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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**

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ABSTRACT

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

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

GLOSSARY: THAI WORDS

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

