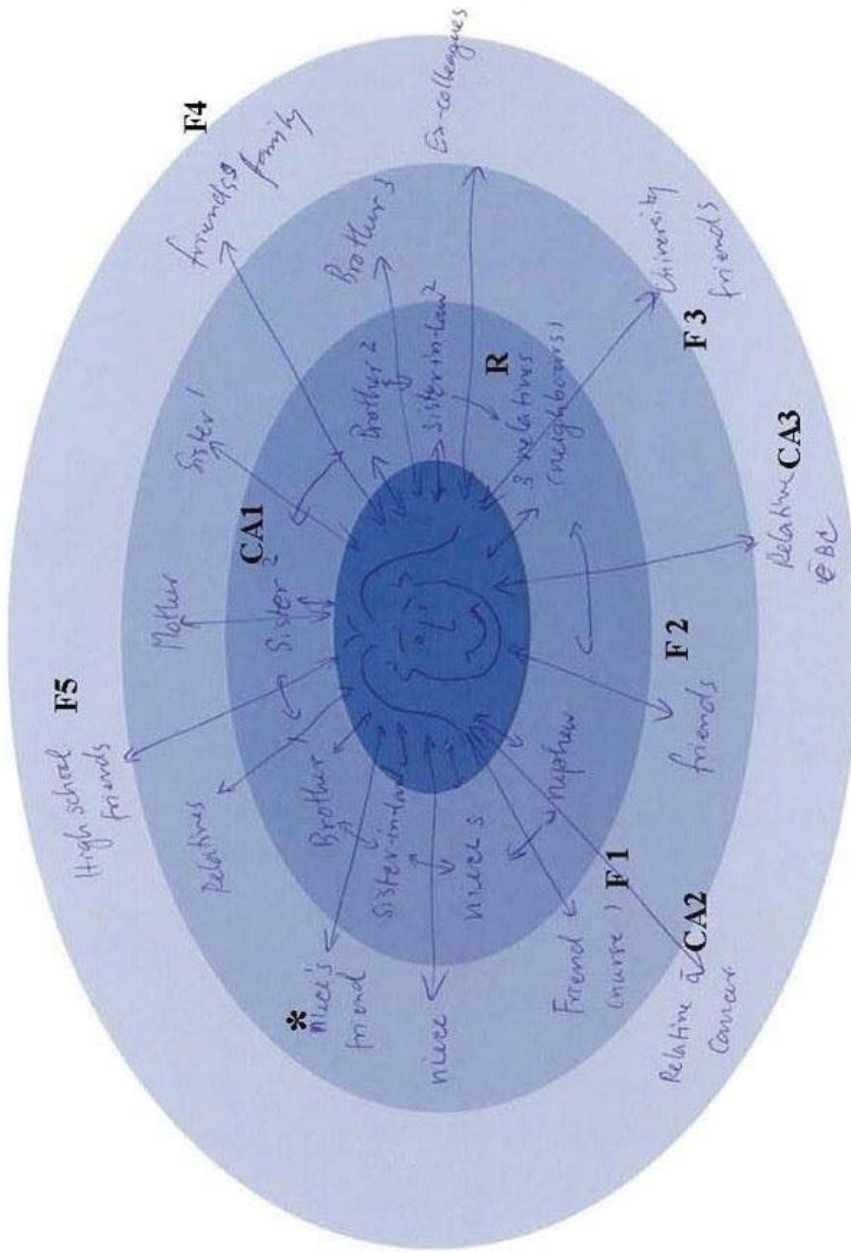


Figure 7.2. The network map of case 9.

In summary, complexities in breast cancer management could result from the advanced stage of diagnosis, the complicated health system, and/or individual preferences related to breast cancer treatments. These complexities led to an increase in needs of support, particularly, when the women continued with their treatment. Specifically, when the complexity in breast cancer management and family complexity occurred in the same time, the support needs increased rapidly, while the capacity of the family to provide support was less at times. However, the networks usually continued the support flow among network members and a number of family adjustments were required to maintain support flow. Additionally, adjustment of the non-family member group of the social network (particularly close friends and relatives) was influenced by perceptions of insufficient family support.

## Long-term involvement in a breast cancer club

(\*The two cases were based on the central women's specific experiences related to their breast cancer club participation. Accordingly, participants were not asked to map their networks.)

Another part of the health service was a formal breast cancer club (as described in chapter 1). Some participants stated that they were not interested in this optional club, while others identified that even though they were interested in it they were unable to participate in the club activities. Other women had a long-term involvement with the breast cancer club throughout their cancer journey and it formed an important part of their networks. In this section, two cases with breast cancer club involvement will be described and discussed.

### Case 10: A retired single woman living with her older single sister in a city centre

**Table 7.3**  
*Information of Case 10's Participants and Data Collection*

<b>Key participant</b>	<i>10.a</i> : a sixty-year-old single woman with her single, retired sister living in city centre
<b>Cancer and therapies</b>	Second to third stage breast cancer, diagnosed nearly five years prior to study participation  Total mastectomy with total lymph node removal; eight cycles of chemotherapy; and 30 doses of radiation therapy
<b>Financial support programme</b>	The programme of social security welfare
<b>The referral participants</b>	<i>10.b</i> : the central woman's sister <i>CM</i> : the breast cancer club manager
<b>Time and numbers of visits</b>	June to August 2012 Total = 7 At <i>10.a</i> 's home X 1; at the breast cancer club setting X 3; and at a place of indoor activity X 2; and a place of outdoor activity X 1
<b>Data collection methods</b>	Conversations, (in-depth) interviews, and (participatory) observations

**10.a** was unmarried female who had lived with her breast cancer for five years. Her small family led to reduced amounts of support available and living in a city centre altered the pattern of available support from community members compared to others living in a village community. Additionally, her retirement from work after getting her breast cancer diagnosis led to an increase in social isolation and also limitation of support from colleagues. As a result of all of these factors **10.a** joined the breast cancer club and had continued her involvement for almost five years. More recently she had developed supporter roles for other women's support networks.

The woman, **10.a**, was one of the daughters of a Chinese Thai family. She graduated with a high school level of education and worked as a clerk for a small company in her town for more than 30 years. After her parents died, she lived with two older single sisters at her parents' home in town and these sisters were closest to her in the family. Other siblings, who lived in either the same or different regions from them, maintained good connections with the whole family.

About two years before **10.a** was diagnosed with breast cancer, she found her breast lump but she felt too embarrassed to let a doctor check it. She told her sisters about her lump and tried to manage it in a natural way, such as by having healthy food. As time passed, her breast lump became larger and painful. One year before her breast cancer diagnosis, her oldest sister was diagnosed with cancer of the abdomen and she died during the next year. Her sister's illness and also the increasing size of her lump then caused her great concern.

*10.a "As my breast lump continuously enlarged it meant I had to change to a larger bra size. At that time, I had not yet gone to see a doctor. My anxiety increased as my lump grew larger and my sister became worse. When I went to participate with my exercise group, my friends observed my worry. One who was a nurse asked me if I had a problem and I told her. As a result, this friend and another one helped me to make appointment with a doctor for investigation at the university hospital". (C10, central woman, Int, 5<sup>th</sup> visit, p. 4)*

When **10.a** decided to undergo surgery, she first had to access her registered health setting—a private hospital. Afterwards, she was referred to the university hospital because her registered setting did not have the capacity to treat her cancer. However, both settings were located in her city, so travel was not difficult. During her hospitalisation and while undergoing chemotherapy and radiation as an out-patient, a sister was her main caregiver and was always with her (at that time, this sister had already retired from her routine job). The other family members also supported her and her sister. Finally, **10.a** could complete her long-term treatment of breast cancer with her older sister's close care.

Two years after her cancer diagnosis, **10.a** retired from her job. Her retirement seemed to increase both her social isolation and the resource limitations in the support available from her network. Additionally, **10.a** mentioned how she had reduced her involvement in social activities. She had been upset by a person's reaction to her hair loss and darker skin that were side effects of her treatment (the person might have thought that **10.a** was a HIV patient). However, she regularly interacted with friends in her exercise group (Tai-chi). **10.a** had a strong belief in the importance of a healthy lifestyle as an adjunct to the medical treatments for cancer. She told me several times about the significance of her self-care based on a healthy way of life, such as having healthy food and doing exercise eastern style. She believed that the healthy lifestyle she adopted had helped her to overcome the therapy side effects and control the cancer metastasis.

*10.a "I love to live in a healthy way, I read a lot of healthy living books and magazines. Previously, even though I had regular exercise I had unhealthy food. I had practiced Tai-Chi regularly before getting my breast cancer diagnosis... When I underwent chemotherapy, I sought information about food that would help me recover my health and would inhibit the side effects that one suffers from receiving chemotherapy. During the period of chemotherapy, there were many things you can't eat such as ... and things you should eat. For example ... I know about these because I had a direct experience of them...//*

*... I love to share my experiences related to my breast cancer and treatments to the cancer patients I meet them as I have implicit knowledge which is experience-based to overcome the suffering with chemotherapy side effects. For example, I met the breast cancer lady at OPD and her sister who came to the hospital with her said to me that the lady might give up receiving treatment because of too much suffering with chemotherapy side effects she faced. Then I spent a long period of time to advise her how to deal with these side effects. What things should do and what things should not do ...". (C10, Int, 5<sup>th</sup> visit, p. 12-13)*

The quote above also reflects how **10.a**'s personality influenced her behaviours and how she was proactive in offering to help others. One day after her surgery, **10.a** was invited by a nurse who was a club manager to participate in the breast cancer club, which was based at the university hospital. Since her first attendance almost five years ago, she has participated in the club activities as a founding member with increasing involvement over the years.

*10.a " I want to help \_ [CM: the club manager's name] to encourage new members into the club. I discussed with my club friends how we could help CM with the club activities. I and some club members volunteered to provide our time for a half day a week to be a consultant for the new cases of breast cancer at ศูนย์อันทันเวช /Soon-Than-Ya-Wade/ [the Centre of Excellence*

*for Breast Cancer]. However, I don't want to be involved with any case on the wards as I am not sure yet if my health is good enough". (C10, Int, 5<sup>th</sup> visit, p 30)*

Throughout my participatory observations within the club activities, the club members including **10.a**, presented their proactive participation during the club meetings as a way of helping the club's staff in facilitating club activities and sharing their ideas about a volunteer activity model at a meeting. **10.a** was sharing her personal experiences of living with breast cancer on the stage in a panel discussion activity at the hospital event. **10.a** also expressed her and other members' intention to me about their further involvement with the breast cancer club that reflected changes in their roles, moving from support recipient to supporter. In this way they were likely to become members of other people's networks who were and were not the club members.

***10.a** "I and my club friends want to help \_ [the club manager] within club activities as much as we can. We know she wanted to see an increasing number of the club new memberships. I tried to introduce our club to others in several ways such as during waiting for my doctor visits I talked other patients about our club... We now are proceeding to set the volunteer activity, like providing consulting and emotional support to new cases. ..." (C10, central woman, Int, 5<sup>th</sup> visit: p 11)*

In this case, participating with the breast cancer club fulfilled some of the woman's needs, particularly her need to help others and share her experiences and served her preference to support others. Importantly, in this case the woman was able to manage her responsibilities in normal life and as she lived in the city she had no difficulties in travelling to the club and was therefore able to regularly participate in the club activities.

## Case 11: A married woman disconnected from relatives for many years

**Table 7.4**

*Information of Case 11's Participants and Data Collection*

<b>Key participant</b>	<i>11.a</i> : a married woman without children who lived in an area with insurgency
<b>Cancer and therapies</b>	Second to third breast cancer, diagnosed nearly five years prior to study participation  Total mastectomy with total lymph node removal; eight cycles of chemotherapy; and 30 doses of radiation therapy
<b>Financial support programme</b>	The programme of social security welfare
<b>The referral participants</b>	<i>CM</i> : the breast cancer club manager
<b>Time and numbers of visits</b>	June to August 2012 Total = 6 At the breast cancer club setting X 3; at <i>11.a</i> 's health setting X 1; at a place for a club indoor activity X 1; and at a place for a club outdoor activity X 1
<b>Data collection methods</b>	Conversations, (in-depth) interviews, and (participatory) observations

*11.a* had participated in the breast cancer club throughout her breast cancer journey for almost five years, similar to *10.a*. However, some differences between these two cases can be observed. For this case, limitation of support provided by her informal network led to the central woman selecting the breast cancer club as the way to fill this gap. However, *11.a* had to overcome many difficulties related to travelling and responsibilities in normal life. Because *11.a* reported a 'happy feeling' associated with club participation and informal interaction with her 'club friends', the woman still continued her breast cancer club participation in the long-term and involvement of her breast cancer club friends as part of her normal life was observed.

*11.a* was a permanent member of the breast cancer club which was located at the university hospital. Even though her home was far from the hospital (around one and a half hours by public transport), she, like *10.a*, had regularly participated in the club activities for almost five years.

*11.a* lived in one of three provinces of insurgency in the lower southern region. *11.a*'s mother died when she was a teenager, thus she went to live with her aunt in this province and started working as a pharmacy assistant. As she did not make regular contact with her family, she did not feel close to them. Later, she married a fishing boat captain. Both had only a primary level of education, and her husband was an orphan who had very little contact with his relatives. After their marriage, both kept working at their jobs for many years and

then when **11.a** was diagnosed with breast cancer, both changed their jobs to run their own business. Before **11.a**'s cancer diagnosis, she had experienced a severe illness; therefore she had experienced long-term treatments at the university hospital, her registered health setting. Five years before her participation in this study, she found a breast lump and she went alone to see a doctor.

*11.a "When I was diagnosed with breast cancer, I decided to resign from my job at the pharmacy. Furthermore, my husband decided to quit his job on the boat too. We started our small business, it deals with the purchase of recycled goods and we still run this business today". (C11, central woman, Int, 1<sup>st</sup> visit, p. 9)*

Before **11.a** was discharged from hospital after her surgery, she was invited by a nurse to attend a breast cancer club meeting. At that time, it was just the initial phase of the establishment of club, which was started by the breast cancer patient care team of the university hospital. **11.a**'s perception about support provided by her informal network as mismatching her needs ( and/or her expectation), might have influenced her club attendance.

*11.a "Mostly, I looked after myself. It is common for me. Before getting the breast cancer diagnosis, I had been seriously sick for a year and I looked after myself as well... I am an experienced person [laughing]. My husband was not able to take care of me ... but he could be my facilitator such as if I wanted anything I could tell him. And he did not provide me the emotional support I wanted." (C11, central woman, Int, 2<sup>nd</sup> visit, p 5)*

**11.a** still worked even though it was for their own business. There were many things she had to manage and then she was able to participate with the club activities. Club activities were usually scheduled in office hours, though some were held on weekends or public holidays.

*11.a "I already managed everything about job before I came here [the hospital]. Yesterday, I did the things I was able to do and then for today just having something left for my husband to work on. So, it is fine for him to work alone... He always lets me come here to participate with the club activities. ... You see this [a package of cooked food], I bought it for him; he will have it for his dinner. I managed everything [laughing]. No problem". (C11, central woman, Int, 1<sup>nd</sup> visit, p 3)*

Furthermore, **11.a** mentioned the challenges related to the physical distance, the travelling expenses, and also the travelling safety because of the insurgency situation of this province.

*11.a "When I know what date I will come to this hospital. The good plan to travel is needed in relation to the safety. ...I ring a van driver to book a seat and then he will pick me from home in the morning of the travelling date to come to hospital / the club at around 7am. And I have to*

*leave from the hospital not later than 4pm as I have to reach my place not later than 5pm. ... In case of the outside-setting activities such as an one day trip, I have to come here earlier for one day and might have to stay overnight for two nights before and after the activity day, something like that. Like the next activity that we will go to \_ [one province in southern region]. One of the club friends invited me already to stay overnight at her place". (C11, central woman, Int, 1<sup>st</sup> visit, p 10)*

**11.a** expressed to me several times that she was happy being an active member of the club. The longer length of club participation resulted in closer relationships, and more personal relationships developed between the club members.

*11.a "I'm always happy with the club programme, however, I don't like to take a proactive part but instead I prefer to be a facilitator as I am not a good speaker. I am happy with health education activities and also with informal socialisation with my club friends. Talking with these friends is different from talking with my friends at home as my club friends and I all have a shared experience with cancer". (C11, central woman, Int, 2<sup>nd</sup> visit, p. 3)*

Each year the club organises a day out for its members and at 7am I arrived at the departure point and saw that many of the members were already on the bus, including **11.a**... **11.a** introduced me to a friend (who was accompanied by her mother) at whose house **11.a** had stayed overnight as she had travelled from her province the day before. That night she would again sleep at her friend's house before returning home the following day...

...On the bus to a tourist place, **11.a** and some friends were discussing their next plan to have a personal meeting at one friend's place. ... Again, on the bus home, while some women were enjoying singing a song, a sub group of **11.a** and her friends was enjoying a discussion about how to manage their artificial breasts and this sub group's discussion became larger and larger.  
(Fn, participatory observation an outside-setting activity of the breast cancer club, 26 August 2012)

The quote above demonstrates that participation in the club helped the woman fill a gap of support needs and the support received from her informal network. Furthermore, the relationships between some club friends become closer and they had involvement in each other's normal life. Similar to case 10, **11.a** was one of the club members who often volunteered her time for the club activities and tried to encourage women newly diagnosed with cancer to attend the club programme as best as she could.

In summary, several differences in contexts between these two networks were observed. The differences in women's married and working status were reflected in differences in responsibilities in normal life. Furthermore, the challenge of travelling to club activities was mentioned only in case 11. However, four similarities by contexts of these two

cases can be observed. They were i) the women's perceptions of having a limited support resource within their families, ii) mismatched or insufficient support from non-family members iii) personal feelings of satisfaction resulting from participation with club activities, and iv) having authority and capacity to overcome barriers such as responsibilities in normal life and travelling difficulties.

## **Conclusion**

With regard to three findings chapters which present the individual and cross-case analysis, the ongoing interplay between three situational categories related to breast cancer, the health system, and normal life resulted in diverse needs of support through the breast cancer journey. Consequently, networks showed interactions with contextual factors on multiple levels. These networks formed and developed their own patterns to provide and maintain the flow of different types of support among network members. As a result, many networks had unique characteristics including, mature support networks, shared networks, family-based networks, family and friend-based networks, network with higher involvement of non-family members in a core supporter group, network with many health-professionals (this was career specific) and networks with a breast cancer club involvement in long term. Ultimately, all networks in this study are '**Family-centred**'. Further, the next chapter will depict the network characteristics through a different analytical lens. The findings based on cross case analysis will be presented as core network characteristics.

# Core characteristics of personal social networks

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## Introduction

In the previous three chapters, the unique features of the women's networks with the presence of a core characteristic of 'Family-centredness' were revealed and discussed through 11 vignettes. This chapter conveys findings emerging from a cross case analysis of the 11 cases. The core characteristics of these personal social networks include i) the interplay between types of support, supporters, and relationships, ii) hierarchies of significance, iii) different degrees of relationships and feelings of *khong* /*Khong*/, iv) fluidity of networks, and the v) network life cycle. These core characteristics are compared to the conceptual framework from the literature to clarify similarities and differences.

## Personal social network framework from the study findings

Through conducting a cross case analysis of the 11 networks, I analysed the participants' perspectives from the data and then compared those findings to the conceptual framework of networks from the literature in order to get a clear conceptual map of the network characteristics of this study. The concepts of personal social networks which were developed from the study findings and that I used as a blueprint to depict the central women's networks are shown in Table 8.1. Analysis of the information gathered from participants' experiences in their networks brought out key dimensions that differed from the key dimensions in the literature in terms of the number of dimensions and their partitioning. (See the first and second columns in Table 8.1). The literature framework comprised three broad and distinct dimensions (structures, interactions or relationships, and functions). In contrast, a larger number of network dimensions were identified in this study with more overlap and interactions among them. Two additional prominent dimensions, called hierarchies and fluidity within networks, which are integrated with all other dimensions, are shown in a separate column.

**Table 8.1**

*Personal Social Networks Frameworks and Characteristics*

Key dimensions of social networks from literature*	Key dimensions of personal social networks from this study	Information about network experiences provided by participants				
		Characteristics of personal social networks in this study				
1. Structures	a. Members	f. Hierarchies & g. fluidity	① Interplay between types of support, supporters, and relationships	② Hierarchies of significance	③ Different degrees of relationships and feeling of <b>Khong</b>	④ Fluidity of networks
	b. Relationships					
2. Interaction or Relationships	c. Support Role & behaviours					
	d. Linkages					
3. Functions	e. Network functioning & balancing process					⑤ Network life cycle

\*(Glanz, 2008; Israel, 1985; O'Reilly, 1988; Pilisuk & Froland, 1978; Valente, 2010)

The five core characteristics of the women's personal social networks emerged from information sets of i) who the network members were and how and why they supported the women (and others), ii) how and why they linked to each other, iii) how (and why) the network functioned throughout their breast cancer journey, and iv) the occurrence of network layers and changes (See the third column in Table 8.1). All the characteristics overlapped with the hierarchies and fluidity of network structure, relationships, and functions. The first core characteristic of how the women identify people who are their network members is detailed in the following section.

## **Interplay between types of support, supporters, relationships**

During data collection, the participants mentioned many supporters involved in their experiences of living with breast cancer; however, only some of them were counted as members of the central women's networks. Network memberships were based on the significance of the individuals, the supports they provided and/or the relationships among members. The types of support included breast cancer-related support (such as delivering or facilitating the receipt of health-related services, taking care of the central woman at hospital or at home), and normal life-related support (such as helping them maintain their jobs, house work, looking after the parents, or participating in social activities). This support, provided by both professional and non-professional members of the groups, can be either direct or

indirect. Accordingly, the significance of network members was identified by the study participants through the interaction of these three factors (support, supporters, relationships) within three significant categories—helpful supporters, being beloved persons (and/or persons of faith) in life, and/or satisfaction with the support provided. Existing interactions then resulted in the varying significance of network members.

The support provided by network members was based not only on the recipient's needs, but also on the persons who provided the support and how the relationship between the support providers and their recipients shifted over time. The central women's conversations with me revealed that they expected some support to be provided by specific supporters and not by others. For example, support related to privacy issues (such as taking care of personal hygiene) would not be expected from non-family members. Support in decision making was provided by close persons with experience related to the circumstances, knowledge or information related to these, or those having a high level of contribution in the central women's journey with breast cancer. While the health services were usually provided by health-professionals, network members provided other support and who did what at different times was influenced by the positions and relationships between the supporters and recipients as illustrated in the following quotation.

*I.c "I am the person suited to be I.a's caregiver [the central woman's caregiver] in hospital, I can't let another one be her caregiver. I know her nature; she would not ask for any help from one who is not close enough and then something we don't want will happen [an accident such as falls].(C1, sister, Int, 15<sup>th</sup> visit, p. 8)*

What emerged from the central women's discussions and the map drawing is that there was a shared coherence among the people that made up the networks. The interplay among support, supporters, and relationships resulted in the identification of three groups of supporters who differed to a significant degree: health professional members, family members, and non-family members. These groupings have been used as further definition of their network membership.

### **Support and supporters were superior in health professional group**

To identify health professional membership, all participants gave explanations that showed they focused on the supporters (persons) and support provided rather than relationships. The professional supporters were identified as significant support members because of their professional positions with (or without) additional properties, such as special skills and experience. This included a doctor who was acknowledged as a skillful and experienced

surgeon in the breast cancer area. Specifically, the professional supporters who were included as members and also were named on the maps were all admired for the way they provided their professional services.

*1.a “หมอ/Mor/[means Doctor] is so nice to his patients, that’s why he is always busy. He gave a lot of time to explain about my disease and the treatments that he had planned for me, but I could understand just some of his explanation [laughing]. And he did the same to other patients. ...Everyone wants him to be their doctor. He is the best doctor in \_ [the province name] I think”. (C1, central woman, Int, 7<sup>th</sup> visit, p.5)*

The quote above shows the participant’s admiration for this doctor and her perception of his services as over and above the support expected. The expectations of the professional supporters, while based on their professional positions, were also affirmed by the participants’ experiences with health-related services.

*7.a “My family and I really appreciated my hospital staff, the doctors, nurses, and others were so good to me. They gave very good services to patients not only me; others got the same services as me ... You see even the cleaning workers encouraged me every day when they came to clean my ward in the morning ... I can remember the day of my operation when I was on the patient cart going back to my bed after operation. My doctor walked out from the ward, when he saw me he said to me he had done the document for me already. You see he was so busy; he just finished the operation but he still gave me his time to solve my problem [7.a had a problem related to the referral process from the local hospital in her home town to this hospital] ... It was over and beyond my expectation. He was so kind to me. My family told me my hospital staff was different from staff of our local hospital. We had had bad experiences with their services many times, and been really disappointed with them ...” (C7, central woman, Int, 1<sup>st</sup> visit, p.9)*

The previous quote is evidence that the interplay between support and supporters resulted in services given by her health professionals that were over and above what was expected by the central woman and her family’s interpretation, compared to their previous experiences with other health professionals. Accordingly, these health professionals were significant supporters. In contrast, some central women identified some health professionals in negative ways, as supporters who provided less than expected services. Often this assessment was due to their communication behaviours. They were perceived as not friendly and difficult to make a connection with. As a result, these professionals were not identified in their networks, even if they provided the necessary health support.

Uniquely, the service pattern of health professionals placed on the network maps differed from other health professionals. Their service pattern was holistic as it covered aspects not only related to the disease but also the social issues, such as the issues related to study, jobs, finance, travelling, or families. Some professionals made the clients feel that there was less professional distance between them by strategies included using informal communication instead of formal communication with their clients and sharing their personal experiences about breast cancer with their clients. Then the connection between them became more personal. Furthermore, another property of their services was the proactive providing of support.

*7.a "I felt like they [the nurses and other staff] opened the gate to welcome me to their unit first. They introduced themselves with their nick names and told me that they were very pleased to help me. I have felt like they are ready to help me if I ask. For  $\hat{w}$ /Pee/ \_ [the nurse manager's name,  $\hat{w}$ /Pee/ is the preface before names for the person who is as a elder sister or brother] you see she came to me at the ward, introduced herself, and told me that she would be away from work for two weeks and gave me her mobile phone number in case I needed any help... you see. ... Oh I forgot to tell you, on the last two days she [the nurse manager] rang me to ask for my permission if on next Friday a home health care team from my hospital could visit me at home." (C7, central woman, Int, 10<sup>th</sup> visit, p. 30-31)*

The quote above illustrates the proactive and informal interactions on the professional's part that overcame the boundary between the health professionals and clients. Consequently, the participants perceived them as their personal support members.

## **Supporters and relationships were superior in the family group**

The members in a family group comprised both those who provided tangible or actual support, and family members who were not able to provide physical or actual support but instead provided psychological support. The family members who provided tangible support received significant identification in relation to the support provided based on their abilities, contributions, and /or the circumstances at a particular time.

*1.c "I should be 1.a's caregiver at hospital as her husband can't [he never goes far from home, or out of his village, as he has severe car sickness] and I also can ride motorcycles thus it is easier to go to hospital by myself. Her husband can do tasks such as fishing [1.a believed cancer patients should have protein only from specific kinds of fish], finding something that 1.a wants, or taking care of her at home..." (C1, sister, Int, 15<sup>th</sup> visit, p.2-3)*

However for this group, apart from the supports they provided, their relationships with the central women were the key factor that distinguished them. The closeness of relationships was used to describe the place of family members within the network when they discussed the significance of the network members.

*1.a* “**1.d** is so good for us; I love her as well, however, she is a sister in law, she is not equal to my sibling. Loving her is a little bit lesser [laughing]. She always volunteers to help me and the family. Anyway she is not my sibling ...” (C1, central woman, Int, 20<sup>th</sup> visit, p. 6)

Many family members who were not able to provide tangible support, however, were identified as significant network members for the participants.

*9.a* “I live with my mother, she is bedridden. When I went to see my doctor, sometimes my brother came to live with mom ... **Ma** [mother] knows I got sick, when I took my hijab [the Muslim headscarf] off, she said I looked like a baby as I have no hair [laughing]. Sometimes, she asked me ‘when you will go to see the doctor again’. It is seldom that mom asked me to do something for her. **Ma** is so nice...” [During our conversation, we could hear mom was reading **Al-Quran** in her bed.] (C9, central woman, Int, 3<sup>rd</sup> visit, p. 3-4)

The quote above is an example that ascribes a close member to the network through being a beloved person in the participant’s life. This mother was significant without providing any actual support. Some beloved persons, even if they were dependent on the participant and others, were people with potential to empower the central women. Accordingly the participants valued them as precious persons; their support was not the key factor for their significance to the participants. The persons identified in this way as significant members for the central women were usually the closest family members such as a spouse, children, parents, and siblings. However in some cases it included family members who had a special role and relationship bond within the family and therefore were assigned this family membership.

*4.a* “When **3.a** [her sister—the central woman of case 3] got her first son, I quit my job and then was his nanny, and then further being nanny for her second son. ... These two boys are the most beloved persons of mine. They are my heart. [Since she got a diagnosis of cancer recurrence] they ring me every day at least two times a day... I know what time they are going to do what, and when they will ring me, and then I am waiting for their calls ... When I got sick and received their calls, it made me cheerful, and I got better. When my phone sang ‘gring gring gring’ its voice reminded me ‘my nephews are concerned about me’. So, I have to live, made me want to keep going, receiving the treatments instead of giving up receiving the chemotherapy ...” (C4, central woman, Int, 5<sup>th</sup> visit, p. 3-4)

The result of this pattern of interplay is that supporters and relationships were highly prioritised, and family supporters that were significant for the central women were the most significant members of a network.

The non-family sub group comprised several types of supporters within different positions, and included both old and new relationships in differing degrees of closeness. Participants identified their support within several levels of helpfulness. To identify their significance through the interplay of the three factors, the participants prioritised supports and relationships as the key factors rather than the persons themselves. For example, the closer supporters, such as cousins and friends were identified as pseudo-family; neighbours and friends were identified as pseudo-relatives; colleagues identified as friends or mentors; the breast cancer patients identified as friends were identified as more significant than others. However these significances resulted from the interaction between support and relationships among the network members.

*2.a "We were nurtured together as a family, we grew up together. Our mothers grew up together as their grandmother passed away early and then my grandmother nurtured their mother further. Then during our generation, my mother has passed away early, these sisters [her cousins] and their sibling helped 2.b [2.a's eldest sister] nurture me and another young sister. So, we have lived together as a family, we are as siblings, not cousins ... When I was sick, they and their families looked after me similar to when I was young". (C2, central woman, Int, 8<sup>th</sup> visit, p. 6)*

Notably, a different way to significantly identify pseudo-family members can be observed. As revealed previously, some pseudo-family members were identified as significant based on their relationship rather than providing support, which resulted in the significance level of a beloved person in life, whereas others were identified based on support provided more than their relationship as in the quote above.

The quotes above and below affirm the interplay between support and relationships. By providing support, the relationship then became closer and vice versa. Close supporters provided support on a more frequent basis than others who were not close.

*2.a "One of my colleagues, she is my junior teacher, has had leukaemia for many years. Previously, our relationship was just as a colleague. When she knew that I got this disease [breast cancer], she got involved with me more than usual. We became closer. I think she is my mentor for living with cancer. She gave me advice, healthy food, and many things..." (C2, central woman, Int, 3<sup>rd</sup> visit, p.9)*

The significance of the non-family group also resulted from inadequate sources of support usually expected from the family group. In some cases, non-family members with friendships were identified as more significant than in other cases, for example, in the case of the central woman who was living with her husband and was far away from her blood-related family. During the period of receiving chemotherapy, insufficient support was provided by family members; consequently, her close friend became more significant as he provided the missing support that kept her going through the critical period of receiving the aggressive treatment.

*7.a “[While receiving chemotherapy] unfortunately, my family is far away from me [approximately 2000 kilometres]. Everyone is busy, especially, now is the time of their children’s study semester, it is hard for them to come to me even if they want... 7.c my close friend rang me frequently asking me do I have anything to eat. It is so sad because I have no family here. However, lucky me, I have a close friend here; he can take care of me instead of my family. He knows my family and he can contact them if anything happens to me. I can trust him and he is so generous. If I have any problem I will ring him [7.c] first”. (C7, central woman, Int, 6<sup>th</sup> visit, p. 7-9)*

In some cases, the perception about limited support either from professional, family related, or other (individual) non-family supporters led to the involvement of non-family supporters within a group into the group of significant supporters.

*11.a “When I was in hospital for breast cancer treatments, the day after my operation, a nurse invited me to participate in the breast cancer club of the hospital. I went to join this activity in the patient uniform. ... I like to join in the club activities, even though I live in the other province [she lives in a province with unrest approximately 100 kilometres away from the club setting] but I can make it. It makes me happy because I can get breast cancer – related information and other support. Even though I can take care of myself, I am happy with the club participation. I don’t know why. It might be like meeting with breast cancer friends. These friends differ from my friends at home. We join with the club. We share everything with the breast cancer friends, in particular, emotional sharing. I become energised when participating with the club activities, during the club activity participation we can do both giving and taking...I feel happy”.(C11, central woman and a member of a breast cancer club, Int, 3<sup>rd</sup> visit, p. 11-13)*

The participants gave membership identification to varying supporters with different levels of significance through the interplay of the three factors—support, supporters, and relationships. Accordingly, three categories of significance identification were found from the participant’s information provided to clarify each network member’s significance and each individual or group was identified through one or more of these three categories:

helpfulness, being the beloved person in life, and satisfaction.

## **Categories of significance**

Through the interplay of three key factors related to providing support in networks, the members' significance existed within three categories. Helpfulness was used to identify the supporter who provided advantageous support; being the beloved person (or person of faith) in life was used for the special person (or the higher being) who provided psychological or spiritual support; while satisfaction was based on the central women's expectation of support provided.

### ***Helpfulness***

This category of significance was based on the usefulness of the support provided. Both professional and non-professional members were identified as helpful with respect to their actual support, their position(s) (related to the breast cancer, normal living, and/or network functioning), and additional properties (such as specific skills, experiences, and contribution in relation to the initial positions). For example, the helpfulness of the doctor was identified according to his/her health professional position and also his specific property of being a skillful surgeon. Another example is illustrated in the quote below, where the sister was identified as helpful according to her health professional and network related positions.

*4.a "My sister, 3.a she is the team leader of my supporters because she is a nurse. She has done and managed everything for me and I just brought the referral document to the university hospital [When 4.a got the diagnosis of the cancer recurrence, she had to be referred from 3.a's hospital to the university hospital—a process requiring many steps.] Previously I have not done anything when I went to her hospital". (C4, central woman, Int, 3<sup>rd</sup> visit, p. 6)*

### ***Being the beloved person (or persons of faith)***

This category of significance was specifically used for supporters who were able to provide psychological and spiritual rather than tangible support. Such members were identified as the beloved person or the person of faith in life who had a higher ability to empower the central women (or other members). The beloved persons were mainly family and quasi-family members (as previously mentioned in the part of the family-related membership).

In some cases, the beloved person or the person of faith in life was identified as their spiritual supporter. One woman identified her father who had passed away as one of her spiritually significant members because she still felt a connection with him and she drew him

into her network (see Fig. 6.3, Chapter 6). Muslim participants acknowledged **Allah** as the most significant spiritual supporter for them. **Allah** was explained as a higher being, and cannot be compared with people. Accordingly, even if the Muslim participants connected to **Allah** daily, **Allah** did not appear in their maps, however, they talked about **Allah**'s role in their lives.

*5.a "Thinking of Allah every day since in the early morning, yes thinking of Allah at least five times a day but actually more than this. After praying, I do blessing of Allah like could Allah please let me get better and healthy, my disease is gone, something like that. In Al- Quran, we can pray 100 times a day if we can".*

*5.b "As we have good faith to Allah then we will get the blessing of Allah".*

*5.a "If, we keep connecting to Allah, Allah will be close to us".*

*5.b "Then we can accept everything which happens in our life".*

*5.a "However, I just bless for Allah to have a longer life as I want to do more merit ..."*

*(C5, central woman and husband, Gr Int, 9<sup>th</sup> visit, p. 22-23)*

*8.a "My thought is 'just place it [her breast cancer] down, don't hold it'. If it is my time, I will [pass away], but if it is not my time, I will not. Just keep thinking like that ... enough. Our religion [Muslim] taught us like that-everything depends on God—Allah. Don't hold it as it has already happened and then keep walking forward ... Now I can live with it". (C8, central woman, Int, 1<sup>st</sup> visit, p.15-16)*

In contrast, Buddhist participants expressed their spiritual connection to their religion regarding the Buddhist teaching rather than any beings, thus their networks had no spiritual beings as the supporter either via mapping or discussions. The Buddhist principles were revealed as the way of spiritual connection through i) keeping the way of thought in relation to the Buddhist teaching (belief about Karma and/or retribution), ii) to behave morally (behaving in good ways with each other), and iii) to do religious performances (by the central women themselves and/or by their close persons) to gain **merit**<sup>19</sup> for the central women such as offering food for monks in the early morning, chanting, blessing, and going to a temple on the Buddhist holy day.

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<sup>19</sup> Buddhist Thais have beliefs related to religious and moral practice as they could make them gain merit. Terwiel (1976) explains the relationship between religious (or folk or supernatural) performances, merit and good luck. Merit can be seen as a beneficial and proactive force which extends over a long period of time, and which links individuals together. For a lay person attending a religious ceremony, performing chanting and blessing, and behaving morally to others, was based on the belief about its good influence on their present, immediate future and future life. Furthermore, some also assume a possible occurrence of good luck or magical power such as the central women's disease can be cured.

**1.a** “Nothing to think more, it [breast cancer disease] already happened with me it might be because of my retribution. ...I am not ready to stay in public as I have no hair and no eyebrows and then don't want to reply to any question about this. Thus I haven't yet gone to the temple as I did previously. I think if I can be a good Buddhist by good thinking, good speaking, and good behaving to each other as the **Lord Buddha**'s teaching, that should be okay for me to be a good person”. (C1, central woman, Int, 11<sup>th</sup> visit, p.7)

**2.b** “Our family has cancer in blood [She meant by heredity], my mother and another sister's causes of death were cancer and then **2.a** [her sister—the central woman], got it... accept and treat it but no more please ... Every night, before bed I worship, chant, and bless for [**2.a**] wish her to get better and nothing happen more ... enough. Nothing for me, it is just for her”. (C2, sister, Gr int, 8<sup>th</sup> visit, p. 11, 18)

### **Satisfaction**

This category of significance was based on participants' expectation of support provided. The participants' expectations were in relation to the supporter's positions and/or relationships; hence, differing expectations of different members (and/or by different persons) was a common occurrence. The participants compared the actual support with their expectation to determine their satisfaction with the members within this affective identification. If support provided by any supporter was interpreted positively, that is they met, or exceeded their expectation, and then the participants felt satisfied with the support and also the providers.

**7.a** “If I have any question I will ask \_ [the nurse who looked after her at the chemotherapy unit—a breast cancer case manager]. She went to visit me at the ward on the second day after my operation and she gave me her mobile phone number that I could contact her if any unit], she is so friendly. On the first day of my chemotherapy, she came to me with her beautiful smile. ... Even though her lips had a mask covered but I saw her smile through her eyes. She introduced herself to me informally. I felt a warm welcome from her. ... Other staff did the same as her to me too. The staff of my hospital did a very good job to me, definitely they could empower me ...” (C7, central woman, Int, 2<sup>nd</sup> visit, p. 10-11)

**4.a** “I really love aerobic dancing exercise but I stopped doing it since I got the diagnosis of recurrence. My friends who were the members of aerobic dancing exercise club went to visit me many times at home as they were so concerned about me. I got a lot of encouragement from them ... The last meeting of us; it was the New Year party of our village. I was really happy. We gave hugs to each other several times. Really miss them”. (C4, central woman, Int, 4<sup>th</sup> visit, p. 31)

The two quotes above demonstrate that the interaction with professional and non-family

members were perceived as positive because the participants interpreted their provision of support as well over their expectation. In contrast, the following quote demonstrates support perceived as lower than expected, leading to negative satisfaction from the participant.

*8.a “If I have any questions I won’t ask the nurses, I think asking the doctor should get a better reply... however, the people that I most prefer to ask my questions to are the patients. For the doctor, even though he was not like the nurses, he didn’t talk badly to patients like some nurses but he used medical language and I felt it was hard to understand and he also always looked busy. For the patients, we used the same language, it is easy to understand”. (C8, central woman, Int, 4<sup>th</sup> visit, p.9)*

Each network member was identified within one or more of these three categories of significance. For example, a friend with breast cancer, who went through the critical period of receiving chemotherapy with the central woman and shared experiences and resources between them, was identified as providing satisfying support to the central woman. In contrast, a sister who was perceived by the central woman as a quasi-mother was the main caregiver and provided very good support to the central woman without obligation, was identified in all three categories; helpfulness, being a beloved person in life and providing satisfying support.

In summary, three categories were used to identify the significance of network members, through the interplay between types of supporters, support and relationships.

## **Hierarchies of significance**

The interplay among support, supporters, and relationships also created awareness of the existence of hierarchies between and within member groups. However, the members with close relationships were identified as more significant than others.

## **Family group was always paramount**

In all cases, the family or *คนใน/Khon-nai/* group was identified as more significant than the non-family or *คนนอก/Khon-nok/*<sup>20</sup> group and the health professional group as closeness was

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<sup>20</sup> *คน/Khon/* means persons; *ใน/Nai/* means inner; *นอก/Nok/* means outer. *ใน/Nai/* or inner is a word that is minimised from the full phrase of inner-family. Similarly *นอก/Nok/* is a word that is minimised from the full phrase of outer-family. Hence, *คนใน/Khon-nai/* means a family member and *คนนอก/Khon-nok/* means a non-family member.

prioritised over other factors. The higher level of significance of *คนใน/Khon-nai/* or family members was revealed in both the network discussion and the network mapping. In the network mapping, the family member names were always placed closer to the central woman (who was at the map's centre) than other members (See Fig 5.1, Chapter 5). Through the discussion of the networks, the family group members were presented as having a higher level of significance compared to other groups regarding their support given. These two groups—*คนใน/Khon-nai/* and *คนนอก/Khon-nok/*—would get different levels of permission to perform support for the central women who expected different levels or types of support in relation to the closeness of the network member. Family members were expected to be the key supporters such as caregivers at hospital or at home, and supporters in personal issues, particularly decision-making about financial or other family-related matters. Participants revealed these differences were supported by feelings of *เกรงใจ/Kreng-jai/*. *เกรงใจ/Kreng-jai/* that determine the social value and obligations to behave toward other social members. This affects the way Thai people will ask for and/r expect help from others. This attribute is shown in this quote.

*I.c* “Before **I.a** got a breast cancer diagnosis, I told my husband’s family that if you need to get hospital services just let me know first and I could facilitate the service process for them easily. However, sometimes they didn’t let me know. They said they felt *เกรงใจ/Kreng-jai/*. Like in **I.a**’s case, firstly her son regularly rang me when [**I.a**] had to go to the hospital. Now her son doesn’t tell me, he can do it by himself without any problem. I think he felt *เกรงใจ/Kreng-jai/* towards me”. (C1, sister in law, Int, 12<sup>th</sup> visit, p. 3-4)

The quote above also illustrates that if *คนใน/Khon-nai/* or family and *คนนอก/Khon-nok/* or non-family group members were able to provide the same support, with *เกรงใจ/Kreng-jai/*, the supporters with family relationships were more likely chosen than non-family supporters. The different degrees of *เกรงใจ/Kreng-jai/* between *คนใน/Khon-nai/* and *คนนอก/Khon-nok/* groups also influenced the different expectations of support shown in the following excerpt.

*5.a* “All of my children have given me good support without me asking. Why do they behave like this?...Uh they are my children so it is normal that good children should look after their parents, particularly when their parents got sick. For others [non- family people], they cannot

*do like that. For example, my cousins lived far away from us and they have their own family and jobs to take responsibility for and other things. They would come to see me if they think my illness is serious like the previous time as they thought I was nearly dead [laughing]... One cousin in \_ [the province's name] used to help me buy supplements and brought it to me at my place. Now I think I won't ask him to buy it for me as he has to drive many kilometres from his home to give it to me and it is now not necessary for me". (C5, central woman, Int, 9<sup>th</sup> visit, p. 11-12)*

This excerpt reflects that the mother—the central woman—felt more *เกรงใจ/Kreng-jai/* towards the non-family members than to her children. Its consequence was inferred through the conversation as the expectation on non-family members to provide support was lower in comparison to family members.

The *คนใน/Khon-nai/* group was consistently superior, even in instances where a family had limited resources and a close friend and/or relatives (*คนนอก/Khon-nok/*) provided the kinds of support usually given by *คนใน/Khon-nai/*. These friends had greater significance than other *คนนอก/Khon-nok/* or non-family members. This meant that the *คนใน/Khon-nai/* group was higher in the hierarchy than *คนนอก/Khon-nok/* where a few *คนนอก/Khon-nok/* individuals might attain higher significance than some family members (See R in Fig. 7.2, Chapter 7).

Health professional members, even if the support they provided was not able to be provided by others, were not identified by any participants as equally significant to or beyond the family group. Additionally, in some cases, as mentioned previously, the health professional supporters who provided the crucial support of breast cancer treatments and care were not identified as significant enough by the central women to be included in their network. This was the result of negative satisfaction the participants felt about the support provided to them. Accordingly, in all cases the *คนใน/Khon-nai/*, or inner family group was perceived as more significant than the other two groups (See Fig. 5.3, Chapter 5).

## **Significant hierarchies within each group**

The hierarchies within each group differed in characteristics. Within the *คนใน/khon-nai/* the relationships were prioritised over other characteristics. The hierarchies within the health

professional group were strongly related to expectations of and the satisfaction with their support. While the hierarchies within the group of the *คนนอก/Khon-nok/* members were mainly based on the helpfulness, regularity and /or frequency of providing support.

### ***Hierarchies within the group of คนใน/Khon-nai/ or family members***

Differences in significance within the *คนใน/Khon-nai/* or family group created a hierarchy largely based on the different levels of expectations of their supporting role regarding kinds of supporters defining by the participants. Some *คนใน/Khon-nai/* or family members who were perceived as potential supporters were expected to provide good support. Less was expected of those who were perceived as having lower potential to provide support. Members, who were identified as the beloved person, were not ascribed any expectation about providing tangible support but they were identified as significant members in all cases.

*1.a “My parents were not well as they are very old. How can they take care of me? They could not do anything for me, being concerned about me was enough ...Their health is not good as now they are very old. My mother has severe back pain, now she can’t go to the temple as she can’t sit for a long time. My dad has dementia. I think he doesn’t remember that I got this disease. He used to walk from his home to see me [around five kilometres in the same village] when he could remember about me and now I think he forgets what happened to me. When he saw me he said ‘Your head is bald, when you will you have hairs? [laughing] Now my two sisters have to look after him’”. (C1, central woman, Int, 16<sup>th</sup> visit, p.1-2)*

For the family members who were not identified as the beloved person in life, the expectation of their support and what they provided had little impact on their significance level. Based on the participants’ interpretation, the family members who provided support that exceeded or met the expectation intended were more significant than the others who provided less than expected supports. As revealed previously, the interplay pattern of the three factors—supports, supporters, and relationships—still held among the family members and relationships were prioritised over support. Hence support from close family members that was lower than expected only slightly lowered their position in the significance hierarchy.

*9.a “My eldest brother was my caregiver in hospital during my admission as others were not available. For him, he has never said no, always yes. But at that time, I rarely needed help from him, just his company. ... For another brother his visit to me and my mom was less*

*frequent as he works in other province and he is quite busy with his family [laughing]. However, his daughter came to live with us during her last study break. ... He is not similar to the eldest one, this brother, the eldest, is always available if I ask him for help". (C9, central woman, Int, 3<sup>rd</sup> visit, p. 15)*

In the quote above, the central woman presented her perception of the hierarchy of significance of her family members. The support of the eldest brother was over and above her expectation, while support from another brother was lower than she expected.

### ***Hierarchies within the group of health professional members***

The hierarchies of significance within the health professional group were observed based on expectation and its consequence (as previously stated). Three layers of significance were identified: lower than expected, met the expectation, and exceeded the expectation. For example, participants identified some members of the health professional group as vital because their support was above the participants' expectation. Some of the support met the participants' expectation and some health professionals were interpreted as providing less than expected.

*2.a "For my doctor, he was nice and kind. I felt he was really concerned about his patients. He said to me 'Not to be worried <sup>พี่</sup> Pee/ [the elder sister or brother], my mother got the breast cancer diagnosis same as you and she got the same treatment as you. Now she is well'. I trust him because he gave me good services and he was sincere, and I perceived this as กำลังใจ/Khamlung-jai/ [Power of mind, it means he can empower her]. He works very hard for us [patients].... ... The nurses who took care of me in the theatre and at ward were fine. They gave me good advice about self-care and one nurse sought information about herbs for the cancer patients for me too. ... But another nurse who worked at \_\_, I felt nothing towards her. ... Honestly, every patient commonly suffers a lot with their sickness, thus health staff should be friendly and kind to them, but her behaviour was opposite... One day, I helped an elderly patient to solve her problem instead of that nurse ...Now I am unclear about my further treatment but I won't ask her." (C2, central woman, Int, 7<sup>th</sup> visit, p. 25-26, 28-29)*

The quote above reveals three types of health professional members in relation to the service provided. Health professionals, who had exceeded expectations, were definitely included in network maps (See Fig. 5.1 in Chapter 5), while those who were perceived as having met expectations, may be included on network maps. All health-professional with negative satisfaction provided support that was less than expected and were absent from the network maps. (See Fig. 6.3, in Chapter 6).

### *Hierarchies within the group of คนนอก/Khon-nok/ or non-family members*

Hierarchies of significance exist within this group based on support-related activities. Participants identified the significance of the คนนอก/*Khon-nok*/ or non-family members based on the helpfulness, and regularity or frequency of providing supports rather than on relationships and expectations. Perceived helpfulness differed because of the many different kinds of support such as taking care of the central women or their parents instead of the family members, providing support in jobs, facilitating significant supporters to support the central women, and encouraging the central women and/or the significant caregivers such as visiting at hospital or at home. Differences in frequency and regularity of engagement in networks were influential in significance levels. The differing significance of the non-family members was reflected in the network maps through the physical distance between the central women and each non-family member; the non-family members who regularly provided the crucial support were placed closer the map's centre than others who were merely a visitor and /or provided support with low frequency or irregularly as mentioned in case 7 in Chapter 6.

**In summary**, the interplay between types of support, supporters, and relationships, led to categories of significance of network members. All networks comprised three member groups: คนใน/*Khon-nai*/ or family group, the health professional group, and the คนนอก/*Khon-nok*/ or non-family group. The existence of significant hierarchies within and between member groups was observed as well as unique patterns of each group.

### **Different degrees of relationships and feelings of ช็อง/*Khong*<sup>21</sup>**

Through the discussion about network members' significance, differences in relationship and feeling of ช็อง/*Khong*/ within each member group were recognised. The คนใน/*Khon-nai*/ or

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<sup>21</sup> ช็อง/*Khong*/ is a southern dialect word, which the local people use to identify the combined feeling of attachment and concern or worry about. Weak/superficial ช็อง/*Khong*/ can be a feeling of attachment with someone when having regular participation with them. For the stronger/deeper ช็อง/*Khong*/, it is the feeling between persons with a close relationship and perception of being together with either ties, bonds or bonding. The feeling of ช็อง/*Khong*/ to others can be reflected through verbal and/or behaviours of being concerned about them particularly when critical situations occur in their lives such as having the breast cancer diagnosis.

family group members became engaged in the support network because of their family relationships with the central women. These relationships were close and long term and had created strong **ข้อง/Khong/** between them and the central women. For the health professional group, the relationships among them were mainly professional-based, though there were some rare instances where members of the health professional group also had a family-related relationship (a niece of a sister in law, a cousin), and colleagues. Additionally, the health professionals selected in networks were unique as the participants perceived them as having not only professional but also personal connections with them (as mentioned previously). For the **คนนอก/Khon-nok/** or non-family group, a difference in relationship and **ข้อง/Khong/** within the group was observed and subgroups were able to be distinguished. The highly significant members of the **คนนอก/Khon-nok/** group were those who had old and closer relationships and higher level of **ข้อง/Khong/**. They were cousins, other relatives, and friends and many were identified as quasi-family.

*2.a “I have known 2.e for five years. I started my teaching at my school before her. When she moved to teach at my school, we made friends with each other and we go together well. Our colleagues said we are twins [laughing]. She is as my sister. She took care of me as usual, either in normal life or when I got sick. She is my closest friend. ... Such as the northern trip of my school during the New Year holiday, if she didn't go, I didn't as well [laughing] because she was my mentor, my best supporter”. (C2, central woman, Int, 8<sup>th</sup> visit, p. 4)*

The quote above shows the central woman had deep or strong feelings of **ข้อง/Khong/** with her close friend because of their close and long term relationship and the very good support provided by this friend. In the following quote, the central woman reflects on the emotional connection and feelings of **ข้อง/khong/** with her husband's sisters because of their earlier support.

*1.a “Two of my husband's sisters went to visit me at home for two or three times. If they can walk to me, I know they would do. Presently, they can't walk to me as the distance is too far for them. ... However, I know that they always **ข้อง/Khong/** [have ties] with me. ...They supported me a lot when I started new family with my husband here [her home in the farm land], they are as my parents”. (C1, central woman, Int, 7<sup>th</sup> visit, p. 5)*

In the same way, the difference in closeness among the sub-group of acquaintances was presented through friend-like identifications. For example, a central woman called colleagues who were closer than others her ‘teacher friends’. Breast cancer patients, who received aggressive treatments at the same time and shared experiences and/or support with the central women, were identified as ‘breast cancer friends’ because their shared experiences made them feel closer to each other. Furthermore, feelings of **ห่วง/Khong/** between the central women and these members were presented through being concerned or considerate about each other, providing support without asking, and regular /frequent contacts they made.

*4.a “\_ [name] is my older friend. I met her when I was in hospital for my first diagnosis. She is such a nice person. She helped me walk to toilet when my family was not with me, her husband too. She told my family doesn’t worry about me she would look after me instead if my family couldn’t come to me. After hospitalisation, we still kept in touch via phone; however, she rang me more frequently than I did. Last time she rang me as she worried about her disease when she knew about my recurrence. ...” (C4, central woman, Int, 9<sup>th</sup> visit, p. 11)*

As revealed previously, in Thai culture, the feeling of **เกรงใจ/Kreng-jai/** affects the way Thai people will request and/or anticipate help from others. The differing levels of closeness in a relationship were reflected through differences in the feeling of **เกรงใจ/Kreng-jai/**. Accordingly, support was expected or requested of each member as a reflection of the differing closeness in relationships the participants perceived within and among groups of members.

*6.a “My nature is having very much feeling of **เกรงใจ/Kreng-jai/** to each other, it is very hard for me to ask for help from others. I think a lot to ask any help from someone including my family. Mainly, my family and my friends proactively support me rather than by my request. Especially, I have never asked for any help from the outer family and I really feel **เกรงใจ/Kreng-jai/** to receive support from them... I have a few close friends, for my close friend who is a nurse, I used to ring her to consult about my illness just one or two times as I knew she was so busy with her job and her family. She and her husband visited me when they could ...” (C6, central woman, Int, 5<sup>th</sup> visit, p. 30)*

The quote above is very typical of the way Thai people think about seeking help. It is evidence of the existence of hierarchies in relationships occurring in the networks and the

way *เกรงใจ/Kreng-jai/* interacts.

**In summary**, the relationships and feeling of *ข้อง/Khong/* within each member group differed. Strong feelings of *ข้อง/Khong/* linked the family members and the central women together. The relationships and feelings of *ข้อง/Khong/* of the pseudo-family subgroup were similar to the family group's linkages. Non-family members and acquaintances had lesser levels of relationship and feelings of *ข้อง/Khong/*. The linkages of members of the health professional group included professional linking with or without the personal connection by having co-relationships of relatives or friends, or by the participants' perception of having personal connection with them. The differences in support provided were in relation to the differing degrees of *เกรงใจ/Kren-jai/* the participants felt toward network members.

## **Fluidity of networks**

During the network discussions, all participants described many changes in their networks along the breast cancer journey designed to keep providing support within the network. These changes were in relation to both the breast cancer disease and its treatments, and the normal life of the central women and/or their significant supporters. Another factor that impacted on network changes was the mismatching/inconsistency between expectation and performance of providing support. Multiple changes in networks to maintain, re-provide, or recover the support flow among network members throughout their journey were identified through our network discussions. Observable differences and similarity in network changeability existed within the three member groups related to the situational changes at a particular time of the journey.

## **Situations affecting network changes**

The changes in network circumstances regarding breast cancer and its treatments occurred sequentially phase by phase from the pre-diagnosis, undergoing investigation and initial treatments, undergoing chemotherapy and/or radiation, to completion of aggressive treatments. For some cases, their breast cancer circumstances remained stable in the follow up phase for a long period of time, while the journey of one case returned to the beginning phase, because the breast cancer recurred (See Fig 4.1 Diagram of the phases of living with

breast cancer in Chapter 4). In all phases except the follow up, the breast cancer and its treatments had the potential to disturb the central women and their members' lives at any time. Therefore, those phases were unstable and/or critical periods of time and the network members' perception at those times was that the demand for support was higher. This was to assist the central women to achieve completion of all the processes involved in receiving the suitable treatments for their disease.

*2.c "We could do everything for her [for 2.a—the central woman], everything, just let us know. We want her to complete her treatments and then get well".*

*2.b "Yes, everybody was ready to support us, just let them know. During 2.a's chemotherapy, 2.c's husband was standing by during the night if I rang him to pick 2.a and me from hospital to home after 2.a finished a dose of her chemotherapy. ...and as everyday 2.d was at home thus she was my father's caregiver when I was at hospital with 2.a. And ...."(C2, sister and cousin, Gr Int, 7<sup>th</sup> visit, p. 15)*

The follow up phase is the more stable period of the journey as the disease is treated and there were no aggressive therapies for the women to face. Accordingly, during this phase the requirement for support, either physical or emotional, was perceived by the members and by recipients, to have decreased. However, living with breast cancer is not only related to the breast cancer disease and its treatments, but also to the normal living of the central women and their network members. The changes in their normal life included changes in families, jobs, study, and also the health status of significant supporters.

The interplay between changes in the breast cancer disease and the changes in normal life occurred continuously throughout the journey, for instance, the change of the breast cancer phases from investigation to undergoing aggressive treatments and the impact on the supporter's normal life. In one case the central woman's sister told me she gave up her part-time job and adjusted her farming routine as she aimed to take care of the central woman both at hospital and at home by herself until the central woman had recovered.

*2.b "When 2.a had to be admitted for her surgery and chemotherapy, I was her caregiver in the hospital every day. ... Nobody assigned me to be 2.a's caregiver at the hospital; I did it on my own. I had to be her main caregiver as I would not sleep at home when she was at the hospital. Then I brought her to my home to nurture her until she recovered before letting her be at home with her husband. ... I quit my part-time job ... In the early morning I went to the rubber trees garden for tapping and went back home to take care of her and my father. For the process of selling the collected latex, my cousin's husband helped me do it..." (C2, sister, Gr Int, 7<sup>th</sup> visit, p. 7 - 11)*

Furthermore, in one case the central woman disclosed the contradiction between expectations and performance in support roles that impacted on the flow of support in her network. The central woman expected her husband to be able to be her caregiver during her recovery after each cycle of chemotherapy. On the other hand, the husband did less than she expected, which affected the network's function for a short time.

*7.a "When my sister and her family went back home, he [her husband] said he will be my caregiver instead, he will reduce his working hours to take care of me. But he can't ... The last time after coming back from receiving chemotherapy at the hospital; I had no one looking after me at home and ..."*

*7.c "At that time she rang me she said to me that she wanted to die... I told her that she should move to live with her family as they can give her a good care but she doesn't want that"*

*7.a "You see, I am sick, I need his support but he can't..., I didn't tell my family as I know they will get high stress about this and I want to finish my treatment first. ... Sometimes, I didn't answer my family's calls but I rang them back when I felt better"*

*... //*

*7.a "Now I feel better. I can manage myself. My friend who is in \_ [city], suggested to me to prepare things for my daily living before getting the chemotherapy such as ... then I can survive [laughing]. And 7.c comes to me more frequently and he rings me or I ring him if I need any support from him... Now I can manage myself."*

*(C7, central woman and close friend, Gr Int, 7<sup>th</sup> visit, p.20 -21)*

The quote above illustrates that the network functioning was interrupted by inconsistency/mismatching of support over a short period of time. This occurrence then forced some changes in the network to improve the support provided to the central woman so that she was able to keep going with the breast cancer treatments. When situations change within the breast cancer disease, normal life responsibilities and perceived support, requiring changes within the network function, the three member groups respond differently to these changes.

## **Changeability of the *คนใน/Khon-nai*/or family group**

Changes within the *คนใน/Khon-nai* or family group related to the fluctuation in needs for support, ability to provide support, and /or contribution in networks. The changes within this group then occurred in terms of providing support and persons who provided support rather

than relationships among them.

[9.a was living with her elderly bedridden mother.]

*9.a “When I was admitted in hospital for my surgery, my nephew was one of my caregivers in hospital as he was free and at that time I didn’t need support from others much, mostly I took care of myself. ... When I was receiving chemotherapy, he stayed with me at home in the early phase but he was not useful enough [laughing], a boy. He could not do certain things like preparing food for me or my mom; he could just be my company [laughing]. I love him but he is not able to be my caregiver [laughing]... Thus, sometimes my brother came to live with me if he got the day off. Sometimes, my nieces lived with us [she and her mother]. Sometimes, my female neighbours (and they are my relatives as well) came to my place to take care of me and my mom. ... They kept an eye on us and if I had nobody with me, they would come to take care of us such as cooking food and managing things for our daily living and also other things I wanted ...” (C9, central woman, Int, 4<sup>th</sup> visit, p. 21-22)*

The excerpt above shows the change in persons providing support within the family group as the needs for support became more advanced and the previous caregiver did not have the ability to serve the changed needs. Initially, support changed within the family group to maintain support flow to the central woman. When the family group members were not able to provide enough support, network contribution from the *คนนอก/Khon-nok/* or non-family group increased.

Another form of network change was the exchange in support roles between members when changes in normal life occurred.

*1.a “On my next doctor visit, I will go to hospital with my younger son. Yesterday he rang me and told me that for the next doctor visit he will come to pick me from home to the hospital with his motorcycle. We didn’t need to go early as I finished my chemotherapy. ... He asked me ‘Can you go to the hospital by my motorcycle instead of \_’s car’ [the eldest son’s name]? I replied to him that it is not a big matter for me. ... Since my eldest son has moved to his new workplace, it was harder for him to come to see me regularly as previously, so my younger son came to me every week or fortnight, and sometimes he came with his daughters”. (C1, central woman, Int, 16<sup>th</sup> visit, p. 21)*

In the quote above the participant ascribes the change in job of the previous significant supporter—her eldest son—as affecting his network contribution. As a result, an exchange in responsibility between two sons then took place to ensure their mother continued receiving health services.

When the women's breast cancer journey transitioned from unstable to stable periods and remained stable, normally the support provided from the family members decreased in relation to a perceived lessening of support demand. However, all participants declared that they still had good ties with their family supporters as they felt these members always were with them and were standing by to provide support to them at any time. In the quote below, three months after completion of chemotherapy, one central woman provided me information about both persistence and changes of support from her family members. However, she perceived that the network connection and relationships among all family members were consistent.

*1.a* "Now I am quite well. *1.c* [her sister who was one of her key supporters] and my sons still visit me and look after me the same as previously. But another sister and brother visit me less frequently than previously. Why would they have to come to me frequently, there is no need. Now I can look after myself... .. They were always concerned about me. I know even if they don't visit me, they ǎ/Wang/ [the southern dialect: keep monitoring] me if I need any support. And I can contact them if I want any support ..." (C1, central woman, Int, 17<sup>th</sup> visit, p. 1-2)

Networks that were grounded within normal networks with close relationships, strong ties, good connection, and family cohesion, demonstrated fluidity and represented 'mature networks'. These were available to provide good support and also adjust themselves in relation to changes in circumstance. Some participants felt they now had closer relationships among their family because of the increased interactions while providing support to their mother.

*5.e* "Since *Ma* [mother] was diagnosed with this disease, we had to keep being together to support my mom with her sickness and her shop. I felt closer with my siblings during the critical periods until now [three months after the completion of receiving chemotherapy], we spent more time together, chatting with family members more than previously..." (C5, son, Int, 10<sup>th</sup> visit, p.13)

In summary, the changeability of networks within the family group revealed changes in providing support in terms of what and how to provide support among the group, rather than changes of persons and relationships. Particularly, throughout the journey all family members remained engaged in the networks. Additionally, the changes within the family group were able to impact the changes within non-family group.

## Changeability of the *คนนอก/Khon-nok/* or non-family group

The changes within this group existed in different patterns between two subgroups—the members with close relationships (such as pseudo-family members or close friends), and the members who were acquaintances. For the subgroup of close members, changes were most similar to the change pattern of the family group. Changes in providing support and supporters related to the changes in needs for support, ability to provide support, and contribution in networks. Similar to the family group, an absence of close friends or relatives was not mentioned. For example, the closest friend of a central woman explained to me that the support she provided to the central woman changed in degrees of dependency related to her perception about the central woman’s needs. (See the quote below)

[Four months after chemotherapy completed]

*2.e “Now 2.a [the central woman] is very much better, she needs little support from others. Now her confidence comes back. Then I withdrew my support from her, just keep monitoring her if anything I can facilitate her back to normal life. ...” (C2, close friend, Int, 7<sup>th</sup> visit, p. 7)*

In contrast, the involvement of acquaintances such as other breast cancer patients, friends, colleagues, and neighbours, was not consistent as it changed in relation to changes in phases of the breast cancer. As time passed, the participants presented the absence of non-family members from networks in relation to a decrease of frequency and/or regularity of interactions between them.

*5.a “I had a lot of visitors when I was at hospital, some of them hadn’t seen me before as they were my children’s friends ... When I was admitted in hospital or when I went to see the doctor, I have had conversations with many cancer patients. It was nice to talk to them... Now I haven’t seen them for a while as I just go to the hospital every month for a check-up and next time will be on the next two months and I might not see the patients that I used to talk with”. (C5, central woman, Int, 9<sup>th</sup> visit, p. 11)*

In some cases, a process of engagement of new network members occurred, particularly in the non-family group. The participants mentioned that this kind of change occurred if their current networks (at that time) lacked ability and /or resources for support needed and/or wanted.

*9.a “I am under the บัตรทอง/Badh-dhong/ program [the financial programme for the universal coverage scheme], by that system I could not access directly to the tertiary hospital as the*

*university hospital that I and my family felt familiar with. Hence, I had to be referred from the local hospital to the provincial hospital in town where we had no experience with it. .... Finally, I rang my high school mate who works there. \_ [the friend's name] helped me get there very much easier. She selected the good doctor for me, made an appointment with the doctor and ...". (C9, central woman, Int, 2<sup>st</sup> visit, p. 6)*

For this case, a connection with the high school friend was rebuilt to seek support and she was identified as the significant support of non-family group.

## **Changeability of the health professional group**

As mentioned previously, the group of health-professional members was relationship-based with a personal connection perceived by the participants. During the periods of undergoing investigation and treatments, the participants stated that the personal connection with health professionals was related to the frequency of interaction between these health professionals and the participants. When their health was stable and interactions with their health professionals had decreased, the participants verbalised their personal feelings about these professional members less often. The two quotes below demonstrate the change in personal feelings about a health professional when the journey transitioned from unstable to stable.

[After completion receiving chemotherapy for one month]

*I.a "My chemotherapy finished and I will go to see her doctor again next month ... He is so nice. If I can I want to visit him... like just having friendly chat with him". (C1, central woman, Int, 16<sup>th</sup> visit, p. 15)*

[During the follow up phase, after the completion of chemotherapy for 5 months]

*I.a "I don't know how much he [her doctor] is concerned about me [laughing], as he is always busy. New cases come to him every day. Sometimes he could not remember my details, I understand about this as he has a lot of patients to look after and they are more serious than me right now." (C1, central woman, Int, 19<sup>th</sup> visit, p. 20)*

The characteristic of fluidity in networks was observed along the journey related to the situational changes in the breast cancer and/or normal life, and inconsistency or mismatching of support between members. Consequently, changeability in networks occurred and recurred throughout the journey to keep networks in balance and maintain the support flow among members. The changeability characteristic within member groups then brought up the process of balancing networks that will be presented in the following section.

## Process to keep networks in balance

The central women's networks were functioning in changeable circumstances. As these changes had the potential to make the network unbalanced, ongoing adjustments of the members, members' functions and resources occurred either to prevent network imbalance or to help networks function better. However, different patterns of network adjustment between the phases of living with breast cancer during the unstable and stable periods can be observed.

### *Adjustments during unstable periods*

During the unstable periods of breast cancer investigations, diagnosis and treatment of the first and any recurrent diagnosis, these support networks functioned with the higher prioritisation of the breast cancer and its treatments than issues related to normal living. In this period, the pattern of adjustment in networks occurred to maintain assistance for the central women and the significant supporters to achieve completion of the breast cancer treatment. This was evident both within and between member groups of networks and also with outsiders. The outsiders (non-members of the networks) were usually friends or relations of network members who were called upon to help in special circumstances.

The network adjustment within and between family and non-family groups was exposed many times through the network discussion activities relating to the situation changes. Network adjustment occurred in many aspects: adjusting members providing targeted support, adjusting functions assigned to members (assigned by others and/or the providers themselves), adjusting resources for support, and /or adjusting needs for support.

*1.a "Yes, 1.c is sick, she told me she had felt not well for two to three days. ... Then the next time of my receiving chemotherapy, another sister told me she will be my caregiver in hospital instead of 1.c. I will go to the hospital with my son and then my sister's husband will take my sister directly to the hospital to be with me there. Normally, my sister's grandchildren come to sleep with her every night, so she will ask her husband's daughter to sleep with the kids instead of her. ..."* (C1, central woman, Int, 6<sup>th</sup> visit, p. 2)

The quote above shows that when a situation changed (the key supporter was sick), the functions assigned were adjusted among the family members and related persons to keep up the significant support to assist the central woman to maintain the treatment. Next, the excerpt below delineates the adjustment in needs for support. This central woman kept her network in balance by reducing her need for support from her supporters by refusing to

request support. This was because of her concern about the disturbance in her supporters' normal lives.

*9.a "Lately, sometimes I went to the hospital by myself, went there by the public van. I know if I ask for support from my brothers, they will provide it to me even though they might have difficulty about their work... sometimes the difficulty happened I knew. When I went to the hospital without their support, they rang to me several times...asking me 'Where are you? Are you at home yet?' Something like that." (C9, central woman, Int, 2<sup>nd</sup> visit, p. 5)*

Furthermore, the adjustment in resources for providing support was mentioned in many cases because the intentions of supporters were to keep the support flow to the central women parallel with their normal roles. For example, in the quote below the central woman's children kept working out who could do what role to keep up their responsibility to the central woman in relation to both her sickness and her business. These children managed their resources together to maintain their supporter roles in the network and their normal roles.

*5.e "I and my brother were the main drivers for **Ma** [Mother] when visiting her doctor in town, but if my dad had to go to the university hospital, I drove for him mainly because my brother was not fine to go there as he was not used to that hospital. Normally, he and I talked together like this. 'The next appointment of **Ma** on the date \_ and who will be more available to take her to there.' as it depended on our jobs too... .. Sometimes, my sister had to drive to the hospital by herself but just one or two times since **Ma** had to go to the hospital. Mainly my two sisters took the responsibility of being **Ma**'s caregiver at hospital and at home and my father too. The elder one will help do **Ma**'s shop duty in the early morning before she goes out for her job..." (C5, son, Gr Int, 10<sup>th</sup> visit, p. 8)*

Additionally, the network adjustment in this period can be seen within networks and also through the involvement of the outsiders. For many networks, the adjustment occurred within the family group first and more frequently than within the non-family group because the greater the closeness of the relationship, the lesser the feelings of *เกรงใจ/Kreng-jai*/. In the same way, more adjustments among the close members of the non family group such as relatives or close friends can be observed than within the sub-group of acquaintances. Extra resources and/or supporters were recruited into networks if necessary and/or wanted. For instance, in many networks, the central women and their members disclosed that they sought information related to breast cancer and sourced this from outside their members' networks.

*2.e "As my sister is a nurse, I consulted her many times about **2.a**'s disease and how she*

*should look after herself while undergoing the breast cancer treatments. They haven't met each other yet. They just have known each other through me. ...* (C2, close friend, Int, 6<sup>th</sup> visit, p. 8)

**9.b** *"I live with my close friend in the dormitory behind her hospital. When my aunty [the central woman] had to get radiation from this hospital, she stayed with me. In case, I had to go out for work or had lab work on some days, my friend took my aunty to the hospital and collected her from the hospital when she finished the radiation. ..."* (C9, niece, Int, 6<sup>th</sup> visit, p.3)

For the first quote, the outsider was used as the information resource but the person was not recruited into the central woman's network as a member. In the second quote, the member's network member provided direct support to the central woman and was later counted in network. (See \* in Fig.7.2 in Chapter 7).

Some central woman engaged with the breast cancer clubs, while other central women informed me that they would have liked to attend the club but they were not able to manage their daily activities to suit the club activity schedule. Others said that they were not interested in formal groups like the breast cancer clubs. Some central women kept contact with their club, including the club as a part of their networks as they felt they fulfilled some of the missing things in their life by participating in the club activities and/r having informal interactions with other club members.

**10.a** *—I used to have long and nice hair. When I was undergoing the chemotherapy, I looked weird [laughing]. Somebody might think I got something like that [HIV] [laughing] they won't talk to me and won't share a seat with me when I went to the Chinese temple on any Chinese festival. ... I got breast cancer diagnosis for five years and it was quite an advanced stage thus many experiences I had during five years with it. Such as ... I was invited to participate with the club activities since I was admitted in the hospital and then being the club member until now. I have a lot of experiences about the breast cancer and practicing self care, they were gained by reading books, from the speakers in health education activity, experiences shared by other members, and my own experiences. I am happy to share these with others in particular the new cases. ... For me, I have less chance to have problems to participate with the club's activities. Each time of going there, I went with my sister either to the indoor or outdoor activities. [They have always live together]. She went there with me as my mentor... My sister retired from job for six to seven years and I quit my job two years after getting this disease".*  
(C10, central woman and a member of a breast cancer club, Int, 3<sup>rd</sup> visit, p. 10-11)

In the quote above, the central woman felt fulfilled particularly with the part of her social life through the club activities involvement and she felt that participating in the club activities did not interrupt her everyday life. As a result, she continued going to the club as a part of

her social life.

The central woman who was diagnosed with a recurrence of breast cancer reported the repetition of adjustments in members, functions assigned to members, and resources. As relationships were superior, the family and other close members were the first groups in the network that readjusted to perform the support needed for the new circumstances.

### *Adjustments during the stable periods*

When the central women's breast cancer was stable, the central women and their members perceived that less support was needed as the breast cancer was steadily less significant, and life became increasingly normal. All networks adjusted in this period by contraction of the non-family and health professional groups, while close members such as family, family-like and close friends still remained. However, functional adjustments within the close members were revealed.

All participants described a contraction in size of the subgroup of health professionals and acquaintances (and outsiders), and a decrease in their interaction and support.

[Four months after the completion of treatments]

*2.a "After finishing my chemotherapy, I have to go to hospital once a month and the nurse told me that I did not need to see **Mor A** [her surgeon], as other doctors can provide me with checkups after treatments and give me the medicine prescription. ... Sometimes I hesitated to ask him [**Mor A**] my questions as I was afraid I would waste his time, in particular, when I saw many patients were waiting for him after my visit. Hence, sometimes during my hospital visit I did not meet him. He is so busy with many patients, he might not have enough time for my case" [she means her sickness is not serious enough.] (C2, central woman, Int, 5<sup>th</sup> visit, p. 26-27)*

*3.a "Many college friends and high school friends visited me during my hospitalisation. ... My master classmates and the lecturers rang me several times asking about my illness. These people provided very good encouragement for me. When my health got better, it is normal that their visits and calling me decreased or stopped. However, I know they will come back to me if I need them." (C3, central woman, Int, 4<sup>th</sup> visit, p. 15)*

The two quotes above, demonstrated the existence of network adjustments by the steady decrease of interactions and support provided that lead to a reduction in the groups of members without close relationships in networks.

During the stable period, the close group (family, pseudo-family and close friends) showed

adjustments in provision of support and numbers of interactions. However, the size, relationships and ties within the network were reported by both the central women and their close members as persistent.

*9.b* “My aunty [*9.a*—the central woman] now is very much better, we talk together almost every day. This is our family pattern in daily living. I think after she finished receiving the radiation therapy I haven’t met her yet [During the radiation phase, *9.a* stayed with *9.b*]. Even if I haven’t seen her for a period of time as I was busy with my new job, I knew about her from her or from my parents or from another aunt”. (C9, niece, Int, 6<sup>th</sup> visit, p. 1)

Furthermore, during periods of instability or stability, planned and unplanned changes in normal life happened at any time. Accordingly, the network adjustments were expressed by the participants as an ongoing occurrence throughout the journey either by nature or the members’ intention.

## **The network life cycle**

These support networks functioned in the changeable circumstances of breast cancer, normal life, and interpersonal relationships, and five steps in network development emerged from the network data showing this ongoing adaptation (See Fig. 8.1 the diagram of network development). Firstly, the initial members of all support networks were groups of (quasi) family members (and close friends). Secondly, the network membership grew in number to serve the enlarged support needs, in particular for the breast cancer and related issues. Thirdly, during the long-term phase of undergoing aggressive treatments, network adjustment continued to maintain a good support flow among members. Fourthly, when the aggressive treatments were completed, the networks started to downsize the roles of health professionals and the members who were not close in relationship. Close members changed their forms of support from giving support to facilitating and monitoring instead. Finally, during the stable period of follow up, the long-term relationships and strong ties of family and close friends with the central women persisted.

In the case where the disease recurred, network development returned to the first step then developed again to the second step of network expansion, and then kept going in the steps of (re) adjustment to maintain support flow assisting the central woman to keep going with the prolonged treatments<sup>22</sup>. However, within this case, the developing movement of the network within the recurrence loop from step to step was quicker than within the loop of the first

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<sup>22</sup> No central women had completed treatments for the recurrent diagnosis

diagnosis.

*4.a “Two years ago, I found the hard lump at my sternum,... .. I told my sister who is a nurse again. Next we went to see the doctor at the local hospital and he referred me to the university hospital. He said my disease had possibly recurred. From that time until now, I have been undergoing the university hospital’s treatments. Initially, I went to the hospital sometimes with my nurse sister, sometimes with my elder sister, and sometimes with my nephew. For many months I went there alone, I don’t need company, I can do by myself. Exceptionally, in the case my appointment is at the same time as my father’s and my sister’s appointment with their doctor, we go there together and my sister is our driver”.*

*[Her father and her nurse sister (the central woman of case 3) had been diagnosed with cancer and were undergoing the university hospital treatments before her recurrence diagnosis]*  
*(C4, central woman, Int, 4<sup>th</sup> visit, p. 11)*

The quote above shows the quicker development of this network when the central woman’s disease recurred. When the potential for recurrence of the breast cancer became known, the reunion of the network, especially the family group quickly occurred. According to the experiences with the first diagnosis the breast cancer of the central women and their remaining members, they had breast cancer-related knowledge, and support and action needed. In the recurrence case, the phase of undergoing aggressive treatments continued long-term and the central woman tended to live with the breast cancer as part of normal life.

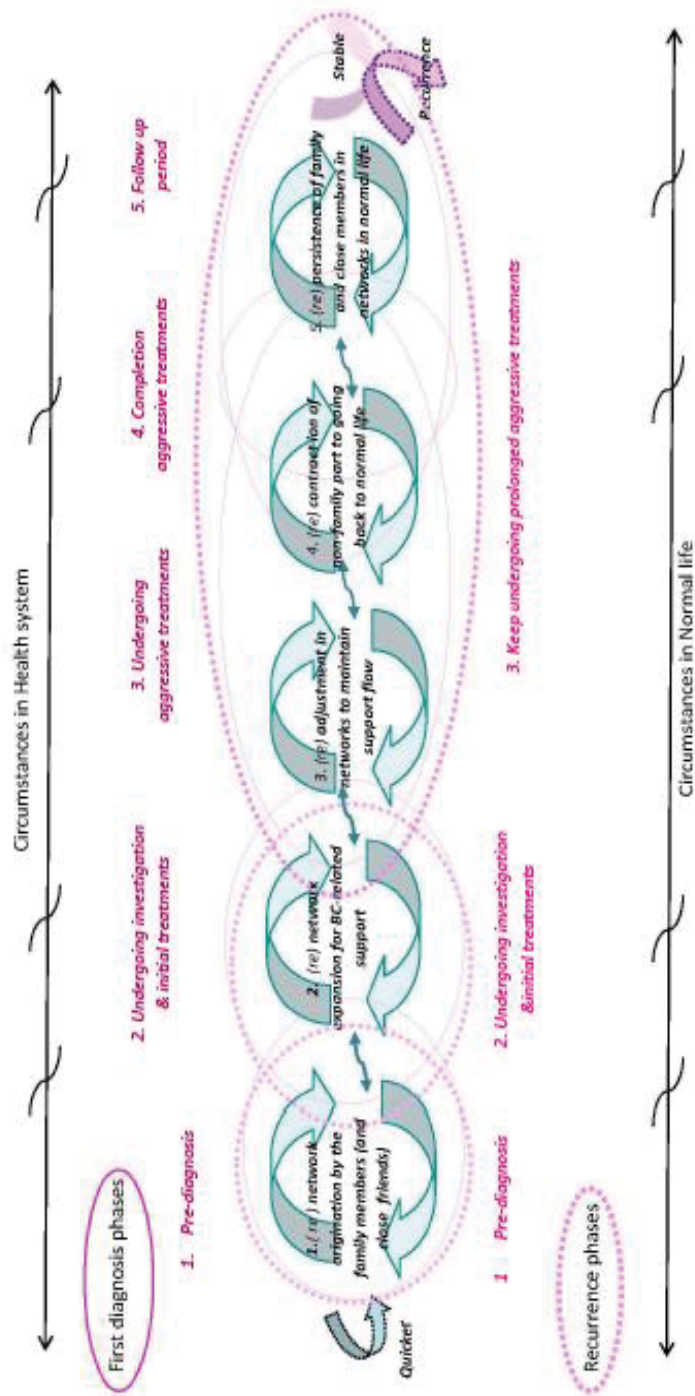


Figure 8.1. The diagram of Network development.

## Conclusion

Throughout the breast cancer journey, due to an ongoing interplay between three categories of disease-related situations, health system situations, and normal life situations, the women's networks were formulated and developed to deliver support to the women and relevant people within five core characteristics. They were i) membership based on the interplay between types of supports, supporters, relationships, iii) hierarchies of significance iii) different degrees of relationships and attachment kept members together, iv) fluidity in networks existed to keep the network balanced, and v) the network life cycle. Even though, some networks were family and friend-based, all networks were family-centred as their relationships and core-members were majorly (pseudo) families. For health professionals, they were considered as members, when they were perceived having personal relationships, feeling of admiration for their services and/or be able to fill a gap of personal support.

In the last chapter, the network concepts based on these study findings will be discussed within a holistic nursing perspective.

## CHAPTER 9

### **'People who are together with me'**

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#### **Introduction**

This chapter presents a discussion, summary, and conclusion of the study. My personal experiences of living with breast cancer in my family, and a Thai health policy emphasis of formal support clubs for patients with chronic diseases, including breast cancer, but low success in terms of membership numbers, provoked my professional and personal interests about the 'personal social networks' of women living with breast cancer in the circumstances of the lower southern Thailand (my hometown region). I expected that an in-depth understanding about the women's experiences of their networks and breast cancer club participation could enhance breast cancer care.

As living with breast cancer is long-term, complex, and changeable, I purposively selected 11 networks of women living with breast cancer as the study's cases and explored these networks in depth over a period of months through a collective qualitative case study approach. Themes that emerged from the analysis related to network and contextual complexities. Later, two overarching themes related to network characteristics emerged.

In considering my study findings from a nursing perspective I argue that for holistic nursing care to be provided to women with breast cancer four aspects need to be considered: i) nursing care needs to shift from a narrow focus on the disease and medical treatments to a focus on the whole person; ii) the women's circumstances of family and daily life responsibilities need to be recognised; iii) the numerous personal supporters and support needs throughout the breast cancer journey should be recognised; and iv) nursing care should continue throughout the breast cancer treatment course. Implications of my study findings for nursing policy, practice, and education will follow, emphasising a need for ongoing nursing consideration of networks and the support they provide at both hospital and community-based levels and recommendations for improving breast cancer club activities. This chapter will conclude with a discussion of the study limitations, and recommendations for further research.

## A whole personal social network is the study case

This study aimed to examine personal social networks of the central women living with breast cancer and their significant supporters. ‘Personal social networks’ are larger and more complex than social support or types of caregivers as they comprise multiple groups providing different kinds of personal relationships and support. The research questions were:

1. What are the experiences of personal social networks of women with a breast cancer diagnosis and their significant supporters?
2. How do the contextual factors of living with breast cancer in the lower southern region of Thailand influence their personal social networks?
3. How do the women with a breast cancer diagnosis become involved in a breast cancer club and why?

## Summary of the study themes

The study themes consist of three categories. The contextual themes of four unique patterns of living with breast cancer resulted from the interplay between the disease of breast cancer, the complexities of the health system, and normal life circumstances. Network themes contain six core network characteristics. Two further overarching themes are that ‘personal social networks mean people who are together with me’, a conceptual theme in relation to networks themselves, and ‘personal social networks are disease, relationship, and culturally specific’. This second conceptual theme relates to factors underpinning network characteristics (see Fig. 9.1).

‘**People**’ or network members were predominantly family members or those who held (quasi) family relationships with the central women, such as relatives or closest friends. Membership was based on the interplay between three types of interactional properties: support, supporters, and relationships. Participants identified the significance of each member in their network with consideration of three categories: the member’s perceived helpfulness, being a beloved person (or person of faith), and/or being satisfied with the support the member provided. With regard to these identification processes the central women ranked their network members against hierarchies of significance. ‘**Being together**’ was explained by the central women and some of their network members as ‘different degrees of relationships and feeling of *Khong*/ that kept network members together’.

During the breast cancer journey, the women and their network members experienced an ongoing interplay between the contextual factors related to the breast cancer disease, the health system, and normal life responsibilities in four categories; living with mature networks, living with complexities of family circumstances, living with complexities in breast cancer management and family circumstances, and, for some women, long-term involvement with a breast cancer club. This interaction then resulted in fluidity in the nature of the support and a pattern of the network life cycle, to balance their breast cancer journey with differing degrees of success.

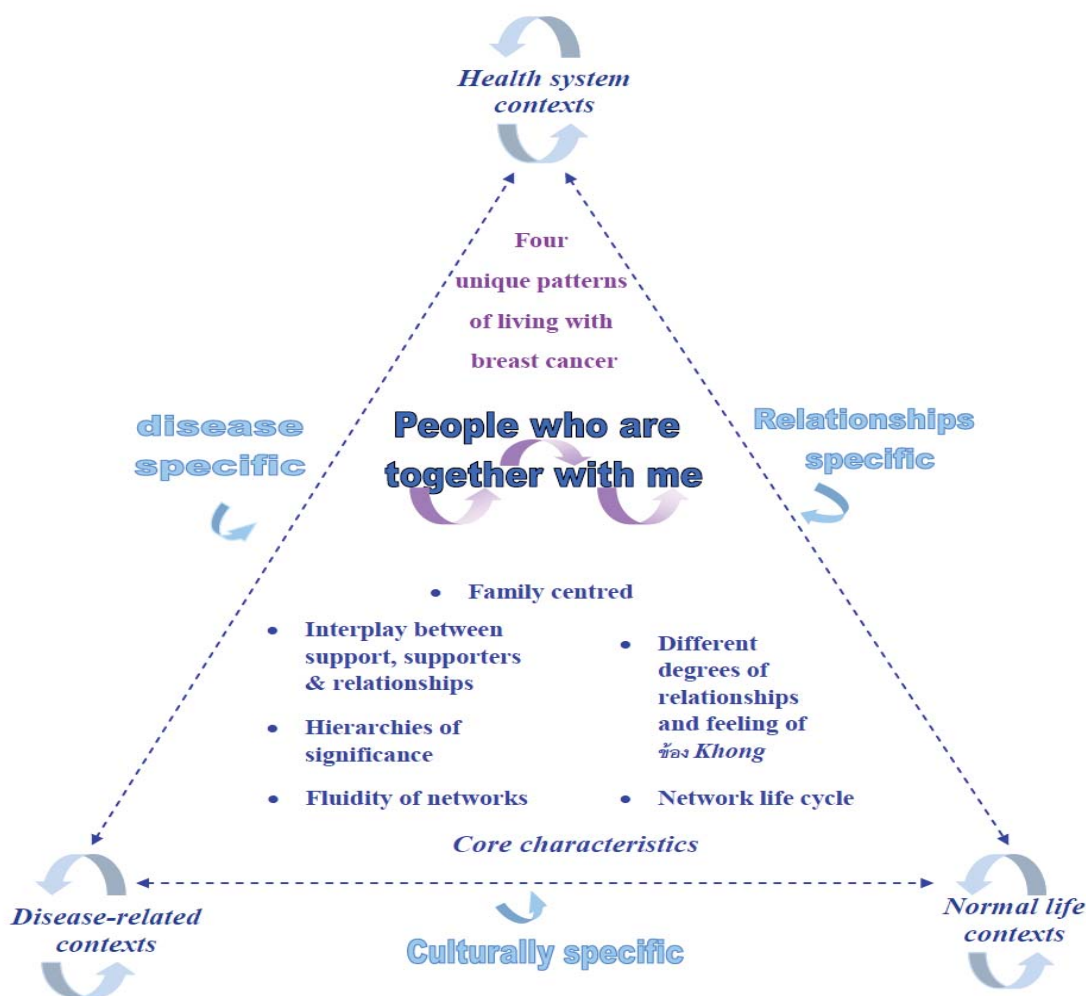


Fig.9.1. Conceptual diagram of personal social networks of women living with breast cancer in the lower southern region of Thailand.

Now I turn to considering what nurses can learn from these experiences of personal social networks to enhance breast cancer nursing care.

## **Discussion**

The discussion of the study findings is approached through a nursing perspective that aims to examine the implications of these findings for improvement of nursing care. In this section, I will discuss four major themes related to network characteristics, network circumstances, and formal network participation respectively.

### **People who are together with me**

The study findings highlight the range, breadth and depth of support that women needed as they lived with breast cancer, the medical treatment, and also managed their responsibilities in daily life for work and family. Women with mature support networks had access to more resources to manage the complexities in their circumstances and those networks were more able to respond to changes in a timely manner so as to continue to offer the support needed throughout the long journey. This theme is consistent with numerous previous studies that report the importance of personal social networks, in particular supporters with close relationships for the women living with (breast) cancer (Arman et al., 2001; Arora et al., 2007; Beasley et al., 2010). In a study by Thomas and Morris (2002) personal social networks, and especially the core supporters, were identified by the women as “the people who ‘shared most’ in their cancer experience” (p. 180) and these people also helped the women to keep going through their breast cancer journey (e.g. Arora et al., 2007). My study finding that the women’s personal social networks continue to support the women throughout their journey, including after completion of treatment, is consistent with other prior studies (e.g. Lethborg, Kissane, & Burns, 2003; Thewes, Butow, Girgis, & Pendlebury, 2004) and is congruent with the significance placed on family as network members.

The significance of these networks and the support they provide throughout the breast cancer journey is strongly confirmed by the reports about impacts of personal social networks on both quality of life and survival rates. Kroenke et al. (2013) conducted their longitudinal survey about social networks, social support, and quality of life and report a positive relationship between social networks with positive social interactions and women’s quality of life. A lack of social support resulting in social isolation, and increased the risk of mortality after a breast cancer diagnosis was reported (C.H Kroenke et al., 2006). As well, studies by nurses report a positive relationship between social support and quality of life in women with breast cancer diagnosis (Manning-Walsh, 2005; Somjaivong, Thanasilp, Preechawong, & Sloan, 2011).

No other studies by nurses that focused on a whole network of women with breast cancer could be found in the literature, however, studies about social support from selected supporter groups such as family or informal carers, confirm the importance and/or needs of personal support in the (breast) cancer journey (e.g. Given et al., 2001; Junda, 2004; Meecharoen et al., 2013) and extending in the long-term after treatment and follow up is completed (Vivar & McQueen, 2005).

The personal nature of networks meant that the network seemed almost continuously available and able to quickly respond to the women's needs and problems. Health professionals, in contrast, had episodic encounters with the women. As a result their response to problems was delayed compared to the personal supporters. Health professionals approached breast cancer care as a series of treatments in a complex system where there were few links between hospital and community-based care. Nurses were overloaded with tasks and with a very limited number of nurses per shift to provide care. Furthermore, there was little continuity of care between nurses. Importantly, many problems that the women were concerned about or needed support with arose outside of hospital admissions and therefore the women and their networks needed to manage these problems or concerns on their own. The difference in availability of personal supporters and health professionals to address the women's concerns, needs of support and problems is consistent with Sharpe et al.'s (2005) study where the authors found that the significant members or informal carers of the women with breast cancer had higher levels of availability to provide support for them compared to health professionals. The perception about high availability of personal social networks may be one significant factor that influences a dependency on those networks.

For nurses this theme implies that many personal social networks provide significant support to women with breast cancer and those networks should be considered as part of the health care team, if the whole team is to work towards the best outcomes for the women. Consequently, it is crucial that nurses understand the nature of personal social networks.

### **The nature of personal social networks**

With regard to the unique patterns of interactions between the cases and their contexts and the core characteristics of personal social networks that emerged in this study, four major network characteristics are important. Networks are; family-centred; have hierarchies of significance; have fluidity in support provision; and are disease, relationships, and culturally specific.

### *Personal social networks are family-centred*

In this study, networks were, in the main, family-centred, similar to many previous studies conducted in different contexts (e.g. Given et al., 2001; Junda, 2004; Muhamad, Afshari, & Kazilan, 2011; Northfield, 2010). However, family centredness in my study existed with a unique characteristic of ‘family’ as those with a blood-related relationship rather than those with a married relationship. Two features of networks being family-centred were that family formed a core supporters group for the women and at the same time provided support to the rest of the family. These findings reflect the importance of ‘family’ and family relationships that reflect cultural patterns.

The ‘family’ support group in my study had unique characteristics. ‘Family’ was defined based on the southern dialect—*คนใน/Khon-nai/* where the meaning was based on blood related relationships rather than relationship by marriage. Their family group or *คนใน/Khon-nai/* comprised the women’s parents, siblings, children, spouses and siblings’ children (nieces and nephews), including relatives who feel close as pseudo-family. These people were identified as family even if they lived together or not. Thus, the characteristic of ‘family’ in my study is different from other studies, particularly, studies conducted in Western contexts where ‘families’ are predominantly partners (and children) rather than parents and siblings (Bakas, Lewis, & Parsons, 2001; Grunfeld et al., 2004; Soothill et al., 2001). The family characteristic in my study clearly related to the cultural life ways of Thai people that reflected patterns of family living and cultural norms and values in Thai society. This is confirmed by the characteristics of family caregivers described in Meecharoen et al’s (2013) study that reviewed 23 studies about family caregivers for cancer patients in Thai contexts. These authors reported that family caregivers usually referred to a person in an extended family.

The interaction between relationships and cultural norms may explain the predominance of the emphasis on family as those with a blood relationship in my study cases, underpinned by feelings and values about closeness in relationships, emotional attachment and the cultural value of connectedness of Thai people. Thai people are collectivistic rather than individualistic, similar to most other Eastern ethnic groups. This living culture is predominantly interdependent with regards to connectedness and emotional attachment to groups (H. S. Kim, Sherman, & Taylor, 2008; Makabe & Hull, 2011; Taylor et al., 2004; Triandis, Bontempo, Villareal, Asai, & Lucca, 1988).

Another difference from Western contexts was the way in which the blood-related family tended to have a high contribution in the network, sometimes with more involvement than the women's husbands, for those who were married. This feature may relate to the collectivistic characteristic of Thai culture and the role of family in sharing with the women's concerns (as discussed previously). Furthermore, it may be related to the gender-specific nature of breast cancer as a mostly female specific disease, when female supporters may be preferred. Females tend to have better connections and/or stronger ties with female kin than males (Hirsch, Mickus, & Boerger, 2002). Additionally, it may reflect cultural expectations and gender differences in the responses to sick and supporter roles. The different expectations about caring roles for male family members is reported in both Eastern (Hasson et al., 2010) and Western ethnic groups (Northfield, 2010; Papastavrou, Charalambous, & Tsangari, 2009). Another important factor is the influence of religious cultures on responsibilities of caregiver roles between genders in particular religions such as Islam. The feature of female dominance of network members, then, resulted from the interaction between disease, relationships and cultural contexts.

The finding that families are a core supporter group of (breast) cancer patients is consistent with many studies conducted in different contexts, both Western (e.g. Girgis & Lambert, 2009; Given et al., 2001) and Eastern (Balneaves et al., 2007; Effendy et al., 2015), including Thai contexts (Meecharoen et al., 2013). Families provided the most support and had the longest contribution in the networks - the close and long lasting relationships linked the women and their family members together. In my study, the central women and their network members described their feelings of 'being together' with their network members related to personal relationships in different degrees of closeness and *ห้อง/Khong/*—in the southern dialect it means the combination of feelings of 'attachment' and 'concern or worried about'. Family members or *คนใน/Khon-nai/* were identified as having higher degrees of attachment and *ห้อง/Khong/* compared to non-family group or *คนนอก/Khon-nok/*.

Accordingly, the higher the degree of the closeness and feeling of *ห้อง/Khong/*, the higher the degree and length of period of contribution in networks, that occurred. Consistent with this theme, nursing studies of social support or networks reveal that the partner's and family's contribution in networks to provide support or caring relates to feeling of 'attachment' and 'sharing concerns with the women' (Kayser, Watson, & Andrade, 2007; Y. Kim, Carver, Deci, & Kasser, 2008; Meecharoen et al., 2013; Peters-Golden, 1982; Subgranon & Lund,

2000). With regard to their attachment and shared concerns, family members are more likely to be able to better recognise and understand the women's needs of support than others. Family tended to address the women's needs with understanding, respect, empathy, compassion, and love, and these findings are supported by other studies (Finfgeld-Connett, 2005; Meecharoen et al., 2013). However differences existed as in my study the women's parents and children were always identified as significant supporters whether or not they were able to provide any tangible support. These findings may reflect that the women perceived these relationships as superior.

Furthermore, support provided by family members with what Finfgeld-Connett (2005) calls 'unconditional positive regard' (p. 3) was related to the family members being more available to provide that support. This availability tended to overcome difficulties and barriers to serve a number of support roles more easily than non-family members. For the family members, the woman's illness took priority over their own personal issues. For instance, one older sister resigned from her part-time job to look after her younger sister with breast cancer while she underwent aggressive treatment. This demonstration of 'unconditional positive regard' of the central women by their family members has been found in other studies (Balneaves et al., 2007; Junda, 2004; Meecharoen et al., 2013). In addition, the 'trust' of family members and on their support underpinned the importance of the family as the centre of networks in my study. The place of trust in networks, especially in the caregiver group is confirmed by Ray and Street (2011) who developed the concept of socio-connective trust. These authors define social network trust as "the synapse between the social structures and processes that underpin relationships in positive care networks" (p. 1). They also found that socio-connective trust influences caregivers to sustain their provision of support.

In addition, cultural perspectives combine with relationships as underlying factors of the centrality of the family in networks in my study. Feelings of *เกรงใจ/Kreng-jai* that is valued in the Thai way of living may be used to explain this theme. Different degrees of *เกรงใจ/Kreng-jai* between the family groups and non-family groups in each network explain the different degrees of closeness - the higher the degree of *เกรงใจ/Kreng-jai* the central women felt to others, the more reluctant they were to ask for help or to receive support from them. This finding is in line with other studies in social support that reveal the unique pattern of seeking help or support of people from Asian cultures who tend to feel reluctance to

expressly ask for help or support from others (H. S. Kim et al., 2008; Taylor et al., 2004). In Kim et al.'s (2008) study, the authors further explained why Asian people may be reluctant to ask support based on a concern about the negative consequences of support seeking. On the other hand, for Thai people, the feeling of *เกรงใจ/Kreng-jai* is perceived as being deference to others and consideration of each other. It is culturally valued in social behaviours. However, the lesser the closeness in relationship, the much more reluctance Thai people have when asking for help from others. Moreover, this theme may be explained by the social norms and obligations that create the responsibility of being family members (Makabe & Hull, 2011; Meecharoen et al., 2013). The family predominance in networks was related not only to relationship and cultural criteria, but also a distress resulting from physical changes.

Some of the women's patterns of socialization and involvement in their community activities were affected by changes in their body image and psychological changes related to the cancer diagnosis, the surgery and effects of other treatment. These patterns were also affected by cultural expectations. When undergoing adjuvant therapies, the women tended to reduce and/or escape from their social activities, especially with those whose relationships were not close. This related not only to the women feeling unwell, but also to their body image changes; however, individuals responded differently. For example, most women withdrew from participation in routine career meetings or seminars, and stopped going to the market, or to performances of religious practices at a village temple or mosque, and participation in community activities or relative's ceremonies because of their distress about their body image changes. This distress about body image changes has been identified in many other studies (e.g. Lavin & Hyde, 2006; Pelusi, 2006; Sheppard & Ely, 2008). Holmberg, Scott, Alexy and Fife (2001) also identified changes in patterns of social activities of women with breast cancer and also highlighted how breast cancer (and its treatment) can also result in relationship issues for women and their partners. In my study the women who reduced their social activities had an increased dependency on family support. The predominance of family members as a core support group in networks is in line with Newman and Roberts's (2013) discussion about relationships difference and motivation to support that are influenced by familiarity, closeness, attachment, and empathy.

Further, my findings show a significant network role was in providing support to the women's family in parallel with providing support to the women throughout the breast cancer journey. This major network role included assisting the women with their family many cases network members took over care of the women's dependent family members,

such as young children, or elderly parents, and other sick family members. The need for help in caring for women's young children is a specific support that is identified in many breast cancer studies (Banning, Hafeez, Faisal, Hassan, & Zafar, 2009; Connell, Patterson, & Newman, 2006). Some women asked family supporters to take over their responsibilities for caring for their young children, elderly parents and/or sick family members. Some supporters took over these roles without the women requesting the support. Some supporters assisted the women to maintain these roles. These findings are consistent with the studies by Balneaves et al (2007) and Subgranon and Lund (2000). In Thai culture the care giving role for elderly parents and/or sick family members is influenced by cultural values and obligations of female adult members as one role within Thai families (Wongsawang, Lagampan, Lapvongwattana, & Bowers, 2013).

Considering the importance of family and blood relationships as the core of networks highlights the need for family focused breast cancer nursing care that recognises the women's family as co-clients and significant resources of personal support for the women with breast cancer. Furthermore, personal identification of who the women count as their family is important for nursing care to be individualised.

#### ***Personal social networks have hierarchies of significance***

Another significant feature of the networks in this study is the ways in which the women attached hierarchies of significance to their network membership related to members' perceived helpfulness, their role as a beloved person (or person with faith), and the women's satisfaction with the support provided. This means each supporter in each network was rated using an appraisal of objective and subjective criteria. The presence of hierarchies of significance in networks is in line with the model of network zones introduced by Boissevain (1974; 1979). In Boissevain's zone model, layers or zones of groups of network members are explained with regard to objective and subjective interactional properties. However, in Boissevain's network zones, intimacy and actual benefits are indicators to distinguish network members. In my study, the subjective indicators were of intimacy or closeness in relationships and feelings of satisfaction with the support provided. The women undertook a comparison between their expectations and network members' performance of support roles to identify their level of satisfaction. Furthermore, beloved persons were identified as high on the hierarchy without any expectation that those supporters would provide any tangible support. Therefore relationships influence the expectations and satisfaction with assistance. Consistent with this finding, Vaux and Harrison's (1985) study reveals a relationship between network member's identification and support perceptions that relate to satisfaction.

Furthermore, a difference in expectations to provide support based on different relationships has been identified (Pierce, Sarason, & Sarason, 1992). It is therefore important for nurses to understand the women's circumstances and their networks, and who the women identify as the most significant supporters. Then nurses are able to investigate (potential) gaps between perceived support needs and the provision of support and the satisfaction with the support received.

### ***Fluidity in support provision***

Women's needs differed at different phases of their breast cancer journey and a major theme in my study related to the way in which the network was fluid in its support provision. The fluidity occurred throughout all phases of living with breast cancer as revealed in Chapter 8. This fluidity is in line with the 'network dynamics' identified by Valente (2010), who explained the ongoing changes of networks related to network membership and linkages, between members. Changing patterns of network fluidity were found related to the patterns of breast cancer disease and its treatment course. Changes to support provision relied on the dynamic needs and support roles and actions that related to perceptions of support needs. This is in line with the findings in Nijboer et al.'s (2000) study, however, some differences existed. The dynamic support patterns and roles of caregivers, Nijboer, et al's study reveals, comprised three phases: the initial or acute, chronic, and resolution phases. In my study, the focus on a whole network rather than only on a group of caregivers, allowed identification of two 'loops' of network fluidity in relation to the disease diagnosis and its treatment patterns; the loop of living with the first diagnosis and the loop of living with recurrence diagnosis. Living with the first diagnosis comprised five periods; i) pre diagnosis, ii) undergoing investigations and initial treatment, iii) undergoing aggressive treatments, iv) completion of aggressive treatments, and v) follow up. In the single case in this study where the woman experienced a recurrence of her breast cancer the process of living with the recurrence comprised three periods; i) pre diagnosis, ii) undergoing investigation and initial treatments, and iii) undergoing prolonged aggressive treatments.

My finding of network fluidity within the patterns of the disease and its treatments can be used by nurses to consider the how the needs and assistance from the women's personal supporters has the potential to change patterns of needs related to the diagnosis and treatments. The characteristic of network fluidity in my study is congruent with many studies (e.g. J Boissevain, 1974; Snijders et al., 2010; Valente, 2010). Fluidity in support provision implies that personal support needs and support provision are not static and therefore an ongoing assessment of support needs is important throughout the breast cancer journey.

### *Personal social networks are disease, relationships, and culturally specific*

The previous discussion about the overarching theme and the explanation of the nature of networks and their contexts support the existence of an overarching theme of ‘personal social networks as disease, relationships, and culturally specific’. Not surprisingly, the disease patterns and its treatment course had a direct impact on the women’s networks because they resulted in needs or demands for personal support. However, the women’s support needs were complex. As personal support or support behaviours among the women and their network members is a social process, it reflects perceptions of support providers and recipients about i) needs of personal support, ii) relationships, and iii) culture norms related to social behaviours within the individual, group, and society. In the book *Health and Social Relationships: The Good, the Bad, and the Complicated* Newman and Roberts expound the idea that “social relationships (and our internal representations of these relationships) are inextricably embedded within a rich cultural context that determines many of the parameters for how individuals approach others or comport themselves in relation to others” (2013, p. 203). Conclusively, any assessment of networks requires consideration of the interaction between the conditions of the disease, the social relationships and cultural sensitivity.

### **Complexities of breast cancer management and family circumstances**

Two major aspects of complexity in the women’s breast cancer journeys —the breast cancer management, and family circumstances—tended to have a high impact on the networks. As a result, these women experienced living with breast cancer differently. Firstly, in my study, the complexities in breast cancer management related to interlinked factors of the disease itself, the different treatments, the health system, and individual preferences for treatment and treatment providers. For example, in the case of the woman who had a recurrence of her breast cancer, she had to cope with complexities in breast cancer management resulting from the advanced stage of diagnosis and complicated treatments. Consequently, the more specialized the treatment required, the more complex the processes of accessing and using health services, and the financial system. Another case of complexities in breast cancer management occurred in a case when the women’s stage of diagnosis was not advanced. However, for her the complexities related to her and her families’ preference to access specific health professionals and hospitals. These challenges then tended to increase the

personal support needs when undergoing treatment.

My study findings showed several aspects of complexities in family circumstances affecting needs and resources including complexities related to family living patterns (such as living separately and far away from adult children, living far away from blood-related family, living in a remote area away from family), family responsibilities (such as having dependent family members to look after), other family problems occurring at the same time (such as many burdens resulting from family sickness, accidents, and job changes for significant supporters), including disruption to the family income.

In four out of five cases where there were complexities in the breast cancer management and/or family circumstances, some non-family members (close friends, relatives, and neighbours) were included in the core supporter group. Involvement of non-family members in a core supporter group represented a significant sign of difficulties for the family in providing support. Health professionals were included in only one case as a result of perceived complexity in the network. Furthermore, complexities in breast cancer management and family circumstances are crucial information sets for nurses to assess, and to consider whether the family may require additional support.

In my study, there were several reasons why health professionals might have an involvement in the networks. The reasons included i) positive appraisal of their services, ii) having personal kinship or collegial relationships, and iii) personal connection development throughout a long period of treatments. With regard to cultural perspectives, naming their health professional in their network map may be a way the women used to present acknowledgement and gratitude to their health professionals. With regard to relationship perspectives, the old and new personal relationships then influenced the women's feeling of closeness to their health professionals. The findings in my study about health professional identification seemed somewhat different to Finfgeld-Connett's (2005) study that revealed health professionals were expected to provide social support when other supporters cannot provide the support needed. I would argue that this finding from my study related to health professional identification resulted from the difference in patterns of nursing care between different hospitals. In my study one hospital had a nurse case manager to coordinate nursing care for women with breast cancer who needed complex treatment or who were experiencing personal difficulties. Other hospitals seemed to provide nursing care focused on the disease and treatment rather than the woman, as a person, and her individual needs. Those hospitals had no breast cancer case manager nurse role. Therefore consideration should be given to the development of other breast cancer nurse case manager roles so that care can be better

coordinated and that the wider support needs of women can be addressed.

The latter part of the discussion section will explore the specific living pattern that formed part of the breast cancer journey for some women in relation to the professional provision of support through the formal support network of a breast cancer club.

### **Competency to manage barriers to attend a breast cancer club**

One unique pattern of living with breast cancer in my study relates to the ‘long-term involvement in a breast cancer club’ for a few women. For those women a perception of lacking necessary support from informal supporters seemed to be the initial factor that influenced the women’s engagement in this formal peer support group, consistent with Helgeson et al.’s (2000) study. The support provided in this formal social network by health professionals who ran the club and by peers (other women with breast cancer who attended) included tangible and intangible support, similar to the findings from many studies in peer support groups (e.g. H. S. Campbell et al., 2004). The women’s positive feeling about the club itself, the club activities and/or (personal) interactions with peers who joined the club, or health professionals who shared their concerns, were one significant factor motivating the women’s participation. On the other hand, several women were unhappy and/or uncomfortable with the club activities and socialization with unfamiliar people when participating in club activities. This finding is supported by studies which identified how some women with breast cancer experienced negative feelings towards activities and/or interactions in formal peer groups (H. S. Campbell et al., 2004) and some women reported negative perceptions about these support groups (Grande, Myers, & Sutton, 2006). Therefore attendance at a breast cancer club was based on individual circumstances and needs. This is in line with Helgeson et al.’s (2000) findings that breast cancer clubs were not suited for all women and their perceived helpfulness was based on individual differences and preferences. Friendships, a sense of belonging within the group, and volunteerism were motivating factors for long-term, regular participation or memberships. This is somewhat similar to ethnographic research conducted by Coreil, Wilke and Pintado (2004). These authors explored the culture of breast cancer support and identified that club participants moved from formal relationships to personal relationships over time.

Barriers to participation were mentioned by both club participants and non-participants. First, the time schedule of activities was one significant barrier of activity attendance. As the club activities were mostly held during office hours, difficulties in managing responsibilities related to jobs and families were perceived as a barrier to attendance. Second, lack of access

to transport was another barrier identified, which made participation difficult or impossible for some women even if they had intended to be involved. The hospital in my study provided care for women from a number of provinces. When the breast cancer club was situated in the hospital it meant that women from outside the province might have difficulty attending because of (perceived or actual) barriers related to transportation times and expenses. However some women could overcome these barriers. Accordingly, 'competency to manage barriers to attend a club activities' was a factor that enabled the women to be able to attend the club activities, the competency related to the women's authority and capacity to manage their responsibilities in normal life including those related to family and transportation and cost. Other women perceived they were unable to participate or maintain their participation in club activities even if they wanted to be members. In my study I was able to capture the perspectives of women who were eligible for club membership but who, for a number of reasons, may not participate, however other studies of similar clubs focus on the perspectives of members only and so the non-members' voices are unheard.

These findings are important for health professionals, including nurses who take responsibility for breast cancer clubs. Formal support networks are an optional support group rather than a core support group for women with breast cancer. Club activities that meet women's needs address their many requirements for information and peer support. It is challenging for health professionals to attempt to meet women's individual needs through breast cancer clubs when women's individual circumstances, their cancer journeys, and the barriers to participation are so different. However attention to where the club is sited and the times of club meetings, as well as the activities women wish to participate in is important if the clubs are to best fulfill their support functions.

From a nursing perspective, the study findings reflect three features of networks in relation to breast cancer nursing care. The first feature identifies gaps in the process of breast cancer nursing care in the study setting. The second feature identifies the nursing meanings of network personal network themes that emerged in my study. Considerations for breast cancer nursing care are considered in the last feature. The relationship between these three features is shown in Table 9.1.

**Table 9.1**

*The study findings related to breast cancer nursing care in Thailand*

<b>Gaps in nursing care in the study setting</b>	<b>Network findings from a nursing perspective</b>	<b>Considerations for improving breast cancer nursing care</b>
<ul style="list-style-type: none"> <li>Breast cancer nursing care takes an episodic approach with little connection between hospital and community based sectors</li> <li>The importance of personal support not yet recognised in breast cancer nursing care</li> </ul>	<ul style="list-style-type: none"> <li>Personal social networks can be part of the care team</li> </ul>	<ul style="list-style-type: none"> <li>Nursing care should continue throughout the breast cancer journey</li> <li>Personal support should be recognised in nursing as part of informal care</li> </ul>
<ul style="list-style-type: none"> <li>In several settings, nursing care seemed focused on the disease and medical treatments rather than a whole person</li> <li>It was rare for complexities in breast cancer management and family circumstances to be recognised</li> </ul>	<ul style="list-style-type: none"> <li>Family and family relationships are important and impact on both support needs and resources</li> <li>Complexities in breast cancer management and family circumstances have a high impact on personal support needs and ability to support</li> <li>An involvement of non-family members in a core supporter group is a significant sign of difficulty in family support provision</li> </ul>	<ul style="list-style-type: none"> <li>Nursing care needs to include individuals and their families as their unit of care</li> <li>Knowing the individual circumstances of the women's breast cancer management, her family, and her responsibilities will enable nurses to individualise care</li> </ul>
	<ul style="list-style-type: none"> <li>Understanding the nature of personal social networks is crucial for nurses:               <ul style="list-style-type: none"> <li>Individual definitions of who is family</li> <li>Network members are identified as having different levels of significance based on objective and subjective criteria</li> <li>There is the potential for ongoing changes in the support needs and provision within the disease and treatment pattern</li> <li>Personal social networks are disease, relationships, and culturally specific.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Nurse should consider the changes of personal support provision related to the disease and its treatments pattern</li> </ul>
<ul style="list-style-type: none"> <li>There was very little individualization or flexibility in the way this Breast Cancer club provided support.</li> </ul>	<ul style="list-style-type: none"> <li>Formal network supports individual breast cancer patients differently due to the women's needs, willingness for participation, perceptions and barriers in participating, and abilities to solve their barriers</li> </ul>	<ul style="list-style-type: none"> <li>Support from formal support networks is optional rather than a core type of support.</li> <li>The contents, places, times, designs, and clients' circumstances should be considered in the management of formal support networks.</li> </ul>

## Implications

In this section, I will articulate my ideas about the implications of my study findings related to nursing considerations for nursing policy, practice, and education respectively.

### Nursing policy

To minimise gaps in the individualised care of women with breast cancer, it is recommended that the notions of women's personal support found in my study be adopted into nursing policy to address personal support recognition, family-centred care, and the roles of nurse case managers in breast cancer.

#### *Recognition of the importance of personal support*

The study findings obviously highlight that the women's breast cancer journey is complex. The continuum of support provided by personal supporters helped the women, to different degrees, with their journey with breast cancer, the medical treatment, and also helped them manage their responsibilities in daily life for work and family. The breast cancer journey of the central women started when they found their breast lump(s). Much support was required, expected, requested and provided and support roles developed by the women' personal supporters related to components of their life related to their health and their normal lives as shown in Table 9.2.

**Table 9.2**

*Roles of the women's networks throughout breast cancer journey*

Possible needs related to health	Possible needs related to normal life
<ul style="list-style-type: none"><li>• Navigating to health settings and services</li><li>• Counselling &amp; decision making</li><li>• Travelling &amp; transport</li><li>• Communicating with health professionals</li><li>• Care giving at hospitals and at home</li><li>• (Breast) cancer-related information and experience sharing</li><li>• Emotional support</li><li>• Spiritual support</li></ul>	<ul style="list-style-type: none"><li>• Facilitating daily living</li><li>• Taking part in responsibilities in normal life such as looking after children or parents</li><li>• Helping in jobs</li><li>• Financial support (if necessary)</li></ul>

With regard to Table 9.2, many roles were undertaken by personal supporters to assist the women to access breast cancer care and undergoing treatment courses under the complicated health system (the left column). Furthermore, assistance to the women in relation to their normal life (the right column) could positively and negatively impact on the women's ability

to access and ability to complete their treatments. For example, if the woman has young children, elderly parents, or sick family members at home, who will look after these dependent family members when she visits and is admitted to hospital? This normal life situation possibly disrupts the woman's treatment and possibly affects treatment outcomes. Accordingly, the presence of personal social networks and support should be acknowledged in the health care system, including by nursing, as one significant support sector for women.

Recognition of the importance of personal supporters and their support for patients with chronic or long-term conditions such as (breast) cancer is stressed in health-related studies as significant for health care development including nursing care (Given et al., 2001; Lugton, 1997; Thomas et al., 2002; Twigg & Atkin, 1995). As a result, nursing policy should legitimately acknowledge the importance of these supporters and their support as part of informal support provided alongside nursing care. This policy recognition is a vehicle to convey the concept and notions of personal support networks and their support within a nursing perspective to nursing practice, education, and research for breast cancer nursing care.

#### *Nursing care with family-centredness*

Significant findings in this study are that 'family' and 'family relationships' are important and impact on both personal support needs and resources for the women living with chronic or long-term conditions such as breast cancer. Complexities in family circumstances and relationships were found to impact significantly on personal support needs and ability to provide support within the family. Breast cancer nursing care, therefore, should be widen the focus of care to cover the women's families as both co-clients and to recognise the significant role of informal supporters. As a result, family-centred nursing care should be considered and designated as the standard in nursing policy level in chronic or long-term conditions as breast cancer to enhance the quality of nursing care.

This recommendation is in relation to the definition of family centred care that is provided by the Institute of Family Centred Care (2015), who with Shields, Pratt, and Hunter (2006, p. 1318) define family centred care as "an approach to planning, delivery, and evaluation of healthcare that is governed by mutually beneficial partnerships between healthcare providers, patients and families. Family centred care applies to patients of all ages, and it may be practiced in any health care setting". With regard to this conceptual approach, the concept of family centred nursing care demonstrates that the focus of nursing care through all nursing processes is widened to individuals and their family within their individual situation. This

recommendation is also supported by the components of family centred care that MacKean, Thurston, and Scott (2005) found from reviewing health care literature over the past 20 years and reported having relationship between the concepts of family-centred care, family supports, and individualised care.

### ***Roles of nurse case managers in relation to personal support***

As the results of this study reveal, complexities in the women's circumstances had a significant influence on the women's lives. Also their personal supporters had more difficulties in maintaining support throughout their breast cancer journey. For these particular cases, I suggest that the involvement of nurse case managers, with responsibility for coordinating care within and across settings, and assessing where complex family circumstances and a potential lack of person support could potentially impact on women's participation in treatment, is an important role. The inclusion of personal support assessment in this role has the potential to improve breast cancer care as care is individualised to personal and medical needs. This recommendation is supported by the responsibility of nurse case managers to individualise care to the needs of patients and their families (Gibson, Martin, Johnson, Blue, & Miller, 1994).

Implications of the study findings for nursing practice will be elucidated in the next section.

## **Nursing practice**

The study findings highlight that family is crucial for the women when living with breast cancer. Furthermore, complexities in the women's circumstances, especially related to breast cancer management and family are highly influential factors in personal support provision. Monitoring, investigation and, when possible, intervening in relation to complexities in women's circumstances and difficulties in family support are recommended to breast cancer nurses to enhance individualised care. Breast cancer nurses need to be aware of the ways in which needs change related to different phases of the breast cancer journey, different family relationships affect support, and also the influence of cultural and religious patterns on personal support.

There are two interlinked levels of nursing responses that reflect the application of the themes related to networks gained from this study into nursing care. These are i) nursing practice for general, uncomplicated cases of breast cancer, and ii) the higher level of nursing practice for complicated cases (related to both breast cancer management and circumstances in normal life, especially within the woman's family). Significantly, both levels of nursing

practice enhance individualized nursing care.

Firstly, for all women with breast cancer, nurses should informally screen the women to assess their levels of personal support and any complexities the women are experiencing in living with breast cancer parallel to performing regular nursing activities. Nurses should consider how the circumstances of the women's lives related to their health and treatment and family have the potential to cause difficulties in their journey. For example, while nurses interview the women to obtain their medical (and social) history, nurses will specifically ask about the support available to the women. Observing who accompanies the women (and if there is any change in supporters) when they attend hospital visits and chemotherapy units, provides a way of considering if there are problems in the provision of personal support, and if further assessment is needed. If nursing care is delivered with consideration of personal networks and support, information about how the women are supported by their networks, how the women's complexities in normal life and difficulties in support are managed, could be gathered. Nurses could then ascertain if further interventions may be necessary.

Through providing nursing care with consideration about the women's complexities in circumstances and their personal networks and support, the women with (potential) difficulties in personal support could be able to be distinguished from general cases. Next, nurses can refer these women to nurse case managers for in-depth investigation, close and ongoing monitoring, and intervention if needed and/or to modify services to fit in the women's situations.

Secondly, in cases with (potential) difficulties to provide and maintain personal support in the family, the women should be referred to nurse case managers for in-depth assessment about their networks. In this process nurse case managers may use network mapping to help them gather information about the women's network (See guidance for network mapping and discussion in Appendix VIII). Moreover, nurse case managers should investigate gaps between support needs and resources and make nursing decisions about further interventions. The intervention types related to personal networks and support may range from an adjustment of health care plans, patterns or schedules, to support by the multidisciplinary team, and coordinating and/or referring between settings.

In addition, the study findings of the women's participation in formal support networks of breast cancer clubs could be applied by club managers to improve the formal support networks to better suit individual needs, preference and circumstances. Club managers should consider the women's needs of support from formal networks related to individual

differences in information needs, and types of support necessary. Where the club is sited, when it meets and its activities should be considered to create alternative activities for the club clients. Furthermore, nurses referring women to breast cancer clubs should recognize the women with difficulties in family support who may benefit from club participation and refer them to the club managers. Importantly, women who wish to participate in club activities but who identify that they cannot because of personal circumstances, should be identified as a group who may need additional support. An online network of formal networks may be created as another alternative support for the women who prefer the formal support network but perceive barriers to participation that they are unable to overcome.

Further, implications related to the study findings about personal social networks and support are relevant for nursing education not only for breast cancer nursing specifically, but also for nursing other patients with long-term conditions. In the next section I will elucidate my ideas of the implications from this study for undergraduate and postgraduate nursing curricula.

## **Nursing education**

In association with nursing policy, recognition of the importance of personal support to patients with long-term conditions should be established in nursing education. Concepts of networks and support in nursing care should be integrated into teaching to provide nursing students with a basis to integrate these concepts in nursing practice.

Consequently, nursing students need to develop specific nursing skills related to ongoing network assessment as part of their planning of nursing care and also the development of interventions related to potential or actual gaps in Network mapping (see guidance of network mapping in Appendix VIII) is one technique that nursing students could use in conjunction with the nursing process, discharge planning, and it is relevant for community and hospital based nursing. Network maps can form one significant information set for a nursing plan, similar to a patient's genogram. Significantly, nursing skills in relation to networks and support have to be customised, based on the way in which networks are specific to diseases, relationships, and cultural circumstances. Nursing care plans and nursing care should be individualised, as the following case exemplifies. One woman in this study who worked in a market had two young children. She experienced financial disruption while undergoing breast cancer treatments, and she was uncomfortable receiving financial support from her family. She designed to return early to her job at a local market while she was still undergoing chemotherapy. Going to work at a local market while receiving chemotherapy increased her risk of infection compared to other patients. However, she still

received nursing care and health education for self-care, similar to others with a much lower risk. If this woman's difficulty in family support had been detected by her nurses, specific, individualised nursing care could have been provided, including adjustment in her treatment schedule to be more suited for her other responsibilities and providing appropriate health education about infection risk.

Ultimately, application of the study findings into nursing policy, practice, and education rely on three major strategies: i) recognition of the importance of networks; ii) nursing care with family-centredness, and iii) screening, monitoring, investigating for potential deficits in personal support and intervening when necessary. As a result of establishing these nursing strategies, improvement of individualised nursing care could be seen. As well, the recommendations for breast cancer clubs are based on these clubs being able to address both the women's disease specific general support needs and those of a more individual nature.

## **The study limitations**

The limitations of this study are related to contextual characteristics of cases, a number of a particular type of study cases, and data translation. The 11 cases of this study comprise networks of women who were either still undergoing treatment or who had completed treatment. None of the cases of this study withdrew from treatments. If I had initially engaged with potential participants at the village or city health centres, the personal social networks of the women who were not completing their treatments may have been included in this study and more diversity of patterns of undergoing treatments may have been shown. Moreover, because it was unsafe to undertake data collection in the area of civil unrest, I did not select either provincial or regional hospitals located in the three provinces with insurgency to initially access potential participants. This also caused a limitation in coverage of the contextual characteristics of this study. However, one case belonged to a woman who lived in one of these three provinces.

Only one woman diagnosed with a recurrence of her breast cancer volunteered to participate in this study, and therefore there is a limitation of the data related to the description of the breast cancer journey. Accordingly, the study findings related to experiences with living with recurrence of diagnosis of breast cancer should be confirmed in further studies.

Furthermore, data gathering and initial data analysis for this study was conducted in Thai including the southern dialect. It was difficult to find accurate meanings between Thai and English languages. Hence, some Thai and southern dialect words are included in this study.

## **Recommendations for further research**

This study was conducted using a collective qualitative case study to derive an in-depth understanding about personal social networks of women living with breast cancer in the context of the lower southern region of Thailand. Initial guidance related to personal social network assessment has been developed based on the study findings and fieldwork experiences in network information gathering. However, as there are few nursing network studies in which a whole network approach is adopted further research is required to validate the findings. These studies should extend the findings into different contexts and also to expand support the research focus into the relationship between personal social networks, personal and nursing interventions. Recommendations for further research include:

1. Research about personal social networks in breast cancer with specific issues: phenomena (i.e. with experiences of incomplete treatments, recurrence of diagnosis, end of life); age groups within the personal social network (elderly, children, teenagers), cultures and ethnic groups (including religious groups), health systems (i.e. health systems of specific countries, systems of primary health care, home-based care, rest home care, and hospice care).
2. Action research, with an integration of a personal social network approach into nursing policy, practice, and education.
3. Research into tool development for personal social network assessment such as network mapping.
4. Research into the evaluation of processes and outcomes of using a personal social network approach and information in nursing care.

## **Statement of conclusion**

The women's experiences of their personal social networks have demonstrated the complex nature of living with a long-term disease such as breast cancer. The complexities relate to the disease and its treatment and also the women's (and their networks') everyday lives. Throughout the breast cancer journey, health professionals provide only some of the care and specific types of support while many other people, especially the women's family, voluntarily provide dedicated support, seemingly without conditions, to the women to help them overcome this critical period of their lives. These personal supporters are identified by the women as the 'people who are together with me'. This meaning relates to more than the

supporters' physical presence, or the tangible and intangible support they provided, but also because these supporters 'shared with the women's concerns', resulting from having close, and for many, long-term relationships with the women.

Questions for nursing that emerge from these findings include when nurses are looking after people with long-term conditions, how and how much do nurses know about their patients' ways of living and their life circumstances, and how do these circumstances affect the person's engagement with treatment? How and how much do nurses know about the difficulties their patients and families encounter with accessing and undergoing treatment? Accordingly, without knowing (and understanding) their circumstances how can nurses address patients' individual needs? Specifically, how do nurses look after these patients as a whole person without knowing their circumstances, and the makeup of their personal social network and support structures, particularly their families?

To improve nursing care for patients with long-term conditions, the shifting of nursing approaches to recognise personal supporters as part of the health care team, and towards individuals and their family as the units of nursing care, is required. To establish these approaches in practice, nursing skill development should include assessment, screening, and specifically the monitoring of gaps in support provision, with intervention if necessary. Formal support, in the form of breast cancer clubs, should be provided with recognition of the individual differences in needs, preferences, and abilities to manage barriers to participation. Flexibility in the types, places, times and activities that form part of formal support mechanisms can provide a different type of personal support that some women need when they are living with breast cancer. Importantly, as personal social network studies in nursing are still limited in number, further research within nursing policy, education, and clinical practice is necessary.

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## APPENDICES

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### Appendix I

#### **Guidelines of breast cancer screening, diagnosis and treatments**

(Alanyali, 2013; Chaiweerawattana, Sookkarayothin, Aimsamran, & Khoohapaerama, 2012)

**Cancer stage** is based on TNM system which was formulated by Union International Cancer (UICC) and the American Joint Committee on Cancer (AJCC), and is being used for every cancer site. T means the size of the tumour, N means lymph node involvement, and M means whether the cancer has spread, or metastasized, to other parts of the body.

**BC stage 0** refers to non-invasive breast cancers, such as DCIS (Ductal carcinoma in situ). No evidence of cancer cells breaks out of the part of breast in which they started, or gets through to, or invades normal tissue.

**The treatments of stage 0** include total mastectomy (radiation after mastectomy rarely needed) or breast conserving surgery (lumpectomy) plus radiation or conserving surgery (lumpectomy) alone. Hormonal therapy (Tamoxifen) is used for people with hormone-receptor-positive cancer.

**BC stage I** describes invasive breast cancer as cancer cells are breaking through to, or invading normal surrounding breast tissue. Stage I is divided into IA and IB.

**Stage IA** refers to BC in which the tumour is measured up to 2 cm and the cancer has not spread outside the breast, and no lymph nodes are involved.

**Stage IB** describes BC in which i) no tumour in the breast; instead, small groups of cancer cells (size from 0.2 mm to 2 mm) are found in the lymph nodes, or ii) a tumour in the breast is no larger than 2 cm, and there are small groups of cancer cells (0.2 - 2 mm) in the lymph nodes. Microscopic metastasis is possible in stage I of BC.

**The treatments of stage I:** Treatments include total mastectomy, radiation after mastectomy (only rarely needed), or breast conserving surgery (lumpectomy) plus radiation, or occasionally lumpectomy alone, with or without internal radiation. Breast reconstruction is possible. The treatment on lymph nodes includes axillary node removal by traditional approach or by sentinel lymph node dissection. Chemotherapy may be given to reduce the risk of recurrence. Hormonal therapy is used for people with hormone-receptor-positive

cancer. Targeted therapy may be used for women with cancers that have certain characteristics, for example, cancers with too many HER2 receptors.

**BC stage II** is divided into IIA and IIB.

**Stage IIA** describes invasive breast cancer in which: i) no tumour can be found in the breast, but cancer (larger than 2 mm) is found in 1 to 3 axillary lymph nodes or in the lymph nodes near the breastbone. ii) The tumour measures up to 2 cm or smaller and has spread to the axillary lymph nodes, or in the lymph nodes near the breast bone (found during a sentinel node biopsy). iii) The tumour size is from 2 to 5 cm and has not spread to the axillary lymph nodes.

**Stage IIB** describes invasive breast cancer in which: i) the tumour is from 2 to 5 cm; small groups of breast cancer cells (0.2 – 2 mm) are found in the lymph nodes. ii) The tumour is larger than 5 cm but has not spread to axillary lymph nodes.

**The treatments of stage II:** the treatments of the breast include total mastectomy (radiation after mastectomy may be needed), or lumpectomy plus radiation, in some cases following with chemotherapy to shrink a large single cancer.

The treatment to lymph nodes includes axillary lymph node removal by traditional approach or sentinel approach (preferred approach for people without enlarged nodes), and possible radiation to supraclavicular and/or internal mammary nodes. Chemotherapy is commonly recommended. Hormonal therapy is used for people with hormone-receptor-positive cancer. Targeted therapy may be used for people with cancer that have certain characteristics, for example, cancers with too many HER2 receptors.

**BC stage III** is divided into IIIA, IIIB, and IIIC.

**Stage IIIA** describes invasive breast cancer in which either: i) no tumour is found in the breast or the tumour may be any size, but cancer is found in 4 to 9 axillary lymph nodes or in the lymph nodes near the breastbone. ii) The tumour is larger than 5 cm and small groups of breast cancer cells (0.2 to 2 mm) are found in the lymph nodes. iii) The tumour is larger than 8 cm and the cancer has spread to 1 to 3 axillary lymph nodes or to the lymph nodes near the breast bone.

**Stage IIIB** describes invasive breast cancer in which: i) The tumour may be any size and has spread to the chest wall and/or skin of the breast and caused swelling or an ulcer, and may have spread to up to 9 axillary lymph nodes, or may spread to lymph nodes near the

breastbone. The inflammatory breast cancer is considered at least stage IIIB. (Typical features of inflammatory breast cancer include reddening of a large portion of the breast skin, the breast feels warm and may be swollen, and cancer cells have spread to the lymph nodes and may be found in the skin).

**Stage IIIC** describes invasive breast cancer in which: i) there may be no sign of cancer in the breast or, if there is a tumour, it may be any size and ii) may have spread to the chest wall and/or the skin of the breast and also has spread to 10+ axillary lymph node, or the cancer has spread to lymph nodes above or below the collarbone, or to lymph nodes near the breastbone.

**The treatments of stage III:** Treatments include total mastectomy followed by radiation or lumpectomy plus radiation following chemotherapy to shrink a large single cancer. Treatments to lymph node include axillary lymph node removal by traditional approach and possible radiation to supraclavicular and/or internal mammary lymph nodes. Chemotherapy is almost always recommended. Hormonal therapy is used for people with hormone-receptor-positive cancer. Targeted therapy may be used for people with cancer that have certain characteristics, for example, cancers with too many HER2 receptors.

**BC stage IV** describes invasive breast cancer that has spread beyond the breast to, nearly all lymph nodes, to other organs of the body, such as the lungs, distant lymph nodes, skin, bones, liver, or brain.

**The treatments of stage IV:** Treatment to breast includes surgery, radiation, or both may be used, depending on many individual factors. Possible treatment to lymph nodes is treatment of enlarged lymph nodes if they are producing signs and uncomfortable symptoms. Chemotherapy is mostly always recommended. Hormonal therapy is used for people with hormone-receptor-positive cancer. Targeted therapy may be used for people with cancer who have certain characteristics, such as, cancers with too many HER2 receptors. Treatment to other parts of the body's radiation is commonly used to relieve specific signs or uncomfortable symptoms and/or surgery may have a role in dealing with specific signs or symptoms.

**Note**

- Guideline follow-up procedures for non-invasive BC (stage 0)

History and physical exam every 6-12 months for 5 years, then annually, mammography every 12 months (and 6-12 months post radiation therapy, if breast conserved)

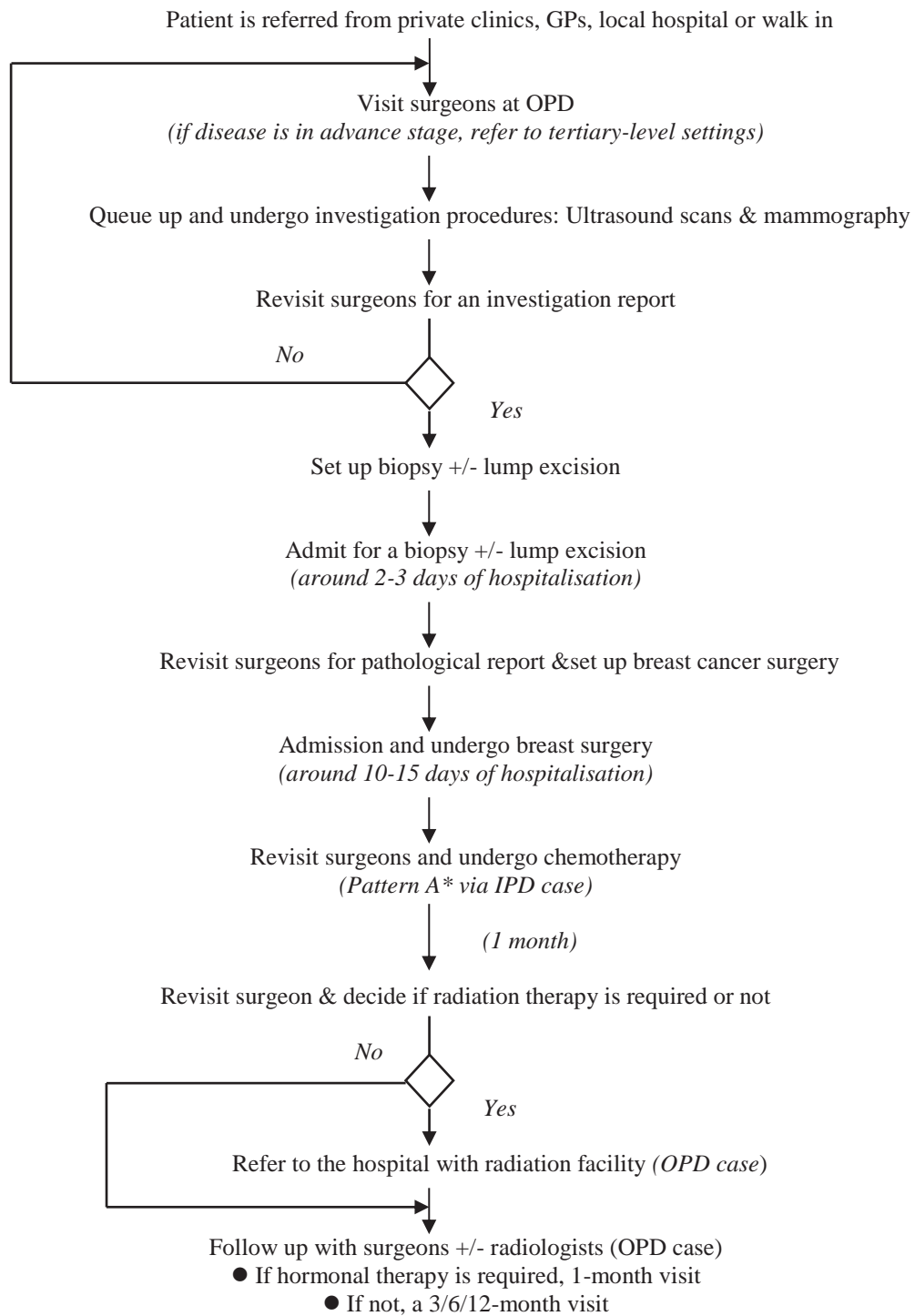
- Guideline follow-up procedures for invasive BC (stage I-IV)

History and physical exam every 3-6 mo for 5 years, then every 12 months; annually mammography Women on hormonal therapy: gynaecologic assessment every 12 months if uterus is present Determination and monitoring of bone density if on an aromatase inhibitor or those who experience ovarian failure

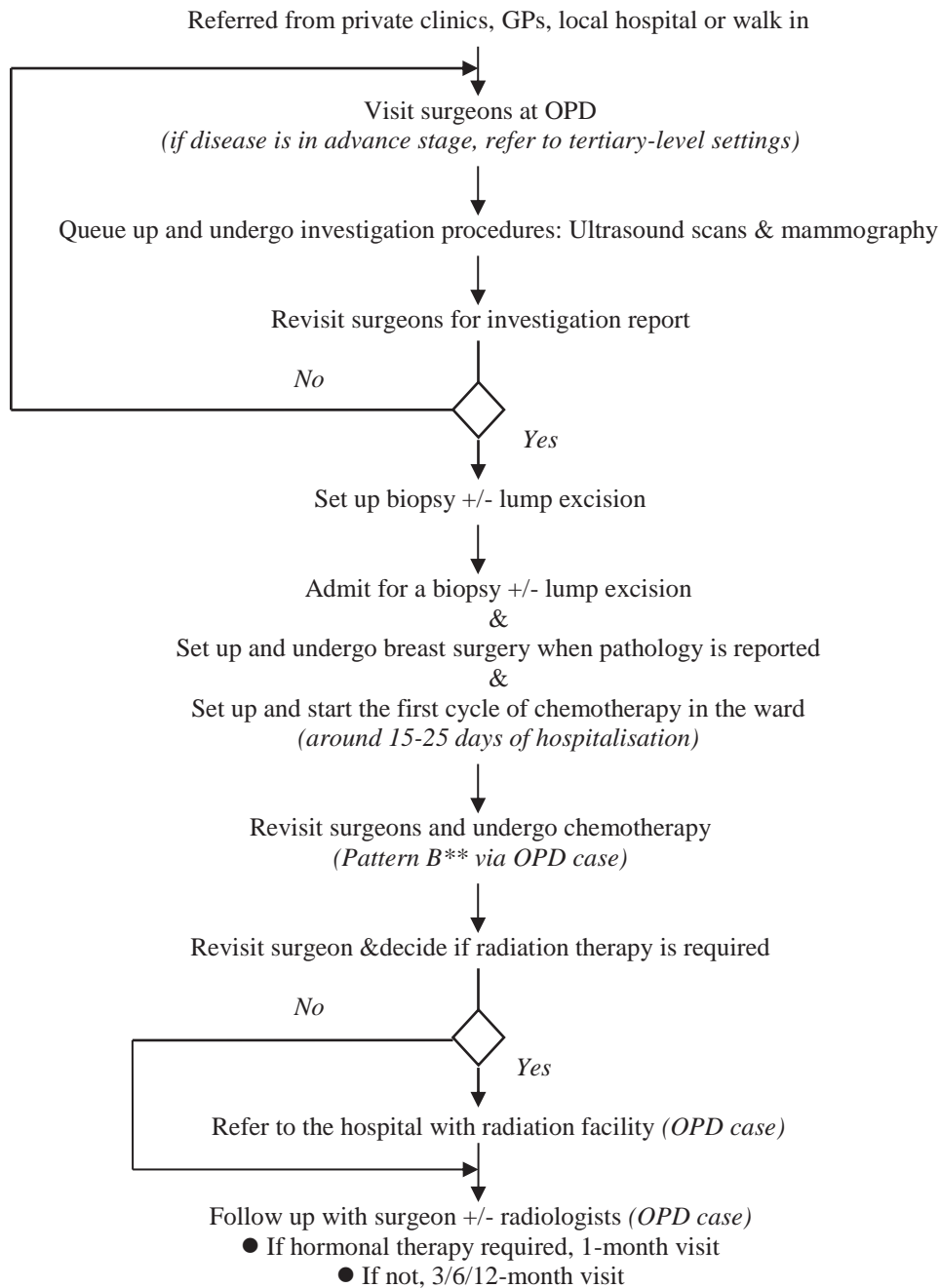
# Appendix II

## 1. Pathways of breast cancer care in Thailand

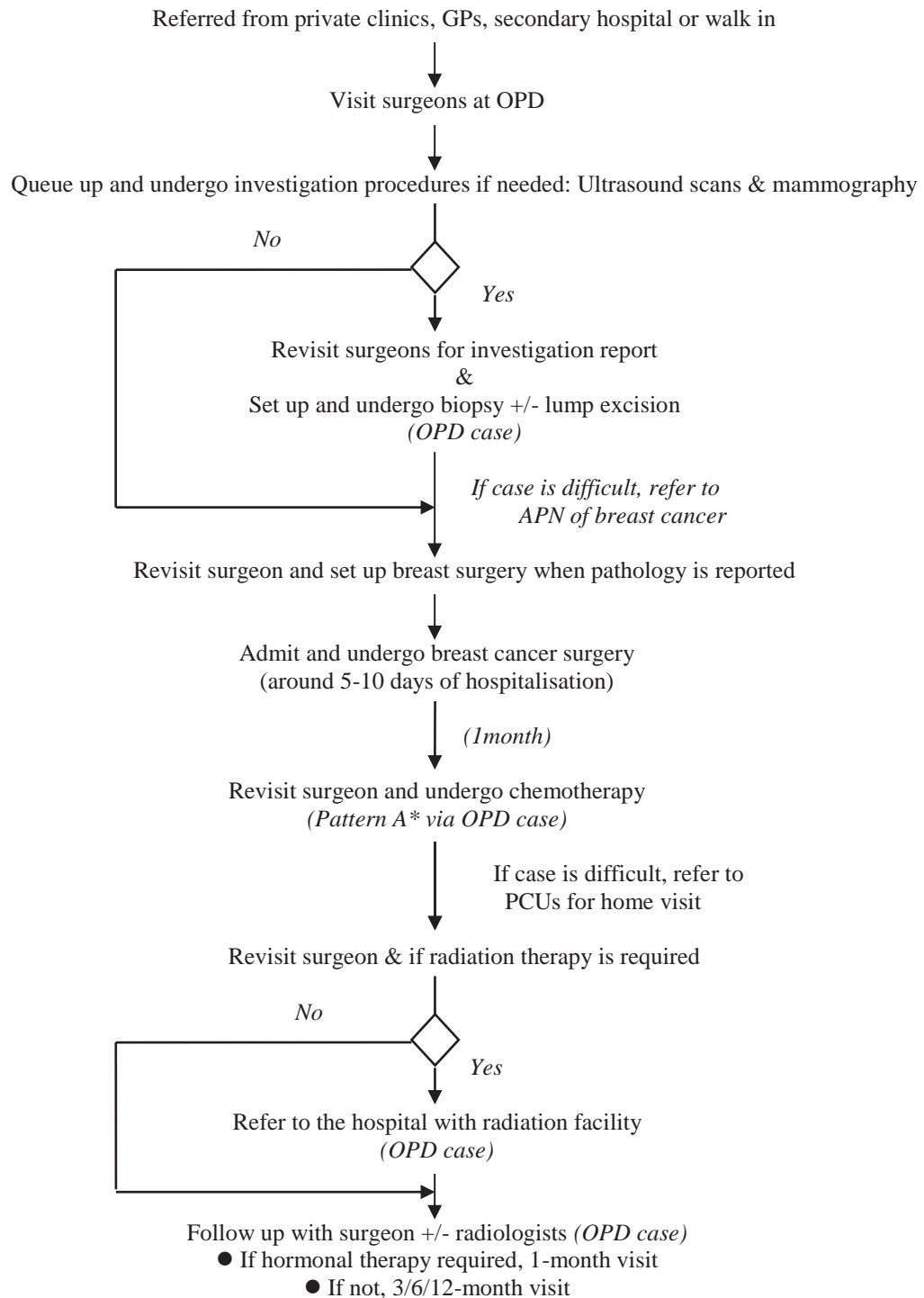
### Pathway of hospital I (secondary-level)



**Pathway of hospital II (secondary-level)**



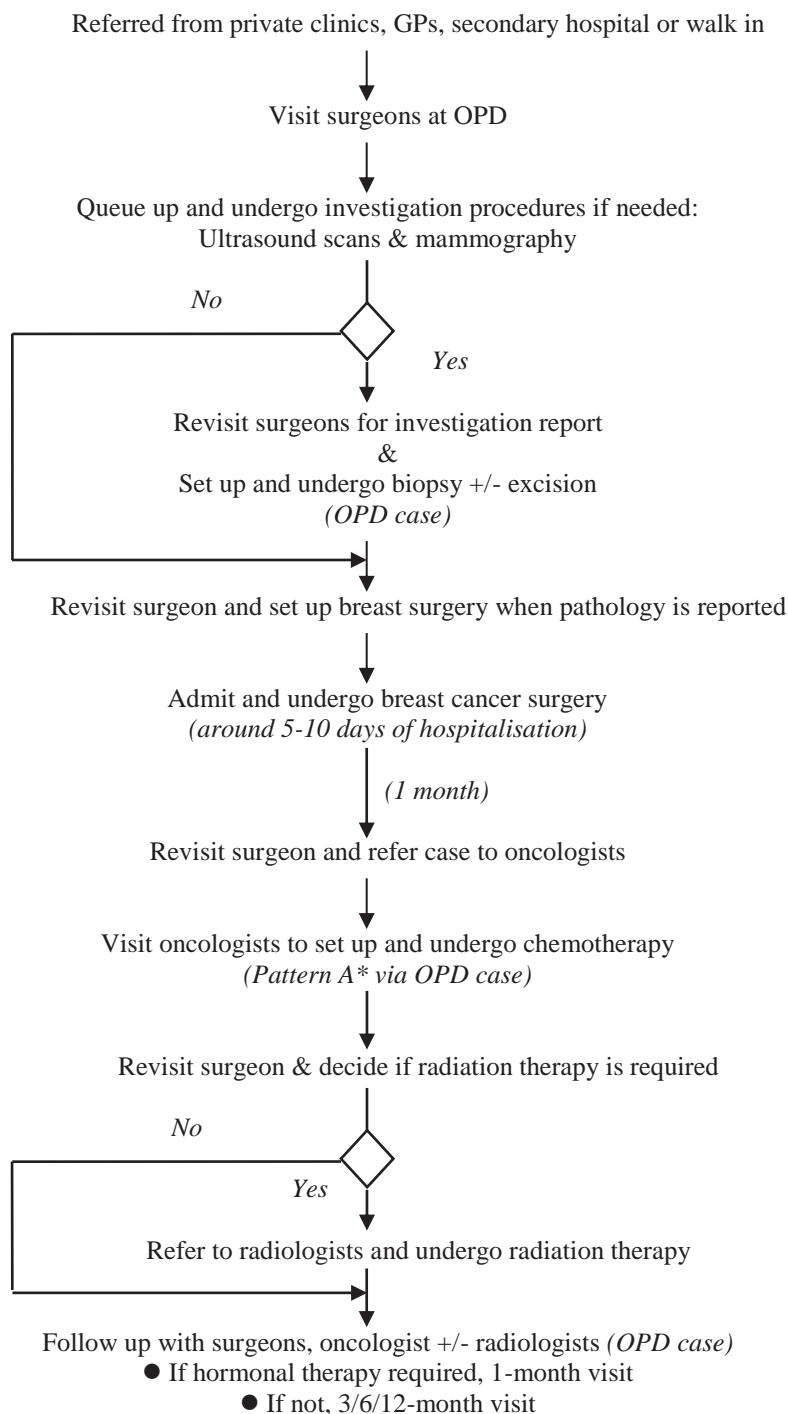
*Pathway of hospital III (tertiary-level)*



**Pathway of hospital IV (tertiary-level)**

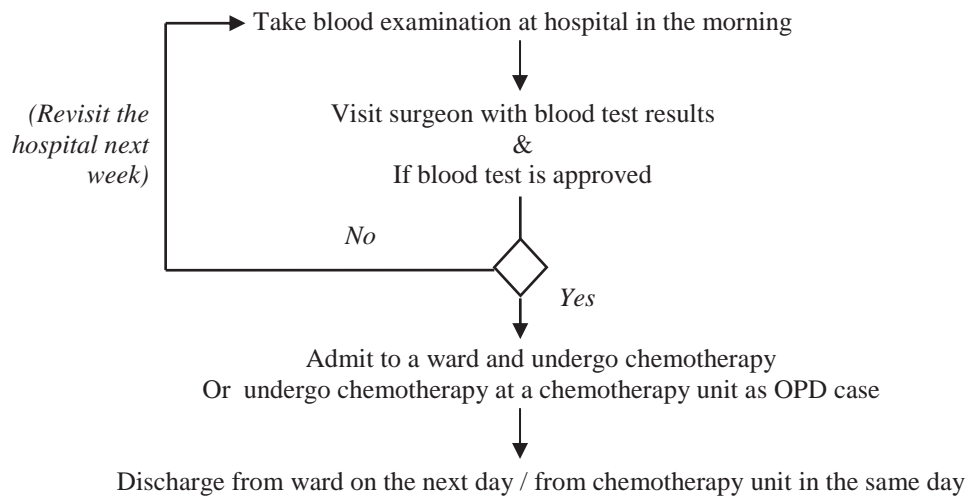
The breast cancer care at this setting can be accessed through two channels.

- I. At surgical clinics of OPD** (accept referral from other hospitals)
  - If case is difficult, refer to APN of breast cancer
- II. At the Centre of Excellent of breast cancer**
  - Pre- and post- counseling are provided in all steps
  - Almost all procedures are provided through one stop services, except major surgery & chemotherapy
  - No service available for referred case (only walk in patients or those advised to come here)

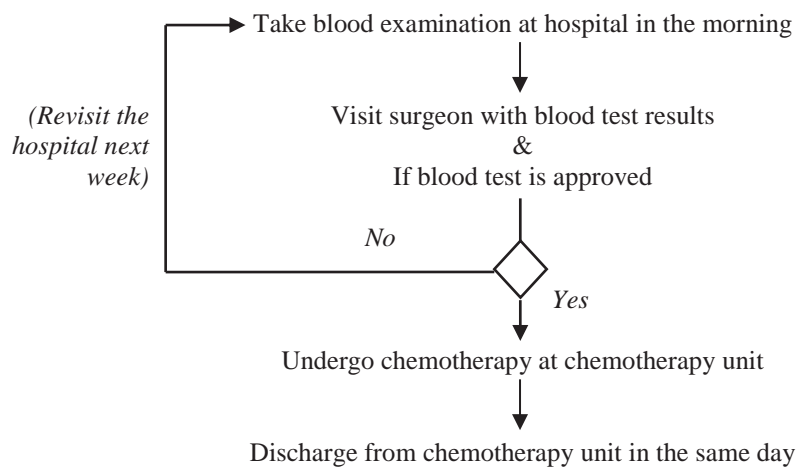


## 2. Patterns of chemotherapy management in Thailand

- *Pattern A: 21 days round and one visit per cycle*



- *Pattern B: One month round and two visits per cycle*





## Appendix III

### *Five levels of breast cancer care in the Thai health system*

Levels of health care	Care / services	Care / service Settings	Providers
<b>1. Self-care</b>	-Health promotion & Prevention <sup>23</sup> -Recovery -First aid	-Homes	-Individuals / family / neighbours
<b>2. Primary Health care</b>	-Health Promotion & Prevention <sup>24</sup> - Home care - Recovery - First aid	-Homes -Village health centres (Villages)	-Individuals / family / neighbours -Village health volunteers
<b>3. Primary care</b>	- Health Promotion & Prevention -First aid (such as for signs and symptoms of therapeutic side effects) -Supportive care - Recovery -Primary medical care -Consulting -Referring to higher levels	-Primary care unit <sup>25</sup> - Municipal health centres -Outpatient departments of public and private hospitals -Private clinics  (*No inpatient beds)	-Health workers -Nurses - +/- GPs
<b>4. Secondary care</b>	-General investigation and treatments (non cancer specific) -Referrals receiving from lower levels -Referring to higher levels	-District hospitals (10-150 inpatient beds)	-Health professionals -Nurses -GPs
	-General to intermediate levels of BC care such as cancer investigations, general surgery, basic chemotherapy (consulting and or referral for uncommon cases) -Referrals receiving from lower levels -Referring to higher level	-General hospitals (200-500 inpatient beds) -Medium-sized private hospitals	-Health professionals -Nurses - GPs - +/- General surgeons with experience in BC - +/- specialists in cancer care
<b>5. Tertiary care</b>	-Investigation and treatment from basic to advanced -Consulting -Referrals receiving from lower levels and to the setting with more resources - +/- Radiation therapy	-Regional hospitals (over 500 inpatient beds) -University hospitals -BC centre of excellence -large-sized private hospitals	-Health professionals -Nurses +/- APN -GPs - BC surgeons - +/- Oncologists, radiologists, and related experts

<sup>23</sup> Breast cancer screening procedures provided at different levels of care and settings. A breast self examination is conducted in self-care level individually. A manual breast examination by a professional is provided by health professionals at primary care, secondary, to tertiary health settings. An ultrasonic scan is provided at secondary and tertiary health settings. A mammographic scan is provided at some secondary and all of tertiary health settings.

<sup>24</sup> Breast cancer screening procedures provided at different levels of care and settings. A breast self examination is conducted in self-care level individually. A manual breast examination by a professional is provided by health professionals at primary care, secondary, to tertiary health settings. An ultrasonic scan is provided at secondary and tertiary health settings. A mammographic scan is provided at some secondary and all of tertiary health settings.

<sup>25</sup> Primary care units are called *อนามัย* /*Anamai*/ by the local people. These health settings are located in every sub-district and a large-sized sub-district could have more than one setting. In 2009, *อนามัย* /*Anamai*/ or Primary care unit's capability was expanded to area of family medicine / family practice and its formal name was changed to be "Health promoting hospital-HPH". (Ministry of public health, 2007)



## Appendix IV

### *Five levels of alternative and traditional breast cancer care in the Thai health system*

Health Settings	Traditional and Alternative medical perspectives	Approach usage <sup>26</sup>	Providers
<b>Public Health Centres &amp; Hospitals</b>	<b>Traditional Medicine</b> (Thai & +/- Chinese)	<b>Complementary</b> -Health promotion -Recovery (Recuperation) -Supportive treatments	-Licensed health professionals -Certificated health professionals
<b>Private Clinics, Health centres &amp; Hospitals</b>	<b>Traditional Medicine</b> (Thai & Chinese) <b>Alternative Medicine</b>	<b>Complementary</b> -Health Promotion -Recovery (Recuperation) - Supportive treatments <b>Alternative</b> -Health Promotion, -Recovery (Recuperation) -Supportive Treatments -Curative treatments	-Licensed health professionals -Certificated health professionals
<b>Informal Health settings</b>	<b>Traditional Medicine</b> (Thai & +/-Chinese) <b>Alternative Medicine</b> (+ Folk Medicine)	<b>Complementary</b> -Health Promotion, -Recovery (Recuperation) -Curative treatments <b>Alternative</b> -Health Promotion, - Recovery(Recuperation) -Supportive Treatments -Curative treatments	-Folk therapists -Trained practitioners  -Folk therapists -Trained practitioners
(Traditional) <b>Pharmacy Shops</b> <b>Healthy shop</b> <b>Online, TV &amp; Direct sales</b>	<b>Alternative Medicine</b> such as natural products and supplements	<b>Complementary</b> -Health Promotion & Prevention - Recovery (Recuperation) -Supportive Treatments	Product sellers / members +/- Traditional pharmacists

<sup>26</sup> **Complementary approach** = the usage is as an adjunct to the main stream perspective.  
**Alternative approach** = the usage is for replacement the previous mainstream perspective.



# Appendix V

## 1. Ethics approval



MASSEY UNIVERSITY  
TE KUNENGA KI PŪREHUROA

28 September 2011

Shutiwan Purinthrapibal  
58 Rangiora Avenue  
Roslyn  
PALMERSTON NORTH 4414

Dear Shutiwan

Re: HEC: Southern A Application – 11/67  
Personal social networks of breast cancer patients in Southern Thailand

Thank you for your letter dated 27 September 2011.

On behalf of the Massey University Human Ethics Committee: Southern A I am pleased to advise you that the ethics of your application are now approved. Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

Please note that travel undertaken by students must be approved by the supervisor and the relevant Pro Vice-Chancellor and be in accordance with the Policy and Procedures for Course-Related Student Travel Overseas. In addition, the supervisor must advise the University's Insurance Officer.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

A/Prof Hugh Morton, Chair  
Massey University Human Ethics Committee: Southern A

cc Prof Julie Boddy                      Dr Lesley Batten  
School of Health & Social Services      School of Health & Social Services  
PN371    PN371

Prof Steve LaGrow, HoS  
School of Health & Social Services  
PN371

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Massey University Human Ethics Committee  
Accredited by the Health Research Council

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*1. Letter of permission*

[Massey University LetterHead]

September 28, 2011

[Redacted] Hospital

Thailand

Dear Director of [Redacted] Hospital

I am Shutiwan Purinthrapibal. I have worked as the lecturer at Nursing Faculty of Prince of Songkla University. I am currently a PhD student of Nursing at Massey University, New Zealand. For my PhD study, I am conducting my thesis “Personal Social Networks of Breast Cancer Patients in Southern Thailand” under supervision of Professor Julie Boddy and the supervision team. This study has been reviewed and approved by the proposal confirmation panel and the Massey University Human Ethics Committee: Southern A, Application 11/67. The study aims to understand the nature of personal social networks via the perspectives of the local women who are living with breast cancer in southern Thailand environment and their network members’ perspectives. A qualitative case study is the customised methodology to explore *what do women experience in their personal social networks during the journey of living with breast cancer in southern Thailand?* There are four particular interests—i) what are the characteristics of their personal social networks? ii) what are the qualities of their personal social networks? iii) what are the contextual factors which influence the functioning of their personal social networks? and iv) how are these women involved in formal social networks for breast cancer patients and why? Understanding their networks will be valuable for health professionals, particularly those who are creating/developing health-related services and policies. Ultimately, the aim is for women to experience a better quality of life during their journeys with breast cancer.

Accordingly, [Redacted] is the purposive setting of this study and [Redacted] hospital which is the hub of cancer care of this area, is a potential place which can enable me to engage with the women who are living with breast cancer in [Redacted]. Helpful supports from nurses at surgical clinic, [Redacted] hospital such as introducing this project to the

women who are the potential participants and distributing the advertisement pamphlets to them are necessary. The anticipated numbers of the women is 5-10 and the places of participation activities will be the participants' home or where they feel comfortable. This data collection processes will be started after getting your permission and the ethics approval from the hospital committee. Additionally, you can choose either the hospital name may be revealed or a pseudonym should be used.

I would greatly appreciate it, if you allow me to conduct the initial process of target recruitment at your hospital. If further information and documents are required, do not hesitate to ask from me.

I thank you for your consideration and look forward to hearing from you.

Yours Sincerely,

(Miss Shutiwan Purinthrapibal)  
PhD Student

(Professor Julie Boddy)  
Professor of Nursing

[Massey University LetterHead]

วันที่ 28 กันยายน 2554

โรงพยาบาล [redacted]

ประเทศไทย

เรียน ผู้อำนวยการ โรงพยาบาล [redacted]

ดิฉัน นางสาวชฎิวรรณ บุรินทรภิบาล อาจารย์คณะพยาบาลศาสตร์ มหาวิทยาลัย สงขลานครินทร์ วิทยาเขต  
หาดใหญ่ ปัจจุบันลาศึกษาต่อระดับปริญญาเอกสาขาพยาบาลศาสตร์ ณ มหาวิทยาลัยเมสซี เมืองปาล์มเมอร์ตันนอร์ธ ประเทศ  
นิวซีแลนด์ โดยการพัฒนาวิทยานิพนธ์ในหัวข้อ “เครือข่ายทางสังคมของผู้หญิงที่เป็นมะเร็งเต้านม ที่อยู่ในภาคใต้ของไทย”  
ภายใต้การดูแลของศาสตราจารย์ บอดี้ ดร.เลสดี แบทเทน (มหาวิทยาลัยเมสซี นิวซีแลนด์) และ ผู้ช่วยศาสตราจารย์ กิตติกร  
นิลมานัต (คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์) โครงการวิจัยนี้มีวัตถุประสงค์เพื่อศึกษาเครือข่ายทางสังคมของ  
ผู้หญิงที่เป็นมะเร็งเต้านมผ่านประสบการณ์ของผู้หญิงที่เป็นคนท้องถิ่นของภาคใต้ รวมถึงบุคคลที่เป็นเครือข่ายสำคัญ โดยใช้  
กระบวนการวิจัยเชิงคุณภาพแบบกรณีศึกษา (a qualitative case study methodology) เพื่อตอบคำถามการวิจัยเบื้องต้นคือ ผู้หญิงที่  
เป็นมะเร็งเต้านมในภาคใต้ของไทยมีประสบการณ์กับเครือข่ายทางสังคมของเขายังไง ภายใต้ 4 คำถามย่อย คือ 1. ลักษณะ  
ของเครือข่ายเป็นอย่างไร 2. ปัจจัยที่มีอิทธิพลต่อลักษณะและการทำหน้าที่ของเครือข่ายเป็นอย่างไร 3. ปัจจัยแวดล้อมของการ  
เกิดขึ้นและการทำหน้าที่ของเครือข่ายเป็นอย่างไร และ 4. การเข้าร่วมกลุ่มกับเครือข่ายผู้หญิงที่เป็นมะเร็งเต้านมแบบเป็นทางการ  
ของผู้หญิงกลุ่มนี้เป็นอย่างไร และมีเหตุผลอย่างไร ผลที่คาดว่าจะได้จากโครงการนี้คือ ข้อมูลที่สะท้อนความเป็นจริงตาม  
มุมมองของผู้ใช้บริการและผู้เกี่ยวข้องที่เป็นตัวแทนของคนท้องถิ่นน่าจะเป็นข้อมูลที่มีคุณค่าสำหรับผู้กำหนดนโยบายและรูปแบบ  
การให้บริการสุขภาพที่ตอบสนองความต้องการของคนท้องถิ่น ท้ายที่สุดคุณภาพชีวิตที่ดีขึ้นของผู้หญิงที่เป็นมะเร็งเต้านมก็ที่น่าที่จะ  
สามารถเป็นจริงได้ อนึ่งโครงการวิจัยนี้ผ่านการสอบป้องกัน (The confirmation examination) และ การพิจารณาอนุมัติโดย  
คณะกรรมการจริยธรรมการทำวิจัย (The Massey University Human Ethics Committee: Southern A, Application 11/67) ตาม  
ระเบียบของมหาวิทยาลัยเมสซีแล้ว

ด้วยข้อมูลดังกล่าวข้างต้น พัทลุงจึงถูกเลือกเป็นพื้นที่ในการเก็บข้อมูลของโครงการนี้และโรงพยาบาล [redacted] ซึ่งเป็นเสมือนศูนย์กลางการให้บริการแก่ผู้ป่วยมะเร็งใน [redacted] จึงเป็นสถานที่ที่ควรจะเป็นจุดเริ่มต้นในการติดต่อกับกลุ่มเป้าหมายซึ่งหมายถึงผู้หญิงที่เป็นมะเร็งเต้านมที่มาใช้บริการที่โรงพยาบาล [redacted] ในการนี้ดิฉันใคร่ขอความร่วมมือจากพยาบาลประจำคลินิกศัลยกรรม โรงพยาบาล [redacted] ในการแนะนำโครงการและเชิญชวนให้กลุ่มเป้าหมายเข้ามามีส่วนร่วมกับโครงการนี้ทั้งด้วยวาจาและการแจกจ่ายแผ่นพับแนะนำโครงการ โดยจำนวนของผู้ให้ข้อมูล (ผู้หญิงที่เป็นมะเร็งเต้านม) ที่เข้าร่วมโครงการคาดหมายไว้ที่ 5-10 คน สำหรับสถานที่ที่จะดำเนินกิจกรรมที่เกี่ยวข้องกับการเก็บข้อมูลนั้นอาจจะเป็นบ้านของผู้ให้ข้อมูลหรือสถานที่ที่ผู้ให้ข้อมูลสะดวก และขั้นตอนการเก็บข้อมูลจะเริ่มต้นเมื่อโครงการนี้ผ่านการพิจารณาทางจริยธรรม และอนุมัติการดำเนินขั้นตอนการติดต่อกับกลุ่มเป้าหมายจากทางโรงพยาบาลพัทลุงแล้ว โดยทางโรงพยาบาลสามารถพิจารณาเลือกที่จะนำเสนอชื่อโรงพยาบาลหรือใช้ชื่อสมมติแทนในรายงานการวิจัยและการนำเสนอในรูปแบบอื่นๆ

จึงเรียนมาเพื่อพิจารณาอนุมัติ จักเป็นพระคุณยิ่ง

ด้วยความเคารพอย่างสูง

(นางสาวชุตีวรรณ ปุรินทรากิบาล)

(ศาสตราจารย์ จูดี บอดดี้)

**Hi Ladies,**

I would like to introduce myself and invite you to be a part of my project. My name is Shutiwan Purinthrapibal. I am a local person who is a nurse and have worked as a lecturer in the Nursing Faculty of PSU in Hatyai. I am presently a doctoral student of Massey University in New Zealand. I am interested to learn about who women with breast cancer contact during the journeys with breast cancer and how social contacts or networks are significant in their journeys. Understanding the networks of those women will be valuable for health professionals, particularly those who are creating health-related services and policies. Ultimately, the aim is for women to experience a better quality of life during their journey with breast cancer.



This project is under the supervision of the supervisors of Massey University, New Zealand and the fieldwork supervisor of PSU, Thailand. The Massey University Human Ethics Committee has approved this project and permission from [redacted] Hospital is granted.



**PERSONAL SOCIAL NETWORKS OF BREAST CANCER PATIENTS  
IN THE LOWER SOUTHERN THAILAND**

*The project by “local persons” for “local people”*

Your life experiences on breast cancer journeys are valuable to help the development of health –related services which listen to the patient’s voices.

*...Are you interested to be a part of the research project related to the life experiences on personal social networks of women with breast cancer? .....*

*Please do direct contact to me for more detailed information or express your interest*

**Shutiwan Purinthrapibal**

**Mobile:** [redacted] / **E-mail:** [redacted]

*Participation or non-participation in the project will not affect your health care.*

I would like to invite you and significant people that you contact about living with breast cancer to share your experiences of those networks since you (the women) have been living with this illness. We would meet together and talk over a few months. The timing of meeting and how often we can meet in this time depends on your convenience, comfort and availability. The setting of activities will be at your home or where you feel comfortable.



*If you think you would like to join in this project, contact me for more information.*

**Shutiwan Purintrapibal**

**Mobile:**

**E-mail**

## **The Project Participants**

### **1. The women** who are

- \* aged 20 or upwards
- \* diagnosed with breast cancer at any stage and treatment.
- \* living in either urban or rural areas.
- \* willing and able to participate in this project.

*You will be involved with:*

*informal conversations/interviews, creating network maps, and optional activities such as participant observations, developing a diary, and selecting or taking photos.*

### **2. The network members** are people who are

- \* nominated and invited to the project by the women as a potential participants.

- \* willing to participate in this project

*The network members will be involved with:*

*informal discussions and interviews, they can be face-to-face, telephone, and/or online communication depending on the participants' comfort.*



สัตว์ดีค่ะ

เอ็ดด (ชุติวรรณ ปุรินทรภิบาล) เป็นคนพัทลุง  
สนใจที่จะเรียนรู้ผ่านประสบการณ์ของผู้หญิงชาวพัทลุงว่า ผู้หญิงที่เป็นมะเร็งเต้านมที่อยู่ในภาคใต้ของไทยมีการติดต่อ พูดคุย  
ปรึกษาหารือ กับใคร อย่างไร ในช่วงที่อยู่กับการเจ็บป่วยนี้ การที่เข้าใจลักษณะและการทำงานของเครื่องสำอางของผู้ให้บริการสุขภาพ  
กลุ่มนี้มีประโยชน์อย่างยิ่ง โดยเฉพาะต่อผู้ที่ทำงานในการพัฒนาระบบบริการสุขภาพเพื่อให้มีการตอบสนองต่อความต้องการของ  
คนท้องถิ่นอย่างแท้จริง ทำ्यที่สุดสิ่งที่เราอยากเห็นคือคุณภาพชีวิตที่ดีขึ้นของผู้หญิงที่อยู่กับมะเร็งเต้านมก็จะเป็นจริงได้ ดังนั้น  
ขอเรียนเชิญท่านมาร่วมเป็นส่วนหนึ่งของโครงการนี้กับเรา



เครือข่ายทางสังคมของผู้หญิงที่เป็นมะเร็งเต้านม

ที่อยู่ในภาคใต้ของไทย  
โครงการ โดยคนท้องถิ่น เพื่อ คนท้องถิ่น

ประสบการณ์ชีวิตของท่านมีคุณค่าอย่างยิ่ง  
ในการช่วยพัฒนาระบบบริการทางสุขภาพที่รับฟัง  
ความต้องการของคนท้องถิ่น

หากท่านสนใจ

ที่จะร่วมแบ่งปันประสบการณ์ที่มีคุณค่าของท่านกับเรา

กรุณาติดต่อ

ชุติวรรณ ปุรินทรภิบาล ((เอ็ดด))

มีชื่อ: หรือ อีเมลล์:



โครงการนี้ดำเนินการภายใต้การดูแลของทีมงานอาจารย์ที่ปรึกษาจากมหาวิทยาลัยเมสซี่ นิเวซีแลนด์ และ คณะ  
พยาบาลศาสตร์ มอ.หาดใหญ่ ร่วมทั้งได้ผ่านการพิจารณาและอนุมัติจากคณะกรรมการจริยธรรมในการทำวิจัย  
ของมหาวิทยาลัยเมสซี่ และโรงพยาบาลพัทลุง

เข้าร่วม หรือ ไม่เข้าร่วมโครงการ เป็นการตัดสินใจอย่างอิสระของท่าน  
ไม่มีผลต่อการบริการทางสุขภาพที่ท่านจะได้รับ

#### ***4.Information sheet***

[Massey University LetterHead]

### **Personal Social Networks of Breast Cancer Patients in Southern Thailand**

#### **Information sheet**

Hi, I would like to introduce myself and invite you to be a part of my project. My name is Shutiwan Purinthrapibal. I am a local person who is a nurse. I have worked as a lecturer at the Nursing Faculty of Prince of Songkla University in Hatyai Songkhla. I am presently a PhD student of the School of Health and Social Services, Massey University, New Zealand. For my PhD study, I am interested to learn about the nature of the 'Personal Social Networks of Breast Cancer Patients' through the experiences of women in southern Thailand who are living with breast cancer. I am also interested in talking with the significant people in their networks about what it is like to be a network member.

#### **What the project is conducted for:**

Women who are diagnosed with breast cancer need a variety of supports. In Thailand formal breast cancer support networks have recently been developed as one form of support. However, women also have their own informal support networks such as family members, friends, neighbours, or co-workers. Presently, some women use only informal social networks, while some use both formal and informal social networks. Thus, the ways these women experience their formal and informal social networks is an important topic that should be explored. Understanding these networks will be valuable for health professionals, particularly those who are developing health-related services and policies. Ultimately, the aim is for women to experience a better quality of life during their journey with breast cancer.

#### **The project participants are:**

1. Women with breast cancer who are utilising [redacted] Hospital services (being 20 years old and upwards, living either in the city or in a rural area, at any stage of diagnosis or treatment). The anticipated number of women is 5-10. *Participation or non-participation in this project will not affect your health care in any way.*
2. Network members who are nominated and invited to take part the project by the women with breast cancer. It is anticipated that each woman may nominate 4-5

network members, who will be approached by those women to see if they are interested in participating.

**What activities you will participate in if you choose to participate?**

With your permission I would like to talk with you and to interview you about your social networks, or what it is like to be a social network member. For the participants who have been diagnosed with breast cancer, I would also invite you to be involved in some other activities, such as keeping a diary about your journey with breast cancer, drawing maps of your social networks and I would also like to spend some time with you during your everyday activities. If you felt comfortable, I would also like to seek your permission for you to share or take some photographs that related to your social network. These activities can be undertaken in your home or where you feel comfortable and at times that suited you. I anticipate that the activities could take place over approximately 1-2 months of time. If at any time you feel under stress or not well, you can ask to stop or postpone the activities or withdraw from the project. If you need any health care you can continue to access this from hospital as usual.

All of the information you provide will be analysed by myself. I will use pseudonyms rather than your name in reports of the study. Photos, diaries and maps will only be used with permission of the people pictured/owners. However, I will avoid using images that identify people. You can exclude any part of your diary from being published. Before the report is written, I will seek your consent to use particular photos, or extracts from diaries and maps. All of your information will be kept in a safe, locked place and disposed of 5 years after the project is completed. The preliminary findings will be shared with you and the final findings will be written into a thesis report, published in articles, shared at conferences and also teaching activities. As the research findings could be useful for the development of cancer care services, a final report will be sent to [redacted] Hospital, hospitals which the formal groups of breast cancer patients are involved with in this project, and the southern branch of the National Health Security office.

**What your rights are if you agree to be a part of this project?**

You are under no obligation to accept this invitation and your participation is confidential. If you decide to participate, you have the right to:

- ask any questions about the study at any time during participation;
- decline to answer any particular question;

- ask for the audio recorder to be turned off at any time during interviews;
- withdraw from the study up until the data collection is completed;
- be informed that your name will not be used;
- access a summary of the project findings.

### **Project Contacts**

You can contact me directly at the addresses below:

**The researcher:** Shutiwan Purinthrapibal: **Email:** [REDACTED]

**Telephone:** [REDACTED]

**If you have any concerns about the project please directly contact my Thai supervisor listed below , or the Director of [REDACTED] Hospital**

### **Project Supervisors:**

#### *In Thailand*

**A/Prof. Kittikorn Nilmanut**

Faculty of Nursing, Prince of  
Songkla University, Hatyai,  
Songkhla 90112

Telephone: 074-286477

Facsimile: 074-286421

Email: [nkittiko@yahoo.co.uk](mailto:nkittiko@yahoo.co.uk)

#### *In New Zealand*

**Prof. Julie Boddy**

School of Health and Social  
Services Massey University,  
Private Bag 11222,  
Palmerston North 4442, New  
Zealand

Telephone: +64-6-3569099  
ext 2541

Facsimile: +64-6-3505668

Email:  
[J.Boddy@massey.ac.nz](mailto:J.Boddy@massey.ac.nz)

**Dr Lesley Batten**

School of Public Health,  
Massey University,  
Private Bag 11222,  
Palmerston North 4442,  
New Zealand

Telephone:+64-6-  
3569099 ext 81687

Facsimile: +64-6-350  
5606

Email:  
L.Batten@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 11/67. If you have any concerns about the conduct of this research, please contact A/Prof Hugh Morton, Chair, Massey University Human Ethics Committee: Southern A, telephone +64-6-350-5799 ext 4265, email [humanethicsouthb@massey.ac.nz](mailto:humanethicsouthb@massey.ac.nz)

**Thank you for the opportunity to inform you about my project and if you are interested to take part in this project please contact me directly (or let the women know, in case of network members). I look forward to hearing from you and regards,  
Shutiwan**

## Massey University Letter Head]

### โครงการวิจัย

เครือข่ายทางสังคมของผู้หญิงที่เป็นมะเร็งเต้านม ที่อยู่ในภาคใต้ของไทย

ข้อมูลโครงการสำหรับผู้เข้าร่วมโครงการ (ผู้ใหญ่)

สวัสดิ์ค่ะ ดิฉัน ชุติวรรณ ปุรินทรากิบาล (เอียด) เป็นคนพัทลุงและเป็นอาจารย์พยาบาลอยู่ที่คณะพยาบาลศาสตร์ มอ.หาดใหญ่ และตอนนี้กำลังเรียนต่อระดับปริญญาเอกสาขาพยาบาลศาสตร์ที่มหาวิทยาลัยเมสซี ประเทศนิวซีแลนด์ ในการเรียนครั้งนี้ ดิฉันสนใจที่จะเรียนรู้เกี่ยวกับ เครือข่ายทางสังคมของผู้หญิงที่เป็นมะเร็งเต้านมที่อยู่ในภาคใต้ของไทย โครงการวิจัยนี้จึงพัฒนาขึ้นเพื่อเรียนรู้ประสบการณ์ชีวิตของผู้หญิงชาวบักย์ใต้ที่เป็นมะเร็ง เต้านมที่เกี่ยวข้องกับเครือข่ายทางสังคมทั้งส่วนที่เป็นกลุ่มแบบเป็นทางการและแบบที่เกิดขึ้นเองตามธรรมชาติในมุมมองของผู้หญิงท้องถิ่นและบุคคลที่เป็นมีประสบการณ์ร่วมกัน ข้อมูลที่ได้จากโครงการนี้น่าจะมีคุณค่าสำหรับบุคลากรทางสุขภาพ โดยเฉพาะอย่างยิ่งผู้ที่มีบทบาทในการกำหนดนโยบายและ/หรือรูปแบบการให้บริการทางสุขภาพเพื่อให้เกิดคุณภาพชีวิตที่ดีขึ้นของผู้หญิงที่เป็นมะเร็งเต้านม

ผู้ที่จะมีส่วนร่วมกับโครงการนี้ ประกอบด้วย

1. ผู้หญิงที่เป็นมะเร็งเต้านมที่อยู่ในระยะและการรักษาใดก็ได้ ที่ใช้บริการของโรงพยาบาล [redacted] มีอายุ 20 ปีขึ้นไป และพักอาศัยอยู่ในจังหวัดพัทลุง จำนวนประมาณ 5-10 คน

การเข้าร่วม หรือไม่เข้าร่วมกับโครงการนี้ไม่มีผลใดๆต่อบริการสุขภาพของท่าน

2. ผู้ที่เป็นเครือข่ายทางสังคมซึ่งระบุชื่อและทบทวนโดยผู้หญิงที่เป็นมะเร็งเต้านม โดยคาดประมาณว่าแต่ละเครือข่ายจะมีประมาณ 4-5 คน ที่จะถูกทบทวนโดยเจ้าของเครือข่าย และสมัครใจที่จะเข้าร่วมโครงการ

เมื่อท่านตกลงใจที่จะเข้าร่วมแบ่งปันประสบการณ์ที่มีคุณค่ากับโครงการนี้ ดิฉันจะสนทนากับท่าน (ผู้หญิงที่เป็นมะเร็งเต้านม) เกี่ยวกับประสบการณ์ของท่านในช่วงที่อยู่กับมะเร็งเต้านม โดยเฉพาะที่เกี่ยวกับเครือข่ายทางสังคมและสร้างสรรค์แผนผังเครือข่ายของท่านร่วมกัน นอกจากนี้ดิฉันขอเชิญชวนท่านทำกิจกรรมอื่นๆร่วมกัน เช่น บันทึกไดอารี่เกี่ยวกับชีวิตช่วงที่อยู่กับมะเร็งเต้านม ขอร่วมวงกับกิจกรรมประจำวันของท่านและการแบ่งปันประสบการณ์ผ่านภาพถ่ายที่เกี่ยวข้องกับเครือข่ายทางสังคมของท่านโดยภาพถ่ายดังกล่าวเป็นได้ทั้งภาพในอดีตหรือภาพที่จะถ่ายใหม่ สำหรับท่านที่เป็นเครือข่ายของผู้หญิงที่เป็นมะเร็งเต้านม ดิฉันจะขอสนทนากับท่านถึงประสบการณ์ร่วมของท่านต่อเครือข่ายของผู้หญิงที่เป็นมะเร็งเต้านมที่ท่านมีส่วนเกี่ยวข้อง โดยช่องทางการสนทนาระหว่างเราเป็นได้ทั้งแบบ ตัวต่อตัว ผ่านทางโทรศัพท์ หรือ อินเทอร์เน็ต ขึ้นกับความสะดวกของท่าน กิจกรรมดังกล่าวข้างต้นกับทั้งผู้หญิงและเครือข่ายจะมีขึ้นที่บ้านของท่านหรือที่ที่ท่านมีความ

สะดวก ในช่วงเวลาที่ท่านเห็นว่าสะดวกและเหมาะสม โดยรวมกิจกรรมทั้งหมดจะอยู่ในช่วงเวลาประมาณ 1-2 เดือน หากท่านรู้สึกเครียดกับกิจกรรมหรือไม่พร้อม สามารถขอยุติชั่วคราว/เลื่อน/ยกเลิก การเข้าร่วมกับโครงการได้

เมื่อรวบรวมข้อมูลมาได้แล้ว ดิฉันจะวิเคราะห์ข้อมูลด้วยตัวเอง การรายงานผลโครงการจะใช้ชื่อสมมติ แทนชื่อจริงของท่าน รูปภาพ บันทึก และ แผนผังเครือข่าย จะนำเสนอเฉพาะกรณีที่ได้รับอนุญาตเท่านั้น จะพยายามหลีกเลี่ยงการนำเสนอรูปหรือข้อมูลที่สามารถระบุบุคคลที่เกี่ยวข้องได้ชัดเจน และก่อนเผยแพร่ข้อมูลจะขอคำยืนยันจากท่านก่อนอีกครั้ง ข้อมูล เอกสาร และ วัสดุต่างๆที่ได้มาจากการมีส่วนร่วมของท่านจะได้รับการเก็บรักษาในที่ที่ปลอดภัยไม่มีใครสามารถเข้าถึงได้นอกจากดิฉันเท่านั้น และจะถูกทำลายภายใน 5 ปีหลังจากโครงการสิ้นสุดลง ผลการวิจัยเบื้องต้นจะส่งคืนให้ท่านตรวจสอบและผลขั้นสุดท้ายจะถูกนำเสนอในรายงานการวิจัย ตีพิมพ์ในวารสาร และนำเสนอในที่ประชุมวิชาการรวมถึงกิจกรรมการเรียนการสอนที่เกี่ยวข้อง และเนื่องจากผลการวิจัยของโครงการนี้น่าจะเป็นประโยชน์ต่อการพัฒนาคุณภาพการบริการสุขภาพที่เกี่ยวข้องกับผู้ป่วยมะเร็ง ดังนั้นผลการวิจัยในภาพรวมจะจัดส่งให้กับโรงพยาบาล [redacted] โรงพยาบาลที่เป็นที่ตั้งของกลุ่มเครือข่ายที่เป็นทางการซึ่งถูกอ้างอิงถึงจากผู้เข้าร่วมโครงการรวมถึงสำนักงานหลักประกันสุขภาพแห่งชาติ สาขาภาคใต้

### สิทธิของผู้เข้าร่วมโครงการ

ท่านไม่ได้ผูกมัดใจตัวเองที่จะต้องตอบรับคำเชิญ การเข้าร่วมโครงการหรือไม่ขึ้นอยู่กับความตัดสินใจอย่างอิสระของตนเอง และการเข้าร่วมวิจัยของท่านเป็นความลับ **สิทธิในฐานะผู้เข้าร่วมโครงการมีดังนี้**

- ถามคำถามเกี่ยวกับ โครงการวิจัยได้ตลอดเวลาที่ท่านเข้าร่วมโครงการ
- ปฏิเสธที่จะตอบคำถามบางคำถามที่ท่านไม่สะดวกที่จะให้ข้อมูล
- ขอให้ผู้วิจัยปิดอุปกรณ์บันทึกเสียงในขณะที่สัมภาษณ์ได้ในช่วงที่ท่านไม่ต้องการให้บันทึก
- ถอนตัวออกจากโครงการวิจัยได้ตลอดเวลา หากท่านต้องการ
- ชื่อจริงของท่านจะไม่นำเสนอในรายงานใดๆ
- ขอรายงานผลสรุปของโครงการได้

หากท่านมีคำถามหรือต้องการข้อมูลเพิ่มเติม ติดต่อได้ที่

นักวิจัย: ชุติวรรณ ปุรินทรภิบาล อีเมลล์ [redacted] หรือ เบอร์โทรศัพท์ [redacted] หรือติดต่อโดยตรงเพื่อสอบถามเกี่ยวกับโครงการกับอาจารย์ที่ปรึกษาโครงการ/ประธานคณะกรรมการทำวิจัยของมหาวิทยาลัย

## ที่ปรึกษาโครงการ

ประเทศไทย

ผศ.ดร. กิตติกร นิลมานันต์

คณะพยาบาลศาสตร์  
มหาวิทยาลัยสงขลานครินทร์  
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Email: [L.Batten@massey.ac.nz](mailto:L.Batten@massey.ac.nz)

โครงการนี้ได้รับการพิจารณาและรับรองโดยคณะกรรมการจริยธรรมการทำวิจัยของมหาวิทยาลัยเมสซี

นิวซีแลนด์ ประธานคณะกรรมการคือ รองศาสตราจารย์ ฮิวจ์ มอร์ตัน A/Prof Hugh Morton, Chair, Massey  
University Human Ethics Committee: Southern A, telephone: +64-6-350-5799 ext 4265, email:  
[humanethicsouthb@massey.ac.nz](mailto:humanethicsouthb@massey.ac.nz)

ขอขอบคุณทุกท่านที่ให้ความสนใจและหากท่านสนใจที่จะเป็นส่วนหนึ่งของโครงการกรุณา

ติดต่อดิฉันโดยตรง หวังเป็นอย่างยิ่งที่จะได้รับการติดต่อจากท่าน ด้วยความขอบคุณ

ชุติวรรณ ปุรินทรภิบาล

[Massey University LetterHead]

## **Personal Social Networks of Breast Cancer Patients in Southern Thailand**

### **INFORMATION SHEET FOR CHILD PARTICIPANTS**

**Hi children/parents,**

I'd like to introduce myself and invite you to join my project. My name is Shutiwan Purinthrapibal (PeeAied). I am a local person who is a nurse and have taught nursing students at PSU, Hatyai. I am presently a doctoral student in New Zealand. My project relates to the social networks of women living with breast cancer in southern Thailand. I am interested to know who those women have contact with while they live with this illness and how. Someone you know, who has breast cancer, has identified that you are a member of their social network and so I would like to talk to you about what that is like. Your direct experiences will help me understand more about women's social networks.

#### **What activities you will participate in if you agree to join with this project.**

I would like to interview you about your experiences of being part of a social network. You can decide when, and where and who else is present. It will probably take between 30-60 minutes. You don't need to answer all my questions if you don't want to. I would also like to record the interviews if you agree. If you decide to be a part of my project, I won't use your name in any report and presentation. All of your information will be kept in a safe, locked place and destroyed 5 years after the project completion.

#### **What your rights are if you agree to be a part of this project.**

You are under no obligation to accept this invitation and your participation is confidential. If you decide to participate, you have the right to:

- ask any questions about the study at any time during participation;
- decline to answer any particular question;
- ask for the audio recorder to be turned off at any time during the interview;
- withdraw from the study up until the data collection is completed;
- be informed that your name will not be used;
- access a summary of the project findings.

## Project Contacts

You (your parents) can contact me directly at the address below.

### The researcher:

**Shutiwan Purinthrapibal:** Email: [REDACTED] Telephone: [REDACTED]

**If you have any concerns about the project please directly contact my Thai supervisor listed below , or the Director of Phatthalung hospital**

### Project Supervisors:

#### *In Thailand*

##### **A/Prof. Kittikorn Nilmanut**

Faculty of Nursing,

Prince of Songkla University

Hatyai, Songkhla 90112

Telephone: 074-286477

Facsimile: 074-286421

Email: [nkittiko@yahoo.co.uk](mailto:nkittiko@yahoo.co.uk)

#### *In New Zealand*

##### **Prof. Julie Boddy**

School of Health and Social Services

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Email: [J.Boddy@massey.ac.nz](mailto:J.Boddy@massey.ac.nz)

##### **Dr. Lesley Batten**

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Facsimile: +64-6-350 5606

Email: [L.Batten@massey.co.nz](mailto:L.Batten@massey.co.nz)

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application \_11\_/67\_\_. If you (your parents) have any concerns about the conduct of this research, please contact A/Prof Hugh Morton, Chair, Massey University Human Ethics Committee: Southern A, telephone +64-6-350-5799 ext 4265, email [humanethicsouthb@massey.ac.nz](mailto:humanethicsouthb@massey.ac.nz)

**Thank you for the opportunity to inform you about my project and if you are interested to take part in this project please contact me directly or let the women know, in case of network members.**

**I look forward to hearing from you and regards, Shutiwan.**

## [Massey University LetterHead]

### โครงการวิจัย

เครือข่ายทางสังคมของผู้หญิงที่เป็นมะเร็งเต้านม ที่อยู่ในภาคใต้ของไทย

ข้อมูลโครงการสำหรับผู้เข้าร่วมโครงการ (เด็กอายุ ต่ำกว่า 16 ปีและผู้ปกครอง)

#### สวัสดิการ นื่องๆและท่านผู้ปกครอง

ขอแนะนำตัวก่อนนะค่ะ พี่เอียด (ชุติวรรณ ปุรินทรภิบาล) เป็น [redacted] เป็นอาจารย์สอนนักศึกษาพยาบาลอยู่ที่ มอ. หาดใหญ่ และตอนนี้กำลังเรียนปริญญาเอกอยู่ที่นิวซีแลนด์ พี่เอียดสนใจ อยากจะรู้ว่า ผู้หญิงที่เป็นมะเร็งเต้านม ที่อยู่ในภาคใต้ของไทยมีการติดต่อ พูดคุยปรึกษาหารือ หรือขอความช่วยเหลือกับใคร อย่างไร ในช่วงเวลาดังกล่าว และคนที่น้องรู้จักระบุนาน้องเป็นคนสำคัญต่อเขาในการอยู่กับการเจ็บป่วยนี้ ดังนั้นพี่จึงอยากจะพูดคุยกับน้องเกี่ยวกับเรื่องนี้ โดยน้องจะเป็นคนเลือกวัน เวลา และ สถานที่ตามที่คิดว่าสะดวก (รวมถึงคนที่อยู่ด้วยเวลาที่เราร่วมกัน) การพูดคุยแต่ละครั้งจะใช้เวลาประมาณ 30-60 นาที น้องไม่จำเป็นต้องตอบในคำถามที่ไม่อยากตอบ และจะมีการบันทึกเสียงเพื่อช่วยเก็บรายละเอียดของการพูดคุยถ้าน้องอนุญาต ชื่อจริงของน้องจะไม่ถูกใช้ในรายงานใดๆ และข้อมูลของน้องจะเก็บรักษาไว้ในที่ที่ปลอดภัย และจะถูกทำลายภายใน 5 ปีหลังโครงการเสร็จสิ้นลง

#### สิทธิของผู้เข้าร่วมโครงการ

น้องไม่ได้ถูกภายใต้เงื่อนไขที่จะต้องตอบรับคำเชิญ การเข้าร่วมโครงการหรือไม่ขึ้นอยู่กับความคิดเห็นอย่างอิสระของตัวเอง และการเข้าร่วมวิจัยของน้องเป็นความลับ **สิทธิในฐานะผู้เข้าร่วมโครงการมีดังนี้**

- ถามคำถามเกี่ยวกับโครงการวิจัยได้ตลอดเวลาที่น้องอยู่ร่วมในโครงการ
- ปฏิเสธที่จะตอบคำถามบางคำถามที่ไม่สะดวกใจที่จะตอบ
- ขอให้พี่ปิดอุปกรณ์บันทึกเสียงในขณะสัมภาษณ์ได้ในช่วงที่น้องไม่ขอให้มีการบันทึกเสียง
- ถอนตัวออกจากโครงการวิจัยได้ตลอดเวลา หากต้องการ
- ชื่อจริงของน้องจะไม่นำเสนอในรายงานใดๆ
- ขอรายงานผลสรุปของโครงการ ได้

หาก น้อง และ/หรือ ผู้ปกครอง มีคำถามหรือต้องการข้อมูลเพิ่มเติม ติดต่อได้ที่

นักวิจัย: ชุติวรรณ ปุรินทรภิบาล (พี่เอียด) อีเมลล์ [redacted] หรือเบอร์โทรศัพท์ [redacted]

หรือติดต่อโดยตรงเพื่อสอบถามเกี่ยวกับโครงการกับอาจารย์ที่ปรึกษาโครงการ/ประธานคณะกรรมการทำวิจัย  
ของมหาวิทยาลัย

**ที่ปรึกษาโครงการ**

**ประเทศไทย**

**ผศ.ดร. กิตติกร นิลมานัต**

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โครงการนี้ได้รับการพิจารณาและรับรองโดยคณะกรรมการจริยธรรมการทำวิจัยของมหาวิทยาลัยเมสซี

นิวซีแลนด์ ประธานคณะกรรมการคือ รองศาสตราจารย์ ฮิวจ์ มอร์ตัน A/Prof Hugh Morton, Chair, Massey

University Human Ethics Committee: Southern A, telephone: +64-6-350-5799 ext 4265, email:

[humanethicsouthb@massey.ac.nz](mailto:humanethicsouthb@massey.ac.nz)

ขอขอบคุณน้องๆและท่านผู้ปกครองที่ให้ความสนใจและหากท่านสนใจที่จะเป็นส่วนหนึ่งของโครงการกรุณา  
ติดต่อที่เถิดโดยตรง หวังเป็นอย่างยิ่งว่าจะได้รับการติดต่อจากท่าน ด้วยความขอบคุณยิ่ง

**5. Confidentiality agreement form**

**Personal Social Networks of Breast Cancer Patients  
in Southern Thailand**

**CONFIDENTIALITY AGREEMENT**

I.....(Full Name - printed)

agree to keep confidential all information concerning the project:

**Personal Social Networks of Breast Cancer Patients in Southern Thailand**

I will not retain or copy any information involving the project.

**Signature:**

**Date:**

.....

**Full Name - printed**

## เครือข่ายทางสังคมของผู้หญิงที่เป็นมะเร็งเต้านม ที่อยู่ในภาคใต้ของไทย

### ข้อตกลงการรักษาความลับข้อมูลโครงการวิจัย

ข้าพเจ้า (ชื่อ-สกุล ตัวบรรจง).....

จะไม่เปิดเผยข้อมูลโครงการวิจัย “เครือข่ายทางสังคมของผู้หญิงที่เป็นมะเร็งเต้านม ที่อยู่ในภาคใต้ของไทย”

ข้าพเจ้าจะไม่เก็บหรือทำสำเนาข้อมูลต่างๆที่เกี่ยวข้องกับงานวิจัยนี้

ลายเซ็น.....วันที่.....

ชื่อ-สกุล (ตัวบรรจง) .....

**6. Participant consent form**

**Personal Social Networks of Breast cancer Patients  
in Southern Thailand**

**PARTICIPANT CONSENT FORM  
for woman participants**

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

- I agree/do not agree to the interview being sound recorded.
- I agree/do not agree to allow the researcher to observe my social activities with other people.
- I agree/do not agree to develop diaries of my journey with breast cancer.
- I agree/do not agree to select and/or take of photos related to my social network.
- I wish/ do not wish to have my recordings returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

**Signature:**

**Date:**

.....

**Full Name - printed**

.....

เครือข่ายทางสังคมของผู้หญิงที่เป็นมะเร็งเต้านม ที่อยู่ในภาคใต้ของไทย

ใบยินยอมการเข้าร่วมโครงการวิจัย

สำหรับผู้หญิง

ข้าพเจ้าได้อ่านและได้รับการอธิบายเกี่ยวกับรายละเอียดของการศึกษาวิจัยนี้ รวมถึงคำถามของข้าพเจ้าเกี่ยวกับ การศึกษาวิจัยนี้ได้รับคำอธิบายอย่างเป็นที่พอใจ และข้าพเจ้ารับทราบว่าข้าพเจ้าสามารถถามคำถามอื่นๆเกี่ยวกับ การวิจัยนี้ได้ตลอดเวลา

- ข้าพเจ้า ยินยอม/ไม่ยินยอม ให้การมีการบันทึกเสียงขณะสัมภาษณ์
- ข้าพเจ้า ยินยอม/ไม่ยินยอม ให้ผู้วิจัยร่วมสังเกตกิจกรรมที่ข้าพเจ้าทำร่วมกับบุคคลอื่นในชีวิตประจำวัน
- ข้าพเจ้า ยินยอม/ไม่ยินยอม ที่จะทำ บันทึกส่วนตัว (ไดอารี่) เกี่ยวกับประสบการณ์การอยู่กับมะเร็งเต้านม
- ข้าพเจ้า ยินยอม/ไม่ยินยอม ทำการ คัดเลือกภาพถ่าย และ/หรือ ถ่ายภาพ ที่เกี่ยวข้องกับเครือข่ายทางสังคมของ ข้าพเจ้า
- ข้าพเจ้า ต้องการ/ไม่ต้องการ ที่จะ ตรวจสอบและยืนยันความถูกต้องของข้อมูล ที่ได้จากการวิจัย

ข้าพเจ้ายินดีเข้าร่วมกับ โครงการวิจัยนี้ภายใต้เงื่อนไขที่ระบุในรายละเอียดข้อมูลโครงการวิจัย

ลายเซ็น.....วันที่.....

ชื่อ-สกุล (ตัวบรรจง) .....

# Personal Social Networks of Breast Cancer Patients in Southern Thailand

## PARTICIPANT CONSENT FORM for network member participants

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

- I agree/do not agree to the interview being sound recorded.
- I wish/ do not wish to have my recordings returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

**Signature:** ..... **Date:** .....

**Full Name - printed** .....

### **\*\* For Parents if the network member participants is under 20 years old\*\***

I agree that .....(the child's full name) may participate in this study under the conditions set out in the Information Sheet.

**Signature:** ..... **Date:** .....

**Full Name - printed**

เครือข่ายทางสังคมของผู้หญิงที่เป็นมะเร็งเต้านม ที่อยู่ในภาคใต้ของไทย

ใบยินยอมการเข้าร่วมโครงการวิจัย

สำหรับเครือข่ายของผู้หญิง

ข้าพเจ้าได้อ่านและได้รับการอธิบายเกี่ยวกับรายละเอียดของการศึกษาวิจัยนี้ รวมถึงคำถามของข้าพเจ้าเกี่ยวกับ การศึกษาวิจัยนี้ได้รับคำอธิบายอย่างเป็นที่พอใจ และข้าพเจ้ารับทราบว่าข้าพเจ้าสามารถถามคำถามอื่นๆเกี่ยวกับ การวิจัยนี้ได้ตลอดเวลา

ข้าพเจ้า ยินยอม/ไม่ยินยอม ให้การมี การบันทึกเสียงขณะสัมภาษณ์

ข้าพเจ้า ยินยอม/ไม่ยินยอม ให้การมี การบันทึกเสียงขณะสัมภาษณ์

ข้าพเจ้ายินดีเข้าร่วมกับ โครงการวิจัยนี้ภายใต้เงื่อนไขที่ระบุไว้ในรายละเอียดข้อมูลโครงการวิจัย

ลายเซ็น.....วันที่.....

ชื่อ-สกุล (ตัวบรรจง) .....

**\*\*สำหรับผู้ปกครอง ในกรณีที่เครือข่ายมีอายุต่ำกว่า 20 ปี\*\***

ข้าพเจ้ายินดีให้.....(ชื่อ-สกุล เต็ก ตัวบรรจง) เข้าร่วมกับโครงการวิจัยนี้ภายใต้ เงื่อนไขที่ระบุไว้ในรายละเอียดข้อมูลโครงการวิจัย

ลายเซ็น.....วันที่.....

ชื่อ-สกุล (ตัวบรรจง) .....

*7. Authority for the release of transcripts/materials forms*

**Personal Social Networks of Breast cancer Patients  
in Southern Thailand**

**AUTHORITY FOR THE RELEASE OF TRANSCRIPTS/MATERIALS**

I confirm that I have had the opportunity to read and emend the transcript of the interview(s) conducted with me **and** I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

**If applicable**

I agree/do not agree that my network map and extracts from this may be used in reports and publications arising from the research.

I agree/do not agree that my diary and extracts from this may be used in reports and publications arising from the research.

I agree/do not agree that my photos and extracts from these may be used in reports and publications arising from the research and the identifiable images will occasionally be used with / without obscuring the personal identity

**Signature:**

**Date:**

.....

**Full Name - printed**

เครือข่ายทางสังคมของผู้หญิงที่เป็นมะเร็งเต้านม ที่อยู่ในภาคใต้ของไทย

คำยินยอมให้เผยแพร่สำเนาบท/วัสดุต่างๆ

ข้าพเจ้ายืนยันว่าข้าพเจ้ามีสิทธิที่จะอ่านและแก้ไขสำเนาบทจากการสัมภาษณ์ที่ข้าพเจ้าเข้าร่วมกิจกรรมของโครงการวิจัยนี้ และ ข้าพเจ้ายินดีที่จะให้นำสำเนาบทที่ผ่านการแก้ไขแล้ว และข้อมูลที่เกี่ยวข้องไปใช้ในรายงานและ/หรือการเผยแพร่ในรูปแบบอื่นๆที่เกี่ยวข้องเกี่ยวกับโครงการวิจัยนี้

เฉพาะกรณี

ข้าพเจ้า ยินยอม / ไม่ยินยอม ให้นำเสนอ แผนผังเครือข่าย ของข้าพเจ้าและข้อมูลที่เกี่ยวข้อง ในรายงานและ/หรือการเผยแพร่ในรูปแบบอื่นๆที่เกี่ยวข้องเกี่ยวกับโครงการวิจัยนี้

ข้าพเจ้า ยินยอม / ไม่ยินยอม ให้นำเสนอ บันทึกประจำวัน (ไดอารี่) ของข้าพเจ้าและข้อมูลที่เกี่ยวข้อง ในรายงานและ/หรือการเผยแพร่ในรูปแบบอื่นๆที่เกี่ยวข้องเกี่ยวกับโครงการวิจัยนี้

ข้าพเจ้า ยินยอม / ไม่ยินยอม ให้นำเสนอ รูปภาพ ของข้าพเจ้า ในรายงานและ/หรือการเผยแพร่ในรูปแบบอื่นๆที่เกี่ยวข้องเกี่ยวกับโครงการวิจัยนี้ และรูปที่เผยแพร่อาจจะเป็นรูปที่สามารถระบุบุคคล แบบ ปกปิด/ ไม่ปกปิด ใบหน้า

ลายเซ็น.....วันที่.....

ชื่อ-สกุล (ตัวบรรจง) .....



## Appendix VI

### *Researcher diary*

26<sup>th</sup> October 2011

**“Open mind” to see and hear what happens (Prof. Julie’s sentence).**

The initial approach with the target was conducted immediately when I arrived the Surgical Clinic as [a nurse’s name] sent me the potential case suddenly. Beside [a nurse’s name] station, I introduced myself to the 61 year old woman—[1.a] and then I saw her caregiver—  
// ... (I thought every case is significant and it would benefit for me to learn about them).

[1.a] is a married woman who is a rubber tree farmer.

By following [1.a]’s process of admission to a ward, I could see

- i). The normal process of breast cancer services for those who are undergoing chemotherapy (I didn’t follow her into her doctor’s room but I asked her later what happened inside the room).
- ii) Her participation with other breast cancer patients who were waiting for chemotherapy together with her.
- iii) At that moment, her major concern was which site will be used for her chemotherapy injection / IV (it seems as the IV site is more important / concern than other side effects such as nausea/vomiting and hair loss). *WHY??*

After started approaching [1.a] around 30 minutes, the second case was sent to me. So, I had to manage 2 cases in the same time.

[2.a] is the second case; she is 40 years old, a married teacher of a public primary school. Her chemotherapy was completed and today she visited the doctor for the first time of pill treatment. While [1.a] was waiting for the doctor and went inside the doctor’s room, I spent my time with [2.a]. And I came back to [2.a] again when she was waiting for her home medication (after I visited [1.a] at a ward and I left from [1.a] when she had to wait for the chemo medication from the Pharmacy department at ward). Today, I spent time with [2.a] at the hospital for around 2 hours. I felt she was willing to share her experience after she knew what I am doing. She said she will appreciate it if her experience is useful for others. The

second time of visiting [2.a], I went to her house where she lives with her husband and his daughter (the high school student, year 11/12). I didn't see others only her at home. At her place we spent time together around one hour. I felt some times she led our dialogue direction; it was different from the first time that I almost led the conversation issues. At this time, I allowed myself to get involved in her personal issues, such as what did she feel about her image changes—hair and breast loss? What did she do with her husband and what does she feel about sexuality change? By the way, sometimes my conversation got stuck as I couldn't link my idea flow through the previous dialogue and then, I switched the topic to the new one; it seemed as unnatural and the information flow was not good. ...have to improve my skill and prove the important issues next time. At the end, I asked her would she like to do a diary. She said she used to do her diary but at the moment she has no impulse to do it. (I wish she will prefer to do a diary soon..)

Through conversation and observation with [2.a], I thought I could sketch her social network in particular her supporters. However, I have questions related to her network such as:

- i. Even though she stays with her husband and his daughter, she didn't mention what and how her husband and his daughter supported her.
- ii. It seems as her eldest sister is the most important to her, why and how? (She was crying when she talk about her and would like me to see her sister)
- iii. She didn't mention about nurse actions and supports to her, why?

### **Self-evaluation for the first time of fieldwork**

#### **Data gathering**

- i. What do they do, don't do?
- ii. What do they say, don't say?
- iii. What do they mean?
- iv. What do they think, why?
- v. And what do I do, think and why?

#### **Developing Familiarity**

The better the familiarity, the more frequently I visited and observed the setting. (Sometimes I did informal visits to the hospital as I have to look after my ill uncle there).

*I have a plan to visit the surgical clinic on Thursday 4th and Friday 5<sup>th</sup> Nov 2011.*

## Appendix VII

### *Field note*

**11<sup>th</sup> October 2012**

Today I reached [4.a]'s home at around 11.15am. Her father was home with her. After that her neighbour came to her place for picking her coconuts. [4.a] managed a pie of coconuts with her neighbour, while her father observed. After she finished her business with her neighbour, she asked me for 10 minutes for taking a shower. Thus, I was sitting with her father having a conversation. The father told me that his wife [4.a's mother] got an infection in her foot and now is admitted in hospital for antibiotic injections. His youngest daughter came from [place] to look after her mother for a few days and just has gone back to her home. Today his grandson was with his grandma at hospital. He told me about his grandsons' education with a happy face. I asked him about his sickness he said he felt very much better.

[4.a] came back to me after showering. She invited me to have a conversation inside the house. .. //... She told me with confidence that now she was able to manage her doctor visit alone, no need to ask for help from her sister. She detailed to me how she managed her travel, how she prepared herself and stuff before going to the hospital, how she had planned if in case she could not catch a taxi on time... 'In case I don't understand about the message that the doctor said. I brave to ask him/her. I use a local/common language ...now I don't feel shame to ask him/her.' ... //

During conversation with [4.a], her father rode a motorcycle off home to participate in his friend's funeral. We looked at him until he was out of our sight. [4.a] said to me, 'you see he is over 80 years old but still looks healthy. When I have known he got cancer I thought he will have gone soon and cried a lot. Now he looks healthier than me. For me, just keep going with my treatment. The best I can do...' //...

Before I left from her, [4.a] said tonight she will stay at hospital with her mother and let her nephew have a good sleep at home.

**[4.a], you are the great fighter.**



## Appendix VIII

*(Example)*

### ***Guidance of personal social network mapping***

#### ***Introduction***

Assessment of personal social networks of women living with breast cancer enhances holistic nursing approach in terms of a whole person always within their contexts (e.g. family, relationships, resources, and employees). This information set will allow both patients and health professionals to understand the women's (and their relevant people's) needs and resources of personal support or tend to have related to individual circumstances within personal, family, group, workplace, community, and system levels.

#### ***Aim***

To provide nurses with:

- Steps of assessment and investigation
- Personal social network template
- Example sheet of network information

#### ***Clarification of Terms***

**Personal social networks:** Groups of people and/or networks who are identified as significant for the women in relation to (potentially) providing tangible and r intangible support personally to them and / or their relevant people while living with breast cancer.

#### ***Steps of assessment***

1. A network assessment should be completed by nurses at hospitals and community nurses who take over roles of in-change nurse, coordinators and/or nurse case managers who regularly have contact with the women at hospitals or in the community.
2. An assessment could be conducted with the women with breast cancer with / without their supporters.
3. Initial discussion about expected and actual needs of support and potential supporters related to health-related and normal life circumstances, this initial discussion will enable the women to gather information related to personal social networks (Guideline of support needs as below )

### *Possible needs related to health and normal life*

<b>Possible needs related to health</b>	<b>Possible needs related to normal life</b>
<ul style="list-style-type: none"><li>• Navigating to health settings and services</li><li>• Counselling &amp; decision making</li><li>• Travelling &amp; transport</li><li>• Communicating with health professionals</li><li>• Care giving at hospitals and at home</li><li>• (Breast) cancer-related information and experience sharing</li><li>• Emotional support</li><li>• Spiritual support</li></ul>	<ul style="list-style-type: none"><li>• Facilitating daily living</li><li>• Taking part in responsibilities in normal life such as looking after children or parents</li><li>• Helping in jobs</li><li>• Financial support (if necessary)</li></ul>

4. Discussion about resources of personal support, information should be considered, both objective (Who, what they do or can do, how and/or with any conditions) and subjective criteria (benefits, meanings, and / or feeling of satisfaction or preference).

5. Nurses and the women and/or their supporters complete the 'Network map' after discussion by identifying and labelling names of supporters, and also recording roles and conditions of support of each supporter.

6. Network discussion after mapping is required to identify significant supporters and (expected and actual) support they may be able to provide and record.

7. Discussion with the women and/or their supporters about difficulties in health-related and normal life circumstances and potential gaps related to personal support, and record in a personal social network sheet.

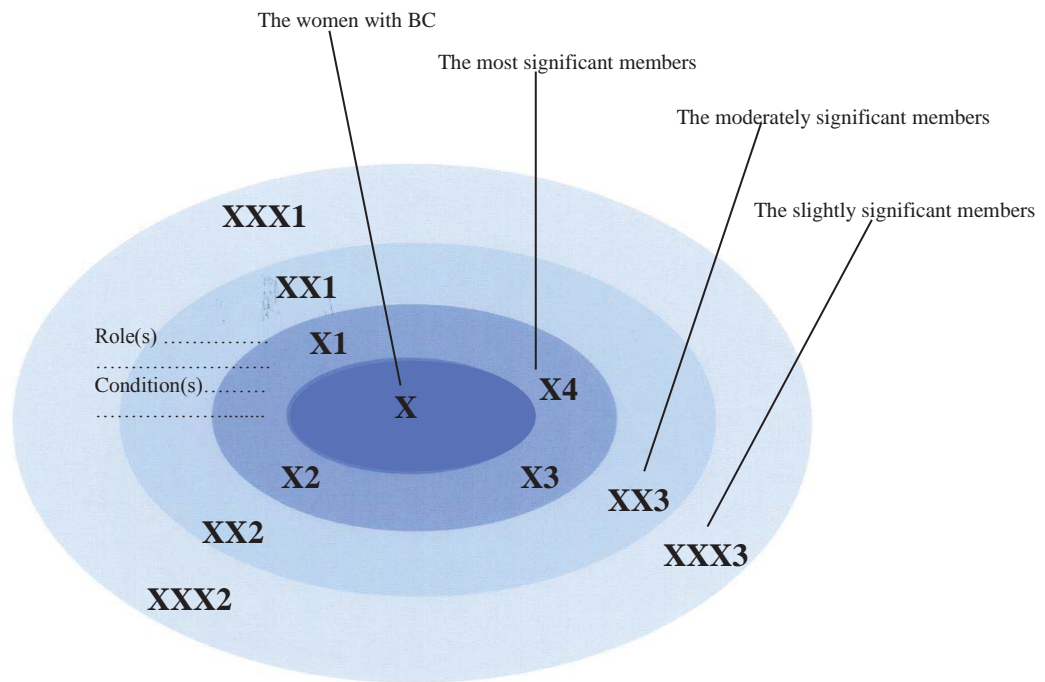
8. The discussion should be related to disease patterns, relationships, and sensitivity to cultural and religious sensitive.

9. Use this information for nursing plans, discharge plan and referral information between health-settings.

10. An assessment is needed on an ongoing basis, reassessment, especially, related to disease and treatment patterns should be undertaken.

Name..... ID..... Assessment No. ....

- |                                     |  |                          |   |
|-------------------------------------|--|--------------------------|---|
| <input checked="" type="checkbox"/> | <b>The first diagnosis loop</b>                          | <input type="checkbox"/> | <b>The recurrence loop</b>                                |
| ...                                 | <b>Pre-dagnosis</b>                                      | ...                      | <b>Pre-diagnosis</b>                                      |
| ...                                 | <b>Undergoing investigation &amp; initial treatments</b> | ...                      | <b>Undergoing investigation &amp; initial treatments</b>  |
| ✓                                   | <b>Undergoing aggressive treatments</b>                  | ...                      | <b>Keeping undergoing prolonged aggressive treatments</b> |
| ...                                 | <b>Completion aggressive treatments</b>                  |                          |   |
| ...                                 | <b>Follow up period</b>                                  |                          |   |

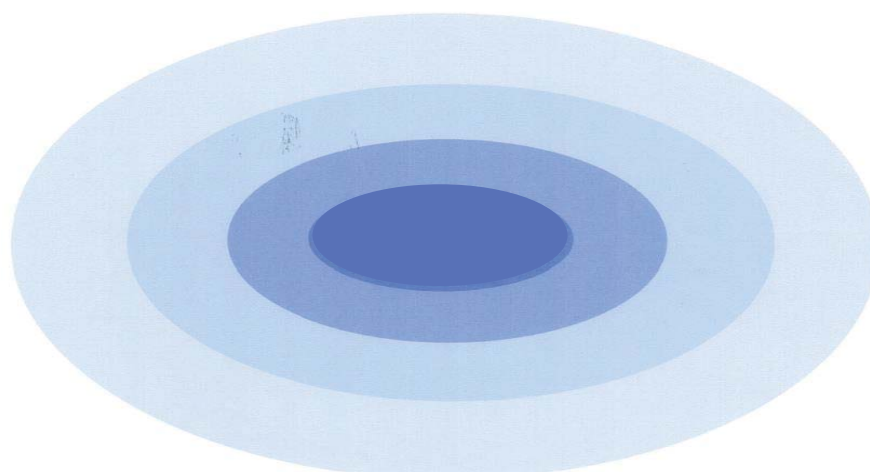


(Network template adapted from Price, 2011)

*Personal social network sheet*

Name..... ID..... Assessment No. ....

- |                          |  |                          |   |
|--------------------------|--|--------------------------|---|
| <input type="checkbox"/> | <b>The first diagnosis loop</b>                          | <input type="checkbox"/> | <b>The recurrence loop</b>                                |
| ...                      | <b>Pre-dagnosis</b>                                      | ...                      | <b>Pre-diagnosis</b>                                      |
| ...                      | <b>Undergoing investigation &amp; initial treatments</b> | ...                      | <b>Undergoing investigation &amp; initial treatments</b>  |
| ...                      | <b>Undergoing aggressive treatments</b>                  | ...                      | <b>Keeping undergoing prolonged aggressive treatments</b> |
| ...                      | <b>Completion aggressive treatments</b>                  |                          |   |
| ...                      | <b>Follow up period</b>                                  |                          |   |



*Network template*

*Personal support gaps and/or consideration issues*

.....  
.....  
.....

..... (recorder name)

