



**MONASH** University

**FACING MALIGNANCY:**

**WOMEN'S LIVED REALITIES OF BREAST CANCER**

**IN CENTRAL VIETNAM**

by

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*To the women who are courageous in so many ways.*

They constantly fight the battle against cancer despite having so few weapons in their hands. They don't give in and never lose hope no matter the losses and pains this malignancy inflicts on their bodies and lives.

*In loving memory of my grandfather who always believed in the power of education and wholly devoted his career to furthering higher education opportunities for many generations*

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## ABSTRACT

Breast cancer has become the most commonly diagnosed cancer among women in Vietnam. In less than ten years since 2012, the number of new cases has nearly doubled and in 2020, breast cancer comprised 25.8% of all new cancer cases among Vietnamese women, claiming 9,345 deaths nationwide. Despite growing attention to studying breast cancer in the last decades, little is known regarding the situated realities and the social and cultural dynamics of living with this illness in Vietnam.

This situation has prompted the development of my research which aims to address three questions: (1) How is breast cancer understood among patients and their families? (2) How do patients and their families respond to their illness? and (3) What are the structural social, cultural, and economic factors that shape the understanding and experience of breast cancer?

Guided by a critical medical anthropology approach, I conceptualise breast cancer within multilevel interactions between individual, local/community, and structural levels. I conducted a nine-month ethnographic fieldwork at both hospital and community settings in the province of Thua Thien Hue, observing and interviewing 37 women patients and their families, 11 healthcare providers, five other stakeholders, as well as holding three focus groups with 21 community people.

My study reveals that people widely perceive breast cancer is caused by food contamination and exposure to toxic environment which overlaps with dominant biomedical discourses of cancer risk factors. However, laypeople cannot identify themselves in discourses in biomedicine that focus upon individual responsibility for breast cancer. Instead, they relate the development of breast cancer to the collective vulnerabilities caused by structural forces, such as the market economy, economic hardships, toxic warfare, or the sufferings of womanhood.

Women emphasise the vital role of biomedical interventions to detect and confirm breast cancer. They act promptly to seek medical attention when experiencing suspicious signs of cancer in their breasts or when encouraged by people in their social network, rather than depending on any routine breast screening program. In their search

for a cancer diagnosis, women experience painfully circuitous trajectories that involve multiple visits across time and space and various forms of delay since their first entry into the health system.

Since a cancer status is confirmed, women and their families devote enormous resources and efforts in accessing urban public hospitals so that they can immediately pursue breast cancer treatment. They have to bear substantial costs even when covered by public health insurance and get exposed to multiple forms of vulnerability and suffering during the periods of repeated hospitalisations. The pursuit of prolonged treatment deprives women of employment and income-generating activities and exhausts household's savings and assets, thereby plaguing their life with uncertainties and burdens.

In the post-cancer life, my research reveals women's reservations about reconstructive surgery. Fears of the surgery and its accompanying risks are a prominent trigger to their decision-making against reconstruction. Women are also discouraged from seeking the procedure as they confront moral judgements against it as cosmetic surgery, but also the scarcity of specialised expertise and insufficient insurance coverage.

## PUBLICATIONS DURING ENROLMENT

- 2021 Trang Do, Pierre Le Bodic, Cally Martin, and Yolande Strengers “Increasing the Representation of Women and Girls in Computing Science and Information Technology,” Monash’s Faculty of Information and Technology: [Equity, Diversity and Inclusion](#)
- 2020 Do, Trang and Whittaker, Andrea. "Contamination, suffering and womanhood: Lay explanations of breast cancer in Central Vietnam." *Social Science & Medicine* (2020): 113360 – [DOI: 10.1016/j.socscimed.2020.113360](#) (included in the thesis)
- 2020 Do, Trang Thu and Nguyen, Anh T. Van. “They know better than we doctors do’: Providers’ preparedness for providing transgender healthcare in Vietnam, *Health Sociology Review*, 29:1, 92-107 – [DOI: 10.1080/14461242.2020.1715814](#)
- 2018 Do, Trang Thu, Nguyen T. Van Anh, Vu Xuan Thai and Nguyen T. Phuong Thao. “Seeking health care as a transgender woman in contemporary Vietnam: Access barriers and the situation of hormone use”, *Regional Journal of Southeast Asian Studies*, Volume 3, Issue 2 - [DOI: 10.13140/RG.2.2.25027.45605/1](#)
- 2018 Khuat, T.H.; Do, T.T.; Nguyen, V.A.T. et al. “The Dark Side of Female HIV Patient Care: Sexual and Reproductive Health Risks in Pre- and Post-Clinical Treatments”. *Journal of Clinical Medicine*, 7(11), 402 – [DOI: 10.3390/jcm7110402](#)

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## ABBREVIATIONS AND ACRONYMS

<b>CBE</b>	Clinical breast exam
<b>CHS</b>	Commune health station
<b>CMA</b>	Critical Medical Anthropology
<b>CPV</b>	Communist Party of Vietnam
<b>DALY</b>	Disability-adjusted life years
<b>DCIS</b>	Ductal carcinoma in situ
<b>DOH</b>	Department of Health
<b>ER</b>	Estrogen receptor
<b>FGD</b>	Focus group discussion
<b>GSO</b>	General Statistics Office
<b>HER2</b>	Human epidermal growth factor 2
<b>HIC</b>	High income country
<b>IARC</b>	International Agency for Research on Cancer
<b>IBC</b>	Invasive breast cancer
<b>LMIC</b>	Low- and Middle-income country
<b>MOH</b>	Ministry of Health
<b>MRI</b>	Magnetic resonance imaging
<b>NCCP</b>	National Cancer Control Program
<b>NCD</b>	Non-communicable Disease
<b>PR</b>	Progesterone receptor
<b>SDG</b>	Sustainable Development Goal
<b>TNM</b>	Tumour-node-metastasis
<b>UHI</b>	Universal health insurance
<b>UXO</b>	Unexploded ordinance
<b>WHO</b>	World Health Organization
<b>YLL</b>	Years of life lost

# Chapter 1.

## Introduction

It was a late morning outside the consulting department. There were not many patients waiting in the corridor and some nurses were about to leave their shifts, chatting with each other about what they would have for lunch. On a steel bench that leans against consulting room 2 sat a dark-skinned, small-built woman who was wearing an old-looking green shirt. She smiled as she noticed that I was approaching her. After several sentences of first introduction, we started to talk about her ultrasound results which she grabbed tight in her hand. She told me that the clinical examination did not indicate any malignant lump, but she was still waiting for the nurse to call her name into the mammography room.

Giang, the 38-year-old woman then introduced me to her husband who was sitting next to her. The man told me that they had left their home in Gia Lai (a province in the Central Highlands) the day before at 4 pm and arrived in Hue at almost 4 am and waited until the Hospital opened at 7 o'clock to check in. Giang told me she had skipped the local hospital and travelled by bus with her husband to the Central Hospital to have her examination immediately after discovering a lump in her breast. She frantically narrated the story about her neighbours: "My village is small, only a few hundred people, but there are many cancer patients. More, year after year. You know in my family my brother-in-law has recently passed away. He had lung cancer and could only live for two years after finding out. Most women in my village who have cancer, it is breast cancer. I was so scared my lump was also cancerous."

The story that Giang narrated when I met her during my ethnographic fieldwork in 2019 is a brief but powerful illustration of the broader picture in Vietnam where the burden of cancer has been growing rapidly in the past three decades. Like other developing countries, Vietnam has been undergoing a sweeping epidemiological transition from communicable to non-communicable diseases (Dibley et al. 2013) in which cancer has

become the second overall leading cause of death (WHO 2018). Latest data show that the number of new cancer cases has more than tripled as compared to 30 years ago and in 2020 alone, 182,563 cases were detected, which was approximately 0.19% of the total population (Anh and Duc 2002; GLOBOCAN 2020a).

Regarding breast cancer, in less than ten years the number of new cases has nearly doubled from 11,067 in 2012 (IARC 2012) to 21,555 in 2020. Now breast cancer has become the most common female cancer, comprising 25.8% of all cancer cases newly detected among Vietnamese women and claiming 9,345 deaths nationwide in 2020 (GLOBOCAN 2020a). Changes in reproductive behaviours, increase in the prevalence of overweight women, and improved diagnostic services are factors believed to explain the growing incidence of breast cancer in the country (see Trieu, Mello-Thoms, and Brennan 2015 for a summary). While data on breast cancer remains sparse at national and local levels (Jenkins et al. 2018), there is much evidence demonstrating wide geographical disparities in access to screening and breast cancer care in Vietnam. It is estimated that during the period from 2001 to 2010, only 10% of eligible women nationwide received appropriate breast screening on an annual basis (Harper 2011). Major screening activities mostly occur in large cities and there are reports of wide inequalities in access to screening services between rural and urban areas (Su and Hoang 2015). Breast cancer patients in Vietnam are often detected at later stages or younger ages than those in Western countries (Jenkins et al. 2018).

In this study, I examine the lived experience of the growing morbidity and mortality from breast cancer in Vietnam. I start with an introduction to the growing global trends of non-communicable diseases (NCDs) and particularly cancer in Lower- and Middle-Income countries (LMICs). Later in this chapter, I provide an overview of biomedical understanding of breast cancer, including its common classification, risk and protective factors, and treatment. I then go to describe the rationale for this research, along with the main questions that my thesis aims to address. This is followed with the discussion of the theory of critical medical anthropology and various concepts guiding the design of my research.

## **The global trends in non-communicable diseases**

The situation in Vietnam regarding breast cancer reflects global trends of the growing importance of NCDs as causes of morbidity and mortality in LMICs. In this section, I draw on international literature to provide an overview of the general situation in relation to NCDs' prevalence across the world and especially the burdens facing LMICs as they tackle this epidemiological transition. Globally, NCDs, including cardiovascular diseases, cancer, diabetes, and chronic lung disease, are collectively associated with 41 million or 71% of the total deaths (World Health Organization 2018) and have been recognised as a leading health priority for intergovernmental organisations and nation states in the last decades. The Global Action Plan for the Prevention and Control of NCDs 2013–2020 (Global NCD Action Plan) proposing policy options was established in 2011 and adopted by the World Health Assembly in 2013 (World Health Organization 2013). Targets specifically addressing NCDs are also included in the United Nations' Sustainable Development Goals (SDGs) 3.4 — specifically to reduce one-third of premature deaths from the four major NCDs and promotion of mental health and well-being by 2030 (Bennett et al. 2018; World Health Organization 2015).

However, it is estimated that only 12 countries across the world will achieve this target by 2030 (World Health Organization 2020) and adults in LMICs still bear double the risks of dying from an NCD as compared to those in high-income countries (HICs). Of all NCD-related deaths, LMICs now bear the heaviest burden as nearly 80% of all deaths and 85% of premature adult deaths (between 30 to 69 years) occur in those settings (World Health Organization 2018). The World Economic Forum estimated that NCDs would cause economic losses worth US\$21.3 trillion in developing countries over the next two decades due to healthcare costs and forgone productive capacities, and NCD-associated burdens would disproportionately strike populations in resource-poor settings (Jan et al. 2018; World Health Organization and United Nations Development Programme 2018). NCDs, as chronic conditions, leave long-term economic consequences for patients and their families, which also affects health and health-seeking behaviours through abandoned or discontinued treatment (Arora, Eden, and Pizer 2007; Jan et al. 2018) and lowers affected people's quality-of-life (Hanratty et al. 2007).

Regarding cancer, it is forecast that by 2040, LMICs will record 67% of annual new cases diagnosed globally (Ferlay et al. 2019). Cancer incidence and outcomes are

determined by social environments and economic status, such as income, education, housing, employment, ethnicity, and gender (for summary, see Martel et al. 2020; World Health Organization 2020). Economically and socially disadvantaged groups are often less likely to attend screening programs, have advanced stage presentation, face barriers to access timely diagnosis and standard-quality care, and thus, are more likely to experience poorer treatment outcomes and survival (see, for instance, Brand et al. 2019; Coughlin 2019; Finke et al. 2018; Foerster et al. 2019).

According to GLOBCAN statistics, nearly 2.3 million cases of female breast cancer were newly detected in 185 countries, accounting for 11.7% of all new cases and claiming 684,996 deaths (6.9% of the total cancer deaths) in 2020. Globally, one in four cancers diagnosed among women is breast cancer. It has surpassed lung cancer as the most commonly diagnosed cancer among both men and women, and become the leading cause of cancer deaths in women across the world (GLOBOCAN 2020b; Sung et al. 2021). Research around the globe has found evident disparities in breast cancer mortality by socioeconomic status, race/ethnicity, and geographical areas and that survival is closely and positively related to country income for certain cancers including breast cancer (Bray, McCarron, and Parkin 2004; Farmer et al. 2010). It is estimated that the mortality rate for breast cancer is considerably higher at 15.0 deaths per 100,000 persons in transitioning countries (countries with low or medium Human Development Index) as compared to 12.8 deaths per 100,000 persons in transitioned countries even though the latter record 88% higher rates of incidence, respectively at 55.9 cases vs. 29.7 cases per 100,000 persons (Sung et al. 2021). The incidence of breast cancer has declined or stabilised in North America or Europe during 2000s but increased rapidly in countries with historically low rates in Africa and Asia (Bray et al. 2004; Joko-Fru et al. 2020). Women in resource-limited countries are less likely to access breast screening services and treatment while more likely to present at advanced stages and die from breast cancer than those in developed countries. The 5-year survival rates vary markedly from 90% in HICs to only 66% in 12 sub-Saharan African countries (Allemani et al. 2018). Far less political attention, funding and advocacy for the prevention and control of breast cancer is recorded in LMICs than HICs (Samarasekera and Horton 2017), which exacerbates women's burdens of the disease.

## What is breast cancer?

### *Breast cancer subtypes*

Breast cancer can be grouped into multiple subtypes, which helps predict a patient's prognosis and informs therapeutic decisions (Dai et al. 2015). Based on whether the cancer has spread to surrounding breast tissues, breast cancer is classified into *in situ* (ductal carcinoma in situ - DCIS) and *invasive breast cancer* (IBC). DCIS (also described as non-invasive or pre-invasive) is a cancer that starts in the milk duct and has not been found in nearby breast tissue. Meanwhile, IBC refers to cancer that has spread into the rest of the breast tissue (American Cancer Society n.d.). According to the presence of estrogen receptor (ER) and progesterone receptor (PR) expression and human epidermal growth factor 2 (ERBB2, formerly HER2), breast cancer comprises three subtypes: hormone receptor positive/HER2 negative, HER2 positive, and triple-negative (Waks and Winer 2019).

When diagnosed, the stage of breast cancer is determined from I to IV on the TNM (tumour-node-metastasis) staging system where IV suggests the detection of distant metastatic disease. The therapeutic goals for patients diagnosed with non-metastatic breast cancer are to eliminate the cancerous tumour and prevent recurrence while for patients initially presenting with distant metastases, the goals are to prolong life and symptom palliation (Waks and Winer 2019). The five-year breast cancer survival rates vary from 85% to 100% among stage I patients and the worst outcomes are observed among patients diagnosed at stage IV and with triple-negative breast cancer (Chavez-MacGregor et al. 2017; Waks and Winer 2019).

### *Risk and protective factors*

Epidemiological research has identified a number of factors that are associated with increased risk of female breast cancer, including *age*: as women get older, their risk of getting breast cancer increases (McPherson, Steel, and Dixon 2000). The risk of developing breast cancer rises among people with *genetic predisposition* (DeMichele and Weber 2000), that is: having a family history of breast cancer (Inumaru et al. 2012; Zucchetti, Peccatori, and Codacci-Pisanelli 2020); or carrying a mutation in BRCA1 or BRCA2 genes (Dyrstad et al. 2015). A woman's *breast density* (Nelson et al. 2012) or

experience of certain *health conditions*, such as previous benign breast disease (Dyrstad et al. 2015); postmenopausal obesity (Magnusson et al. 1998); or diabetes mellitus (Jordan et al. 2009) are also associated with increased likelihood of having breast cancer. Research additionally shows the positive relationship between breast cancer and *lifestyle factors*, such as excessive alcohol consumption (Collaborative Group on Hormonal Factors in Breast Cancer 2002) and smoking (Gaudet et al. 2013; Macacu et al. 2015).

Factors related to the *hormonal environment* to which the breast is exposed from menarche to menopause (Million Women Study Collaborators 2003; Pike et al. 1983); or exposure to exogenous hormones, such as oral contraceptives and hormone replacement therapy (Anothaisintawee et al. 2013; Collaborative Group on Hormonal Factors in Breast Cancer 1996), are also found to be related to the development of breast cancer. Regarding the *external environment*, exposure to ionising radiation is believed to increase breast cancer risk (Carmichael, Sami, and Dixon 2003). Meanwhile, considering *protective factors*, physical activity (Inumaru et al. 2012), pregnancy, and lactation (Anothaisintawee et al. 2013; Zucchetti et al. 2020) are all shown to be independently associated with a reduced risk of having breast cancer.

### ***Biomedical treatment of breast cancer***

Breast cancer treatment is determined according to various factors, most importantly, the type and stage of cancer. In most cases it involves some form of surgery, including radical mastectomy which requires the removal of the entire breast and surrounding tissues, partial or modified radical mastectomy, lumpectomy, or breast-conserving surgery in which only the tumour is removed and breast radiation often follows. Some forms of surgery to remove nearby lymph nodes might also be required when there is sentinel lymph node involvement, for instance, sentinel lymph node biopsy and axillary lymph node dissection (Sledge et al. 2014). Patients can choose reconstructive options to restore the breast's shape which can be performed at the same time with a mastectomy (immediate reconstruction) or as a delayed procedure after a mastectomy/lumpectomy and other forms of treatment have been completed. Depending on how advanced it is, and whether or not the cancerous tumours are hormone receptor-positive or the cancer cells are HER2-positive, a patient might need localised or systemic treatments. In case of localised treatments, the patient might only need to treat the tumour with a surgery and/or radiation whereas drugs that affect the whole body will be prescribed when systemic

treatments are additionally needed. In the latter case, a patient might need to undergo chemotherapy, endocrine (hormone) therapy for 5 to 10 years, targeted therapy, and/or immunotherapy (for summary, see American Cancer Society, undated).

## **Why studying the lived experience of breast cancer in Vietnam?**

But breast cancer is not just a biological disease, it is also a social and economic crisis for its sufferers. Despite growing attention to studying breast cancer in Vietnam in the last decades, a recent scoping review points out that there are minimal in-depth qualitative studies on breast cancer from women's perspectives or those examining cultural, social, economic, and political context that influence the perceptions and behaviours concerning breast cancer care (Jenkins et al. 2018). Most research to date comes from clinical and epidemiological perspectives which predominantly deploy quantitative approaches to explore the disease's morbidity (Nguyen, L. H., Laohasiriwong, and Stewart 2013); associated risk factors (Nguyen, J. et al. 2016; Nguyen, L. H., Laohasiriwong, and Stewart 2013; Trieu et al. 2017); cost analysis and assessment of treatment, or intervention programs (for instance, Nguyen, H. L., Laohasiriwong, Stewart, Nguyen, & Coyte 2013; Nguyen, L. H. et al. 2013; Nguyen, T. T. C. & Nguyen, T. T. T. 2014). While providing valuable insights into the disease patterns or the effectiveness of the medical system in responding to Vietnam's epidemiological transition, such research has not yet illuminated the depth and complexity of women's lived realities, nor how social and structural factors figure in their experiences of breast cancer. Neither do we understand about how women make sense of this health condition and how they attend to breast symptoms and access breast screening and breast cancer care. There is also scarce knowledge as to how the health system responds to the growing incidence of breast cancer in the country through public health programs and policies, and how these programs/policies are approached by people affected by this disease.

This situation has prompted the development of my research which explores the situated realities and specificities of breast cancer in a particular context of Vietnam, and the social and cultural dynamics of living with this illness. In constructing women's lived experiences of breast cancer within broader context, my study demonstrates the structural vulnerability and health access problems facing women during and in the aftermath of a

life-threatening disease. In this way, my research shows how living with a chronic health problem for people in resource-constrained settings is mediated by but also contributes to social and economic inequalities. My research also illustrates that while constrained by dominant factors at a structural level, people's ways of dealing with this devastating medical condition are not devoid of meaning and agency. Throughout my thesis I show that people often draw on various logics to craft their understanding of the illness, as well as deploy care-seeking strategies that resonate with traditional and contemporary circumstances shaping their life experiences. By looking into patients and their families' understanding of breast cancer and the social burden of living with this pathological condition, my research addresses the current theoretical and empirical gap in relation to scholarship on cancer lived experiences in a developing country context. With new insights from social science perspectives, my hope is that this study will also contribute to informing the design of socially and culturally appropriate care and more effective supporting programs for women living with breast cancer in different parts of Vietnam, but also other resource-constrained settings where the morbidity and mortality of breast cancer are both increasing rapidly.

## **Research objective and questions**

My research aims to answer a central question: *How do women experience breast cancer in Central Vietnam?* To achieve its ultimate research goal this thesis addresses three major research questions:

**Question 1.** *How is breast cancer understood among patients and their families?*

I illustrate the meanings that women provide to explain the occurrence of their illness and their notions of breast cancer curability, care, and survivorship. I explore how such understanding is embedded within dominant cultural constructions of gender, health, and illness, but also the interplay with biomedical views delivered to them via formal healthcare sector and public health education programs.

**Question 2.** *How do patients and their families respond to their illness?*

To address this question, I explore women's practices of seeking breast cancer screening and diagnostic services in response to their discovery of symptomatic breasts. I attend to how the women and their families manage cancer treatment and care after the arrival of

breast cancer diagnosis. I also demonstrate the different ways that the advent and treatment of breast cancer impact upon their lives and well-being, and how affected people cope with the burdens of living with breast cancer.

**Question 3.** *What are the structural social, cultural, and economic factors that shape the understanding and experience of breast cancer?*

In response to this question, I illustrate how the availability of breast cancer services, quality treatment options, and the continuity and delivery of care are shaped by contextual factors, including the geographical imbalance of oncology services, an under-resourced healthcare system and insurance scheme, and the limited institutional protection in case of a life-threatening health event, as well as within the emerging importance of peer support networks. My thesis unfolds the multiple ways that the life conditions and social standing of breast cancer sufferers are mediated, altered, and intensified by those influences at the structural level.

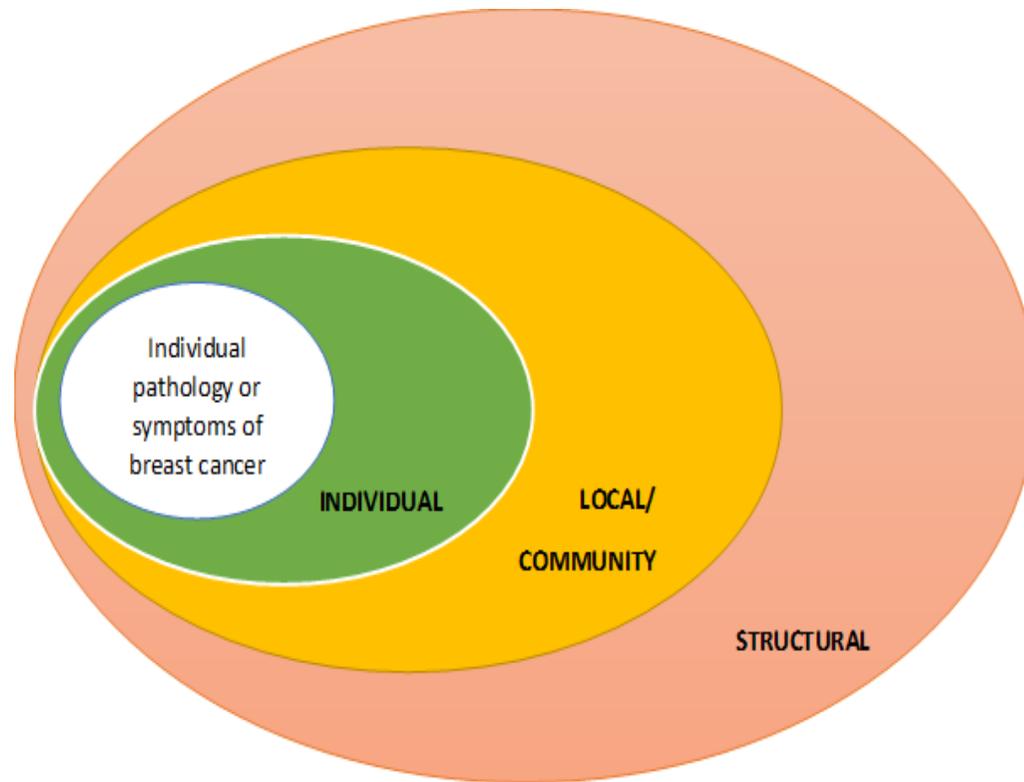
## **Conceptual premises**

My research contextualises women's lived experiences of breast cancer within the broad socio-economic and political context of Vietnam and is based upon the approaches of Critical Medical Anthropology (CMA) where illness and health are situated within large socio-economic and political forces that shape meanings, beliefs, and behaviours (Baer, Singer, and Susser 2013). CMA seeks to understand the power relations affecting biomedicine and their impact on health service delivery at individual, microsocial, intermediate and macrosocial levels. Health inequalities resulting from political and economic forces are the dominant emphasis of CMA. CMA views disease as not only a biological but also a social product, and endeavours to understand the social origin of all diseases. CMA recognises a number of structural economic and political barriers to achieve well-being, including social inequality, class, gender, racial and other discrimination, poverty, structural violence, social trauma, and relative deprivation, which are argued to leave detrimental effects on people's health, both at individual and collective levels (Baer et al. 2013; Dressler, Oths, and Gravlee 2005). Studies informed by political economic medical anthropology extend the base of cultural construction and historically specific social contextualisation by addressing the empirical particularities surrounding

sickness and healing, medical pluralism and the socially constructing process of disease (Frankenberg 1980; Morsy 1990).

Within the CMA's framework, health is "an elastic concept" rather than a state of being (Baer, Singer, and Susser 2013, p. 5). It can be understood by analysing the "vertical links" (Mullings 1987) where the patterning of human relationships, configuration of social behaviours, conditioning of collective experiences, re-disposition of local ecologies, and situation of cultural meanings are determined by the dynamics of political and economic forces, including forces of institutional, national, and global scale. To study health experience and behaviours, the examination of both micro and macro levels, and both within and beyond the health arena is critically required in order to understand the social relationships and social processes within the plural medical system (Singer 1989a). CMA's emergence is regarded as a reflection of both a turn towards the adoption of political economy approaches in anthropology and an effort to engage and extend the broader political economy of health tradition (Baer, Singer, and Johnsen 1986; Morgan 1987; Morsy 1990; Singer 1989a, 1989b).

My conceptual framework situates the lived realities of breast cancer within multilevel interactions to illuminate the interplay between an individual biological body with socio-cultural environments (Lock and Kaufert 2001). Placed at the centre of the inner-most circle of the framework are the two central areas for exploration: understanding and experience of breast cancer as a pathological and biological condition (Figure 1. 1).



**INDIVIDUAL LEVEL**

Breast meanings	Screening
Aetiologies	Diagnosis
Abnormal symptoms	Treatment
Agency	Coping

**LOCAL/COMMUNITY LEVEL**

Family or “therapy management group”	Healthcare providers
Community people	Available services (screening, diagnostic, treatment)
Peer patients	Social norms

**STRUCTURAL LEVEL**

Market economy	National policies/programs, laws on NCDs & breast cancer
Inequality	Universal health insurance
Poverty	Social protection
Gender	Breast cancer support network
Geography	Traditional health beliefs
Culture	
Media	

**Figure 1. 1.** Social understanding of Breast Cancer

The green inner-most circle is the *individual* level at which my analysis aims to explore women's perceptions of women's breasts and breast cancer, including their understanding of aetiologies, abnormal symptoms and beliefs associated with breast cancer treatment. I also examine the practices of attending to breast symptoms, seeking screening and diagnostic services, as well as accessing breast cancer treatment, the experience of coping with this disease, and the agency that the women exercise as they interpret and live with breast cancer.

The yellow circle illustrates the *local/community* level. At this level of analysis, my study examines the interaction between the women with people in their kin or what Janzen and Arkininstall term "therapy management group", that is a set of close kin that comes into the management of illness when an individual becomes ill," as well as that with healthcare providers (1978, p. 4). In Vietnam, treatment of a serious illness like cancer is a collective endeavour, rather than a mere individual affair, in which family members collectively make decisions about treatment and co-shoulder its costs. The relations between patients and their healthcare providers, as well as other peers and people in their communities are analysed at this level. Other important factors to be considered include the presence of screening, diagnostic, and treatment services related to breast cancer available in the locality, and social norms related to illness and care-seeking behaviours.

The *structural* level is illustrated by the largest outer-most orange circle. Within this level, I examine structural factors which influence the experience of living with breast cancer. Analysis at this level considers the wider cultural, economic, and political context of Vietnam, including the market economy, poverty, class, social and geographical inequalities, but also cultural constructions of gender roles, femininity and the female body, and traditional health beliefs. I also review current laws, national policies and public health programs regarding the prevention and control of NCDs and breast cancer in specific, as well as social protection policies applicable for breast cancer patients. Such frameworks have direct impacts on the implementation of health-related programs and projects "on-the-ground" level and the experience of living with this disease. An analysis of existing regulations within the universal health insurance (UHI) is critically important to understand women's experiences and their decision-making process about screening and treatment following a cancer diagnosis. The role of media and the influence of the non-governmental civil society sector which is referred to as the "counter-hegemonic

force” within the CMA framework (Baer et al. 2013, p. 49), specifically patient activism via peer support network, is also taken into account. Patient activism creates a form of bio-sociality – that is the social identities and practices of a group of individuals sharing a biological condition (Rabinow 2010), which has become central to understanding collective practices enacted by alliances united by a similar disease (Petersen, Schermuly, and Anderson 2019; Sulik 2010), but also offered a tool to health educators as they engage with and assist affected communities (Davis 2011). In Vietnam, patient activism at grassroot level play an increasingly important role in enabling patients to voice their medical concerns, mobilise resources to gain support or facilitate access to healthcare services, and influence social and political changes (for instance, see Oosterhoff and Bach 2013; Vu 2014 regarding the role of support groups for different medical conditions). In particular, the past years have seen rising popularity of breast cancer patient networks which have become a significant force impacting the discourses surrounding breast cancer and the delivery of breast care services via awareness raising campaigns and social movements.

In addition, my research is built on the concepts of structural vulnerability, social suffering, and meaning-making within local moral worlds. As an anthropological inquiry, my study adopts an inductive approach that allows me to refine those premises or develop theoretical perspectives grounded in the data collected within my research context.

### ***Structural vulnerability***

My research draws upon “structural vulnerability” as a concept revealing the systemic inequalities in relation to women’s access to breast screening and cancer care. Structural vulnerability was developed from the concept of “structural violence” which Johan Galtung first coined to define “the indirect violence built into repressive social orders” (Galtung 1969, p. 173). Medical anthropologists, most notably Paul Farmer throughout his works on HIV/AIDS in Haiti, deployed this as their analytical framework to reflect upon the devastating effects of unequal distribution of social and economic resources on illness and mortality (see Farmer 2004). Quesada and colleagues (2011) later proposed the concept of “structural vulnerability” when researching Latino undocumented migrant labourers in the U.S to highlight the challenges faced by this marginalised population which were created by one’s positionality resulting from exploitation and discrimination.

In my research I draw on the concept of structural vulnerability to explore people's narratives of their susceptibility to cancer and their powerlessness in acting to reduce exposure to biomedically-established cancer risks due to their positionality within a post-war market-driven society. In Chapters 6 and 7, I also show the application of the concept in revealing the numerous difficulties women in my research context encounter when accessing breast cancer-related services due to structural and systemic barriers, including: the absence of a national screening program; the uneven distribution of oncology expertise and facilities between local- and tertiary-level health facilities; overcrowding and understaffed status at major urban hospitals; improper public health insurance; and a resource-constrained welfare state. Throughout my explorations, I illustrate the multiple ways that different forms of structural vulnerability, including for instance, patients' geographic location, poverty, or employment in the informal sector, form and exacerbate their experience of seeking breast cancer care, the quality of care, and health outcomes they receive, as well as the social burden of living with such a chronic acute disease.

### ***Social suffering***

“Social suffering” as defined by Arthur Kleinman and colleagues is “an assemblage of human problems that have their origins and consequences in the devastating injuries that social forces can inflict on human experience” (1997, p. ix). This concept is central to understanding the lived experience of an illness within a broader context as it highlights the analytic focus on how people's suffering is “caused and conditioned by society” (Wilkinson & Kleinman 2016, p. 14). Medical anthropologists and sociologists have used social suffering as an analytical frame to explore the social origin of people's suffering, its manifestations, and the impacts that suffering leaves on their health and everyday life. They situate suffering at the intersections of both individual and collective experience, concerning how social structural contexts shape and moderate such experiences. This approach avoids examining social problems as individual pathology while not neglecting the subjectivity and intersubjectivity of an illness, and the lived experiences of suffering and healing (see, for instance Broom et al. 2018; Kwiatkowski 2019; Lora-Wainwright 2013; Wilkinson & Kleinman 2016). In such analysis, equal attention is given to how people interpret their illness suffering against the backdrop of their own experience and the social conditions that they live in (Lock and Schepers-Hughes 1996; Wilkinson and Kleinman 2016).

In attending to the experience of cancer across different societies, the concept of social suffering allows for the examination of the bodily experiences of chronic ill-health, but also how the process of suffering experienced by people living with cancer and their families is shaped by and moderated by social context. Drawing upon this concept, in their study in India, Alex Broom and colleagues (2018) highlight that patients living with cancer experience shame, fear, and silence resulting from cultural ontologies of cancer in that context where the disease is largely unknown. Cancer afflicts individual bodies, but the bodies are inseparable from social relations and forces (Tapias 2006), and suffering can be an individual and a collective matter at the same time (Kleinman et al. 1997, p. xxiv). In her ethnography in rural north-east Sichuan province of China, Anna Lora-Wainwright (2013) maintains that through the experience of cancer, family relations are negotiated, reinforced, or undermined, and that these processes create a social and moral world. While some family members transport cancer sufferers to the hospital or cook nutritious foods, others migrate to bigger cities to look for better paid employment so that they can provide financial support to the sufferer. In the same vein, my study demonstrates how people understand breast cancer not only as a pathological condition but a form of both individual and collective suffering. I unpack the different conditions framing the perceptions and care-seeking practices and the different forms of suffering that permeate the everyday life of breast cancer patients and their families.

### ***Breast cancer in local moral worlds***

Because life is all that matters to us, as Kleinman (2007, p. 1) maintains, it is inevitably *moral*. Moral experience includes all existential activities, referring to the flow of interactions between ordinary people. Kleinman (1988) has called illness a “sponge” that soaks up the significance from both an individual and the society from the sick person’s world (1988, p. 31). Phenomenologists, such as Merleau-Ponty (2013), maintain that the human body is not just an object, but the centre of all our being and acting in the world and place the intersubjective nature of experience as their centre of analysis. They pay attention to people’s “life-worlds” which are the individuals’ social world of shared experience (Schütz et al. 1971, p. 312). Given the intersubjective and interpersonal nature of care seeking and provision, that experience involves encounters between what anthropologists term the “local moral worlds” (Kleinman 1999; Yang et al. 2007).

To understand the experience of living with cancer, ideologies related to gender roles and familial relationship need to be considered as the practices of seeking cancer care and caring for cancer patients are invariably imbued with moral connotations. In Chapter 5, I explore how the local understanding of poverty, hard work, motherhood, and harmonious family relations affects laypeople's interpretations of breast cancer aetiologies. Throughout the process of searching for illness explanations, people simultaneously articulate a complex range of attitudes towards the ongoing context of social order and reflect critiques of established and modern values.

My thesis also shows how cancer sufferers act and are regarded as moral subjects as they make decisions about pursuing or forgoing treatment given the chronicity and enormous cost of breast cancer treatment. People encounter moral dilemmas resulting from such decisions (Lora-Wainwright 2013) as to whose needs should be sacrificed and in many circumstances, people are forced to choose between one's pressing health need and the well-being of other family members (see Chapter 7). The women's pursuit of treatment is also subject to ideals for a virtuous woman and a good cancer citizen (Chapter 8) who knows how to use the limited resources for survival and family economy rather for their own sake.

Breast cancer, as can be seen in my thesis, redefines moral worlds. This is reflected in Chapter 5 of my thesis in which my participants evoke the narratives that equate chemical exposure with hard work to account for breast cancer. In this way, they shift responsibility away from the sufferer for a past behaviour that is morally condemned. Chapter 7 shows how the sufferers' position within their family and local communities are altered by the occurrence of breast cancer. For instance, to mitigate the financial burden associated with cancer treatment, sufferers attempt to mobilise social support by disclosing their cancer status, thereby reshaping others' moral obligations to help people affected by a previously stigmatised condition. Breast cancer, therefore, prompts people to search for new meaning in their lives and values, and demands the formation of an alternative, local moral world.

### ***Agency and meanings***

While it is crucial to unveil the socio-economic and political structures in which the experiences of living with breast cancer are embedded, it is also important not to deny

nor constrict the agency of the sufferers (Gammeltoft 2006; Hannig 2017) and the meaning-making process (Kernan and Lepore 2009) they undergo when dealing with their health condition. In my research, I do not downplay the enormous burdens presented to breast cancer patients and their families as their life is ravaged by the occurrence of this illness. However, I extend my analytical explorations to the significance of women's agency and their attempts to find meaning in their struggles with the physical and social hardships caused by breast cancer because the mere focus on structural factors incurs the risk of rendering those forces beyond culture and imposing a "metanarrative of suffering" (Hannig 2017, p. 7).

A meaning-centred approach in parallel with the analysis of poverty and political forces has attracted the attention of medical anthropologists when studying the experience of illness and suffering. In *Death without Weeping* ethnography, for instance, Nancy Scheper-Hughes (1992) explains Brazilian mothers' experience with infant mortality in a local context characterized by extreme scarcity and economic deprivation. While paying attention to social and economic injustice, Scheper-Hughes is also concerned with the mothers' lived experience when child death becomes common and as a strategy to survive in that circumstance, the mothers practice emotional distancing from their infants. In the context of Vietnam, Tine Gammeltoft (2006) expands on the concept of social suffering when she explored the experience of late-term abortion among unmarried young women in the capital city. She was concerned with how social forces, such as societal constraints and dominant moralities that subordinate women to men, inflict harms onto the young women. On the other hand, Gammeltoft pays equal attention to describing the narratives that reflect how the women find meaning in suffering and seeks abortion out of desire and ambition, which leads to her argument that "suffering implies agency just as agency implies suffering" (2006, p. 600).

Literature on the lived experiences of breast cancer has emphasised that as women experience a new sense of identity post-cancer diagnosis, they do exercise agency in the process of finding new meaning, which provides them with a sense of control over an uncertain life period (cf. Wright 2016). In the same vein, as we see in later chapters of this thesis, the women and their families are not passive victims of societal constraints and structural forces, and even in extreme situations, they can still draw on cultural and social resources to carve out their understanding of the illness and care-seeking behaviours that are meaningful to local circumstances and values. In this respect, the attention to the

concept of agency allows us to understand how breast cancer is experienced *in situ* and gain valuable insights into how people find and maintain a sense of meaningfulness (Das 1995; Harris 1989), as well as their capacity to take action (Gammeltoft 2006) in response to a disordered situation. In Chapters 5 and 6, I reveal that participants build their own frameworks to explain the causes of their illness based on biomedical risk models and draw upon public health messages to attend to abnormal symptoms in their breasts. However, they cannot recognise the narratives of breast cancer risk and early detection that focus upon individual lifestyle factors and responsibility. Their frameworks are instead crafted with a range of meanings that resonate with the historical and contemporary circumstances shaping their life experiences. The importance of considering the women as agents of their choice is also highly relevant when analysing women's practices of seeking medical attention. Specifically, throughout Chapter 8, in narratives related to decision-making about restoring their breast post-mastectomy, the women often note dominant structural constraints limiting their choice, for instance, social condemnations, gender expectations, or insufficient health insurance. However, their stories are not devoid of agency and an element of choice. The women patients choose to forgo reconstruction in order to maintain their status as virtuous women and good cancer citizens, but their decision is also one made to defy patriarchal ideals for women's breast wholeness and resume a sense of control and ownership over their bodies.

## **Outline of the thesis**

This thesis is drawn upon the data I collected during my ethnographic study in Central Vietnam and comprises nine chapters. The organisation of the remaining chapters is as follows:

In *Chapter 2*, I review social science research in relation to breast cancer beliefs and women's experiences of cancer across different cultural and socio-economic settings. I describe the wide-ranging metaphors women deploy to make sense of this pathological condition and the fears associated with cancer and its ramifications. Chapter 2 then outlines how cultural constructions of femininity and womanhood play out in the ways women understand and approach their illness. Subsequently, it illustrates how women respond to the uncertainty that the occurrence of breast cancer brings about. This chapter

then looks at the literature discussing the health system barriers that influence women's access to cancer screening and related care services, and the structural context that shapes women's experience of treatment and care, and the life conditions of cancer patients and their families. Lastly, the chapter refers to the most recent ethnographic studies exploring the lived experience of cancer in the context of Vietnam.

In *Chapter 3*, I provide information regarding the socio-economic and cultural context of Vietnam. I describe the influence of Confucianism and Buddhism on Vietnamese people's lives, particularly in relation to constructions of gender roles and worshipping practices. This chapter then outlines "traditional" health beliefs, including Buddhism-influenced concepts related to the causes of ill health, yin-yang principles, and popular beliefs about food that continue to impact upon people's everyday healthcare practices. Subsequently, I present the structure of the health system in Vietnam, its recent changes post-*Đổi Mới (Renovation)* 1986, and the operation of the national health insurance scheme. Major trends regarding the country's epidemiological transition to NCDs and relevant national policies and programs are also reviewed in this chapter. The final section of Chapter 3 introduces Thừa Thiên Huế province and Hue Central Hospital where I situated my ethnography.

In *Chapter 4*, I present the methodology of this research. I provide an account of the ethnographic setting and the challenges I was faced with when seeking access to the hospital sites, as well as the different stages of building rapport with my research participants. Next, I present in detail the different methods of data collection which I deployed during fieldwork, including observation, interviews and focus groups, along with the description of my informants. Later, I specify ethical issues emerging from my fieldwork and close with a description of the process of data management and validation.

From Chapter 5 onwards, I present the findings obtained from my ethnographic fieldwork. In *Chapter 5*, I explore the meanings of women's breasts in local beliefs and the varying frames that people draw on to explain the causes of breast cancer. In viewing cancer as a modern disease which is not recorded in the past, my participants often construct their understanding of breast cancer aetiologies based on prominent biomedical and epidemiological discourses related to cancer risk prevention and control, for instance, attributing the development of cancer to toxic food, the contaminated environment, or prior breast ailments. However, I demonstrate in this chapter how women locate such knowledge in a framework that is meaningful to the situated history and their life

circumstances. In that sense, this chapter illuminates how cancer aetiologies become a means to articulate people's critiques of the ongoing social context of Vietnam related to modernisation, market economy, the legacy of warfare and traditional gender roles.

From Chapters 6 to 8, I focus on certain health experiences along the cancer care continuum, beginning with the discovery of a breast lump leading to a breast cancer diagnosis, until the period of pursuing hospital-based treatment, and obtaining care in the post-cancer life. In *Chapter 6*, I look into women's initial discovery of a breast lump and how they attend to their symptomatic breasts. I explore the various premises people draw upon to assess the benign or malignant potential of a breast symptom and the respective methods they practice when treating a lump perceived to be non-threatening. Chapter 6 also describes the circumstances when women decide to seek medical attention and their encounters with the health sector. In examining the initial experiences of breast cancer screening and detection, I illustrate the availability of routine breast screening, women's preferences for breast care services, but also the non-linear trajectory to obtain a diagnosis of breast cancer. I also examine women's retrospective accounts reflecting the emotions they experience and the ways they interpret the confirmation of breast cancer.

In *Chapter 7*, I begin with the treatment trajectories of two women, H $\ddot{O}$ ng and Long. These two women had varying experiences with breast cancer by the time of my ethnography: H $\ddot{O}$ ng was undergoing chemotherapy after she was diagnosed a couple of months prior to our first encounter, whereas Long had lived with breast cancer for nearly eight years and repeatedly went back to the hospital to obtain her monthly hormone therapy. The two women also differed in the ways they approached and managed their illness due to the differences in their treatment stage and socio-economic status. However, their narratives exemplify the situation facing many of the other women patients I met throughout my fieldwork. Following the presentation of these two cases, I discuss the consistencies in their treatment trajectories and in doing so, demonstrate the crippling and manifold burdens of pursuing breast cancer treatment. I describe the experiences of undergoing prolonged hospital-based treatment for not only the patients, but also their accompanying caregivers. Later in this chapter, I examine the long-lasting impacts on the welfare of the sufferers beyond the hospital settings caused by the pursuit of breast cancer treatment given its chronicity and enormous costs. Eventually, this chapter illustrates the availability of institutional support for people living with acute medical conditions like

cancer and how the patients navigate the state's social protection policies when coping with their illness.

Women's decision-making regarding their bodies post-mastectomy is the focus of *Chapter 8*. I first present a case study of Hải-Anh, a woman from a Northern province who sought breast reconstruction in Hue due to the Central Hospital's prestigious reputation for this type of surgery. However, though breast reconstruction was frequently discussed among my participants, only a small number of women had enrolled for the procedure. I illustrate the different logics provided by women for their decisions about reconstructive surgery as they grapple with their mastectomised body. I explain how people perceive the importance of restoring the lost breast post-mastectomy considering the meanings attached to women's breasts. Throughout the chapter, I show how the fears over the procedure's invasiveness, but also the perceived likelihood of cancer relapse or metastasis discourage women from having reconstruction. Further, this chapter demonstrates how their decision is heavily influenced by a common perception linking reconstructive surgery with a cosmetic practice. In order to explain women's decision-making within its wider context, this chapter also unpacks the influential factors at the health-system level, notably, patient-provider communication and issues related to insurance reimbursement. The nuances of women's agency in making decisions about their mastectomised body and defying the existing social gendered norms is also discussed in this chapter.

Finally, *Chapter 9* summarises the key findings demonstrated throughout the thesis in relation to the research questions developed earlier. It then highlights its major contributions to expanding the scholarship on the lived experience of breast cancer. The last chapter also draws out practical implications for the process of drafting and implementing appropriate interventions to enhance women's access to quality breast cancer care services and better support those living with breast cancer in the particular context of Vietnam, as well as in other resource-constrained settings.

## Chapter 2.

# Understanding Breast Cancer: Social Science Perspectives

### Introduction

Social scientists have sought to document wide diversities regarding cross-cultural beliefs about breast cancer, as well as the complex realities of women's lives as they experience cancer within political economies. Through their accounts from different socio-economic and cultural settings, they underscore that the knowledge and experience of cancer is profoundly dependent on the cultural and religious configurations of a woman's body, health, and illness; the local ideologies of gender roles, womanhood, and femininity; and more importantly, on the varying political-economic contexts that shape access to breast care services and the life conditions of affected people. In this chapter I review existing social science scholarship regarding the construction of breast cancer knowledge and women's responses to the disease across various cultures and societies. My review points out the wide-ranging metaphors women deploy to describe this pathological condition and their apprehensions about the associated detrimental ramifications for their psychological, physical, and social well-being. The literature I review also emphasises how cultural constructions of femininity and womanhood affect the ways women approach their illness and mediate the bodily disfigurement caused by breast cancer. What also emerges from the literature reviewed here are women's varying responses to the uncertainty of breast cancer. This chapter then examines factors at the health system level that are found to influence women's access to breast screening and cancer care services. Following this, I review existing accounts that place breast cancer within the political and economic context and reflect how this disease is predicated upon but also amplifies inequalities at different levels. Finally, the chapter describes the most recent ethnographic studies exploring the lived experience of cancer in the context of Vietnam.

## **Fear and metaphorical associations of cancer**

Particular illnesses often carry meanings that reflect social concerns and are related to the historical and cultural contexts surrounding the disease rather than its particular physiological effects (Sontag 1979; Young 1982). As a serious and life-threatening disease with unclear origin and uncertain treatment outcomes, cancer has become more than a clinical condition but also a metaphor for many terrors of daily life (Helman 2000). There has been significant attention devoted to studying how people in different cultures reflect on their beliefs of this illness.

Tracing back to literature in the twentieth century, Susan Sontag reveals how cancer is used as a metaphor for evil in Western societies (Sontag 1979). According to Sontag, the media, literature and popular discourses depict cancer as a type of unrestrained and chaotic evil force that is unique to the modern world, with cells that destroy the natural order of the body and society. The metaphors associated with ill health such as cancer can seriously affect the ways sufferers perceive their own condition as well as the behaviours of others towards them.

In another Western setting, a study on the embodiment of cancer among Italian women (Gordon 1990) finds that breast cancer is often described as “a type of animal” or “thing.” It is something bad that destroys the good and the healthy. Women call it a “wild beast,” a “black tarantula,” or a “monster.” They perceive cancer as an external force, something “foreign” to the body, attacking it from outside that they cannot grapple with and by which they are eventually defeated. Wide-ranging metaphors have also been used to describe cancer, including as an “alien thing”, connected with creatures having many legs, for instance as an “octopus with lots of arms and suction cups,” “amoeba,” “spider” with sharp legs and antennas, “worm” inside beautiful fruit, or as a “parasite,” as noted in an Israel-based study (Weiss 1997).

Metaphors are not simply a linguistic indication but actually based on the embodied experience of the individuals (Gibbs and Franks 2002; Helman 2000). Patients create metaphors to make sense of their chaotic world caused by cancer (Reisfield and Wilson 2004), convey inexpressible emotions and experiences, or exercise control through the imagery they choose (Skott 2002; Bennett et al. 2006). For instance, patients often use “journey” metaphors to highlight the difficulties they undergo as a cancer sufferer on one hand while on the other hand, it is used to express a sense of control over their illness

experience. The use of journey as a metaphor has become pervasive in both medical and popular language in the twentieth first century as cancer is more widely perceived and experienced as a chronic illness rather than an acute event (Reisfield and Wilson 2004).

Along with “journey,” military metaphors are widely deployed, whereby a “war on cancer” can characterize a national approach to control the disease (Broom 2001). Meanwhile, media usually adopt martial analogies to explain the disease process (Harrington 2012) and patients describe themselves as “fighters,” with a “desire to fight and win” (Semino et al. 2017, p. 63). In an autobiography written by a physician, Madeleine Meldin refers to her accounts of breast cancer as a “battlefield” and herself as “the one who could die in the middle of it.” To her the breast surgery is a “removal of the enemy” in which she and the oncologists “kill the remaining infiltrators and terrorists” (2013, p. 36). The image of fighting indicates the serious and invasive nature of the cancer process and simultaneously reflects a sense of fear and terror facing patients when they are diagnosed (Penson et al. 2004; Reisfield and Wilson 2004).

Women often associate cancer with fear, extreme pain and full of suffering (Bottorff et al. 1998b; Mathews, Lannin, and Mitchell 1994a; Gordon 1990). For most women, breast cancer precipitates fears because they cannot observe it and it is “hidden within the body” (Bottorff et al. 1998, p. 2078). Assuming that breast cancer is a foreign, disease that only affect white women, or themselves not having the risk of breast cancer is often found among women from culturally and linguistically diverse backgrounds (Bottorff et al. 1998; Hubbell, Luce, and McMullin 2005; Taha et al. 2012). For instance, Jordanian women are found to maintain that there is no reason for the development of cancer which they believe comes suddenly or that only Almighty Allah knows about its causes and with such belief, they often find themselves in a state of fear and denial when hearing about the disease (Salman, Zoucha, and Nawafleh 2018).

Breast cancer is also feared because of the social stigma towards the disease. In many cultures, a family with a cancer patient is considered as one with an unhealthy status. Having breast cancer in particular is viewed by South Asian and Middle-Eastern women as jeopardising a woman’s status and the honour of her family, which can impede the marriageability of her children (Baron-Epel et al. 2004; Bottorff et al. 1998; Taha et al. 2012). A study in South Korea, for instance, reveals that in the past when cancer was rare, families with cancer patients might face stigma of shame, ill fate or be considered as those with moral troubles, and as such they attempted to conceal the news of the cancer

occurrence from people beyond their close kin (Cho et al. 2013). In the same vein, Chinese immigrants in Australia regard cancer as a private issue that should be circulated only within their family. Believing cancer to be a bad omen and bad luck, they avoid mentioning the word cancer and instead using euphemisms, such as “lump” or “tumour” or the typical Chinese term *nham* (meaning growth) when being interviewed (Kwok and Sullivan 2006).

### **Loss of womanhood and femininity**

In any given location, a woman’s experience of cancer cannot be considered separately from the social expectations of femininity and womanhood (for instance, see Gibson et al. 2017; Yap 1998) and local ideologies of her roles and duties as a mother and wife (Banning and Tanzeen 2014; Cebeci, Yangin, and Tekeli 2012). Breast cancer is widely perceived to incapacitate women from fulfilling their childrearing and other domestic roles. This is particularly pronounced where the cultural constructions of gender roles and womanhood maintain that women should be submissive to their family’s needs and that their self-worth lies in their ability to care for other family members. Arab-Israeli women, for example, believe that the diagnosis of breast cancer legitimizes a husband’s abandonment of his sick wife as she is “like an old car that is out of order” and “must be replaced” (Baron-Epel et al. 2004, p. 106), which is also articulated in research in other societies in the Middle East or Asia (e.g. Azaiza and Cohen 2008; Yap 1998).

Such notions of gender roles have strong effects on women’s pursuit of care and treatment outcomes. For instance, analysing the narratives of women living with breast cancer in Spain, Ana Porroche-Escudero (2012) illustrates that women’s fulfilment of a patient’s role is seriously impacted by the normative gender behaviours determining their roles as the primary caregivers within the family, which precipitates enormous anxiety and stress to the women and interferes with their ability to recover from cancer treatment. In another setting, ethnographic research by Jessica Gregg (2003) examines cervical cancer in a low-income neighbourhood in Brazil where dominant cultural constructions regard women as hyper-sensual and their sexuality as a dangerous force that must be controlled by men. Brazilian women’s interpretations of cancer prevention discourses are predicated upon such constructions in a sense that they come to see no reason in adjusting their sexual behaviours because they have no control over sex and it is a means of survival.

Instead, women understand pap smears as a form of cancer prevention and treatment and believe that seeking the test regularly prevents them from being infected with sexually transmitted diseases that cause cancer.

Women experience a wide range of bodily changes brought on by their cancer and its accompanying arduous treatment (see Sun et al. 2018 for a summary of breast cancer treatment's effects that women experience with their bodies). When the resulting loss is a body part which defines womanhood and femininity, such as the loss of a breast, hair loss, or disrupted menstruation while being on hormone therapy, women are filled with apprehension about their distorted body image and that they are “finished as a woman and as a mother” (Taha et al. 2012, p. 5). In Denmark, for instance, for women patients, their bald head when undergoing chemotherapy is perceived as a loss of femininity, sexuality, self-confidence, and associated with sickness and even death. They therefore use wigs and make-up not only to resume a womanly look, but also to thwart the death connotation (Hansen 2007).

Meanwhile, a breast lost to mastectomy is for women a major disruption to their body structure, symmetry, and harmony. Women in China, for instance, report dissatisfaction with their body and turn to words such as “ugly” or “abnormal” to describe their body that is absent of a breast (Cheng, Sit, and Cheng 2016). When losing a body part which socially defines femininity, women report the feelings of lowered confidence, self-stigma, discrimination, or social embarrassment, which are noted in studies with different racial groups such as Chinese (Warmoth et al. 2017), Brazilian (Muniz da Costa Vargens and Berterö 2007), or Swiss (Piot-Ziegler et al. 2010) women, regardless of their age (Trusson, Pilnick, and Roy 2016). Across various settings, such body disfigurement is a constant source of anxiety for women because it may have detrimental ramifications for their sexuality and intimate relationships (Cheng et al. 2016; Fifita 2016; Taha et al. 2012; Yap 1998).

As women confront tensions arising from their altered bodies, they are demanded to renegotiate their identity and new sense of self (Sun et al. 2018; Trusson et al. 2016), but also socio-cultural scripts surrounding health and illness (Cromptoets 2003; Gibson et al. 2017). Such bodily changes cause immediate functional limitations and interruptions to a woman's daily life, and can also become permanent disablement and debilitation, leaving her with unsettled physical and emotional suffering (Greco 2021; Mulemi 2010;

Wright 2016). Bodily disfigurement resulting from breast cancer and the radical treatment it necessitates may severely restrict a woman's ability to work or find employment that accommodates her altered health status, thereby deteriorating her status in the nuclear family and the society she belongs to (Greco 2021; Porroche-Escudero 2012; Remennick 2006; Wright 2016).

## **Facing cancer uncertainty and women's adaptive responses**

Ambiguous signs of some suspicious lump that might become cancerous or equivocal pathological results (Manderson 2011), but also unsolved threats of cancer recurrence despite having completed treatment (Elmir et al. 2010; Trusson et al. 2016), create ongoing uncertainty for patients and their kin as they live with breast cancer. Cancer is "problematic" because of how people are determined and interpreted as being at risk (Manderson 2011, p. 326). Uncertainty also derives from irresponsible health promotion campaigns that fail to respond to the level of knowledge of its target groups and unnecessarily evokes public health concerns and anxiety (Boonmongkon, Pylypa, and Nichter 1999). Regarding people's accounts when confronting cancer risk, there has been growing attention to studying the sense of destiny or cancer fatalism, known as the belief in a lack of human's power over cancer, or a sense that "death is inevitable when cancer is present" (Powe and Finnie 2003, p. 454). Cancer fatalism has been a widely established discourse in public health literature as an underlying reason that explains people's cancer care-seeking behaviours, especially in research conducted in low income or resource-constrained settings or involving underserved, immigrant populations in developed countries who are usually described in terms of deficits, such as being "problematic," "irrational" or "ignorant," and in need of health education (for instance, see Drew and Schoenberg 2011; Kassam, Berry, and Dharsee 2017; McMullin et al. 2008).

However, religious beliefs are not necessarily linked with fatalism about cancer. As illustrated in the study conducted by Flórez et al. (2009) among Dominican women, the perceived notion of "*destino*" (destiny) is consistently mentioned by the participants who agree with a statement indicating that breast cancer is like a death sentence. Yet, these women do not describe destiny as a supernatural process but as a convergence of both one's own actions and external determinants, for instance, their family's diseases or genetics that surpass their control. By expressing their endorsement for women's agency

in coping with breast cancer, the women in this study only equate death with breast cancer in certain cases such as late diagnosis or lack of treatment. The belief in individual control over their destiny is articulated among women in other settings who often describe God as an important source of strength, providing them with protective power and helping them cope with breast cancer despite their perceptions of the fatal nature of the illness (cf. Salman, Zoucha, and Nawafleh 2018).

Turning to religious and spiritual practices or sacred forces to seek healing can also be pragmatic actions to address the disruptions and uncertainty that characterise the life with cancer. Similarly, navigating through multiple healing pathways, from self-medication to traditional medicine and alternative therapies, offers women different ways to address their loss of control over health. Such actions are more resonant among women experiencing cancer within a context where there are limited resources available to them (Fifita 2016; Wright 2016; Yap 1998) or when biomedical treatment turns into a miserable experience (Livingston 2012). For instance, in Tonga, an ethnographic study conducted by Fifita (2016) suggests that many women refuse surgical interventions for breast cancer due to their religious beliefs associated with dying with a whole body and the faith of accepting their physical condition as God's will. At the same time, they continue to seek traditional healing practices although they might not admit that. Their behaviours, however, should be considered as responses to a circumstance where a nationwide screening program is absent and cancer is often diagnosed at advanced stage and therefore cannot be settled by biomedicine.

Decision-making regarding cancer care is a process that constitutes complex series of activities and one not readily characterised as simply dichotomous distinctions between fatalist perspectives as one isolated construct and “control” (the practices of seeking prevention, screening or treatment) without taking into account barriers at structural levels (McMullin et al. 2008). Fatalist beliefs reflect people's limited knowledge of those who survive cancer, but can also suggest broader issues regarding access to cancer care. The ethnographic study conducted among Jordanian women by Salman, Zoucha, and Nawafleh (2018), for example, shows a widespread fear of breast cancer's fatality and strong beliefs in destiny. This research, however, points out that the lack of information on breast cancer, the role of media, missing gender-concordant care, and a shortage of qualified healthcare staff can all provide explanations for women's delay in seeking care, not just their fear and breast cancer fatalism.

Further, attributing cancer to fate can reflect people's feelings about the unequal power relations in biomedical practice because such fatalist notions may constitute a form of resistance or a weapon of the powerless (Balslem 1991). Drew and Schoenberg (2011) argue that fatalism is a rational way that the powerless cope with the world and considering this, they view fatalism to be a form what Mark Nichter (2010) terms, "the cultural idioms of distress" (Nichter 2010). Nichter suggests that people use "idioms of distress" to express and as adaptive responses to stressors existing in the present society, such as anger, powerlessness, social marginalisation and insecurity (2010, p. 405). Recognising fatalist beliefs in seeking cancer care as "idioms of distress" also demands paying attention to the importance of context that leads women to experience and voice their concerns.

### **Health-system barriers to care-seeking**

There is an established link between screening and reduced breast cancer mortality (Lauby-Secretan et al. 2015), and better prognosis (Field et al. 2005). In attempts to explain women's screening behaviours, there are concerns suggesting that laypeople's cultural beliefs in relation to women's bodies and illness (e.g Hwang et al. 2017), misinterpretations of abnormal symptoms (Moodley et al. 2016), or understanding of the curability of the disease, particularly the concept of fatalism, as well as the stigma of cancer are deterrents to women's participation in cancer screening practices (Abraído-Lanza et al. 2007; Azaiza and Cohen 2008; Bottorff et al. 1998; Kwok and Sullivan 2006). For those reasons, women might resort not to check for breast cancer themselves or keep their activities and concerns private in order to protect the standing of their family in the community (Banning et al. 2010). However, research has increasingly begun to acknowledge health-system factors that influence women's willingness to undergo breast cancer screening, including: the presence of screening and diagnostic services; availability of a health insurance that covers breast cancer care services; appropriateness of promoting materials; screening-associated costs; timeliness and availability of medical referrals; adequacy of health information; gender sensitivity of the health systems; and the attitudes of the healthcare providers (for instance, Abraído-Lanza et al. 2007; Manderson 2011; Pasick and Burke 2008; Pruitt et al. 2015; Woof et al. 2019).

In various contexts, the doctor-patient relationship is underscored as a factor that prevents women from seeking breast screening and cancer treatment. In the U.S, for instance, Lende and Lachiondo (2009) find that the way doctors interact with women patients, rather than cultural ideologies or beliefs, contributes to African-American women's hesitance to show up for screening despite free mammography and transportation support. Their finding regarding communication with healthcare providers as a determinant of women's health-seeking decisions is consistent with the study by Song, Hamilton, and Moore (2012) which was also undertaken in the U.S. Breast cancer patients of African background in their research report their experiences with insensitive healthcare providers who choose an impersonal style to communicate a cancer diagnosis. Lack of communication about shared decision making is also noted, which renders patients in strained and distressful situations when deciding about their treatment given their limited cancer literacy, all of which profoundly affects the patients' survivorship experiences. Meanwhile, doctors who are believed to be more honest and less money-driven are found to be among the crucial reasons that motivate women to obtain treatment even in a less resourced context instead of resorting to medical travel as noted in an Italy-based research (Greco 2019) .

Existing literature also highlights the lack of gender-sensitive care at medical settings as an issue that needs to be addressed in order to promote the screening uptake of women who feel fear and humiliation at exposing an intimate part of their female bodies to healthcare providers of the opposite sex (Azaiza and Cohen 2008; Bener et al. 2002; Kwok and Sullivan 2006; Luquis and Cruz 2006; Woof et al. 2019). This factor causes women to delay in seeking screening services; it also affects other aspects of obtaining medical care. For instance, women patients may feel scared and anxious to ask questions regarding their treatment bearing in mind a perception that male staff are authoritative figures who cannot be challenged (Im et al. 2002). While some might argue such concerns with modesty is culturally embedded in most traditionally conservative societies, women's reluctance can be remedied by the health system's attention to staffing screening facilities with female providers and communicating the presence of female-only radiographers in screening materials and promoting events (Woof et al. 2019).

Lack of health information or information delivered in a culturally inappropriate manner might evoke uncertainty and concerns among women over the harms associated with breast screening and eventually attribute to their non-attendance to the services

(Watts et al. 2004). A study among Chinese women conducted by Kwok and Sullivan (2006) finds that the printed materials used for mammography promotion materials might not be relevant for the population with poor education. Additionally, fears regarding mammography are not well-addressed in such materials, which renders many women in this study to be frightened about the physical damage inflicted on their breasts because of the screening procedure or raised doubts about mammography's benefits and effectiveness.

Current literature confirms that women covered by health insurance report higher screening rates (Hanson et al. 2009) while being uninsured precludes women's access to preventive services, thereby causing delays or even non-attendance in seeking medical attention in response to abnormal breast symptoms, particularly in resource-poor settings or among minority populations in developed countries (Kasper 2000; Remennick 2006; Yu, Hong, and Seetoo 2003). Women of low-income status without health insurance are left with a lower chance of early detection and, therefore, more likely to present at an advanced stage of cancer with poorer treatment outcomes and a lower chance of survival. Additionally, they have to encounter greater barriers and burdens, such as receiving cancer care of inferior and negligent quality, discrimination, and unemployment risks (Kasper 2000).

### **The political economy and living with cancer**

Social science literature has underscored that class, poverty, and social inequalities profoundly shape women's trajectories into seeking cancer screening and treatment, the continuity of care and compliance with recommended treatment regimens, and therefore heavily influences their treatment outcomes and chance of survival. This prominently figures in ethnographic explorations in resource-constrained countries where many women with breast cancer forgo treatment because chemotherapy and hospital bed charges are beyond their affordability and perceived as an unnecessary burden on their close kin (e.g Mulemi 2010). It is also reflected in research exploring the experience of living with an illness such as cervical cancer which is more likely to affect poor working-class women (Gregg 2003). For instance, Rebecca Martínez (2018) examines cervical cancer at the intersection of poverty, class, and race within the changing landscape of Venezuelan nationalism and neoliberalism. Her account highlights the popular discourses

among doctors and public health professionals that associate cervical cancer with promiscuity and personal hygiene, which implicitly carries moral judgements against women who bear the brunt of this disease as low class, poor, and lacking culture. Meanwhile, in the context of Tonga, as Patricia Fifita (2016) shows in her ethnographic fieldwork, the inadequate provision of screening and treatment for cancer is constrained due to country's poverty and dependency on foreign aid, which makes services that promote early detection unaffordable to most Tongan women. On the other hand, some women prefer and choose biomedicine over traditional healing practice in order to assert their class status and modern subjectivity but not merely because they have trust in the optimal outcomes of Western medicine.

Social inequalities acting as impediments to women's practices of seeking medical attention are also echoed among studies of underserved populations in developed countries. In Canada, for example, research by Donnelly and colleagues (2009) finds that while healthcare is publicly funded, low socioeconomic status associated with migration is a major reason explaining low participation in breast and cervical cancer screening programs among Vietnamese women immigrants. As most of the participants in their study work informally to earn money or help their children at home, taking time off to go to medical check-ups and screening is challenging and costly. Limited language skills also impede their ability to interact with healthcare professionals and attend screening programs. Their study emphasises that the structural context rather than the women's unwillingness to prevent and treat illness should be held accountable.

In capturing the manifold burdens faced by women when living with cancer, social science researchers have devoted attention to unfolding the different ways that cancer is framed by, but also reproduces and reinforces class and poverty. Having cancer exacerbates a woman's social position in various settings, sending them down into a spiral of poverty (Porroche-Escudero 2012), and those who are the most vulnerable, such as the uninsured, unemployed, rural and poor women are further disadvantaged. Limited or loss of employment due to physical impairment directly resultant from their medical condition or treatment after-effects, such as arm lymphedema (after axillary dissection as part of breast cancer treatment) and extreme fatigue, aggravates the financial problems of the women and their families. For those living in resource-constrained settings where UHI is absent or under-funded, women have to sell their assets, including their family's properties or borrow money, in many cases, at exorbitant rates of interest, in order to

finance the enormous resources required to manage cancer (Fifita 2016; Yap 1998). Considering the devastating circumstances facing the women and their family members, but also the uncertainty of treatment outcomes, especially in the case of advanced cancers (cf. Banning and Tanzeen 2014; Greco 2021), research across various settings highlights the situation of precarity in women's cancer experiences, which is often reflected in literature on chronic living with other medical conditions (e.g, Manderson and Warren 2016). For such reasons, the fear and worry about burdening their family with tremendous hardships associated with managing cancer are pervasive among cancer patients across various societies and cultural settings (cf. Ashing-Giwa et al. 2004; Greimel, Padilla, and Grant 1998; Mulemi 2010).

### ***Geography and cancer treatment***

Obvious in this body of research on cancer's lived experiences is how geography and rurality compound the influences of other social factors on women's access to treatment and care. As a life-threatening medical condition, women diagnosed with cancer must search for the best treatment to increase their chance of survival, which, in many cases, requires them to move outside the region of residence within their own country or overseas to access oncological technology and care that is locally unavailable, unaffordable, or of substandard quality (Fifita 2016; Greco 2019; Sargent and Kotobi 2017).

In her analysis of Italian breast cancer patients' treatment trajectories mentioned earlier, Cinzia Greco (2019) explains health-related mobility through the use of logics of access and healing, as well as the logic of cure, and highlights the structural inequality between the northern and southern Italy. For southern women interviewed in her ethnographic research, their decision to go north is influenced by their belief in the higher quality of treatment and better medical techniques they can access in northern hospitals despite having to incur substantial costs and logistic problems.

In more disadvantaged, resource-poor contexts, pursuing cancer treatment and acquiring medications requires lengthy journeys to urban cities or abroad. Even in settings where there is some form of subsidy provided by the government in sending and receiving countries, women still have to bear significant out-of-pocket expenses for transportation, housing, and other non-medical items associated with their medical travel. This situation

renders them more vulnerable to financial precarity and social marginalisation (Fifita 2016; Sargent and Kotobi 2017), let alone the exposure to malpractice or wilful harm in case of pursuing treatment overseas where legal protection is limited for foreign patients (Whittaker, Manderson, and Cartwright 2010).

## **Ethnographic studies of cancer experiences in Vietnam**

In the context of Vietnam, ethnographic accounts on cancer lived experiences are rare despite the shift in Vietnam to neoplasms as a major disease burden in the last decades. Exceptions include the work of Maria Stalford (2017, 2019) whose doctoral thesis focuses on the predicament of rural-dwelling cancer patients and their caregivers at two leading tertiary hospitals in the South of Vietnam. Her ethnographic research reconceptualises rural health as a term that encompasses constant rural-urban travel and lengthy stays in the urban cities for accessing oncology care. Studying patients' medical travel to pursue cancer treatment, such as radiation and chemotherapy, Stalford argues that geographic distance comprises a form of structural vulnerability rather than merely a static access barrier. She demonstrates the varying and compounding ways that spatial geographical disadvantage impacts upon cancer treatment experiences, thereby unfolding the power differentials and the unequal distribution of resources between countryside and urban areas that affect health inequalities. Further research has been conducted by Sara Swenson (2020) during an 18-month fieldwork also in Southern Vietnam. While her work is not directly concerned with the lived experiences of cancer patients, through the examination of Buddhist charity volunteers in Ho Chi Minh City, Swenson's study brings to light the suffering and miserable hardships facing patients undergoing treatment at the constantly overcrowded City Oncology Hospital. These studies provide vital knowledge for the explorations of cancer patients' behaviours of seeking care and the social patterns surrounding cancer in Vietnam. Informed by these studies, my research expands the existing literature by concentrating particularly on women's experiences when living breast cancer and provides new insights into the life of the people whose voices and illness experience remain largely unexplored.

## Conclusion

Social science scholarship has revealed that breast cancer is not merely a pathological phenomenon that can be understood with an exclusive focus on biomedical explanations. The studies in social sciences I have reviewed in this chapter offer important insights into the depth and complexities of women's lives as they come to terms with and experience this illness. Throughout the review of previous research deploying social science methodologies and standpoints, this chapter has described a multitude of factors influencing women's perceptions and decision-making in relation to breast cancer. In doing so, it has also reflected the wider cultural, social, economic and political context upon which the construction of knowledge and experience of living with breast cancer is predicated.

In many cultural settings, breast cancer remains a dreadful, fatal disease that occurs because of some divine powers beyond a human's control and possibly causes harm to affected families' standing in the community. The disease and its accompanying treatment results in debilitating consequences on the women's body image and social status, but also the well-being of their children and future of intimate relationships. Women might be discouraged from seeking diagnostic and treatment services because they believe that the curability of the disease is in the hand of supernatural forces. Nevertheless, the conclusions that focus on culture and religion as solely responsible for breast cancer related behaviours are problematic and health interventions that emphasise changing cultural beliefs are at risk of being misguided and victim-blaming (Abraído-Lanza et al. 2007; Loncke 2016). Women's unwillingness to present at breast screening does not necessarily originate from traditional health beliefs but the lack of culturally competent healthcare providers, the absence or under-funded health insurance, or low socio-economic status. Understanding women's knowledge and practices related to breast cancer requires more thorough examination that should draw on broader views. In this regard, ethnographic research can contribute greater depth to uncovering social constraints limiting women's practices of seeking cancer screening and treatment, and more importantly, the larger socio-economic structures that explain the variances of illness experience and health outcomes.

My thesis corroborates the critical role of social sciences' theoretical and empirical significance in studying ill health by revealing how social and cultural factors influence

women's understanding of and responses to breast cancer in a particular context of the Central region of Vietnam where there is scarce knowledge of this topic. In the chapter that follows, I provide the background to understand the country's political, socio-economic, and cultural contexts, traditional health beliefs, as well as its health system, and the government's recent responses to the growing burdens of NCDs. I also describe the field sites of the province and the hospital where my ethnography occurred.

## Chapter 3.

# Local Settings: The Context of Vietnam and Introduction to Field Sites

### A country's snapshot

The Socialist Republic of Vietnam is a single-party state, headed by the Communist Party of Vietnam (CPV) which assumed power and became the ruling party since 1945 in the North of Vietnam and the whole nation since the 1975 Reunification after the end of the Vietnam War. Since the launch of *Đổi Mới* (Renovation) in 1986 which marked a shift from a centrally-planned to a globally-integrated, socialist-oriented market economy, drastic changes in all social, economic, and political aspects have swept throughout the country. There has been some transition to a “soft authoritarian” state even though the CPV’s commanding role has remained unchanged (Thayer 2010).

Vietnam is the third most populous country in South-East Asia with over 96 million people in 2019. More than 65% of the total population resides in rural areas, but there has been a process of rapid urbanisation in the past two decades. With 54 ethnic groups residing across the country, Vietnam is a multi-ethnic nation state where Kinh-ethnic or Viet group account for 85.3% of the total population (General Statistics Office 2019).

Geographically, Vietnam is divided into six regions, including the Red River Delta, Northern midlands and mountain areas, North Central and Central coastal areas, Central Highlands, South East, and Mekong River Delta. It has 63 provinces (including five municipalities or central-level cities), each of these provinces is further divided into provincial cities, districts, or towns. A district comprises wards (in urban areas) or communes (in rural areas), or township, the lowest level of administrative system (General Statistics Office 2019; World Health Organization 2016).

In the last three decades since *Đổi Mới* 1986, Vietnam has showcased a success story of remarkable economic growth and poverty reduction. GDP per capita has been growing at over 5% annually which is one of the fastest rates in the world and only behind China. Poverty rates have sharply declined from nearly 80% in 1993 to below 6% in 2018 (considering US\$3.10-a-day poverty rate), and living standards have significantly improved across the country (World Bank 2021; World Bank and Ministry of Planning and Investment 2016). With a GDP per capita of over US\$2,700 in 2019, a 2.7-fold-increase as compared to early 2002, Vietnam has transitioned from one of the world's poorest nations to a lower-middle income country and among the most vibrant economies globally. However, regional and social inequalities emerge and grow as the consequences of rapid economic transformations. For example, ethnic minorities, who comprise less than 15% of the country's population, but now constitute over 80% of the poor (Priwitzer 2012; World Bank 2021).

According to results from this latest census (General Statistics Office 2019), the national average life expectancy is 73.6 years (71.0 among men and 76.3 among women), which is the highest among countries recording similar income levels (World Bank 2021). As can be seen in Table 3. 1 illustrating the country's major socio-economic and health indicators, Vietnam has a young population. However, Vietnam has become a rapidly aging country due to declining fertility and growing life expectancy for both men and women, which negatively affects economic growth and social security financing (for summary, see Giang, Pham, and Phi 2019).

**Table 3. 1.** Vietnam's major indicators (2009-2019)

Indicator	Value	Year
Population growth rate (%)	1.14	2019
Population density (persons/km <sup>2</sup> )	290	-
Age distribution (%)		-
0-14	24.3	-
15-65	68.0	-
65 and above	7.7	-
Married population aged 15 and above (%)	69.2	-
Average age at first marriage	25.2	-
Women	27.2	-

Men	23.1	-
People aged 5 and above with disability (%)	3.7	-
Total fertility rate	2.09	-
Adult literacy rate (%)	95.8	-
Sex ratio at birth (boys/100 girls)	114.8	2018
Health budget in GDP (%)	4.02	-
Health budget in state budget expenditure (%)	13.8	-
Health budget per capita (1,000VND)	2,351.90	-
Number of doctors per 10,000 population	8.67	-
Number of hospital beds per 10,000 population	30.10	-
Population covered by public health insurance (%)	86.80	-

*Source:* General Statistics Office (2019) and Ministry of Health (2018)

## Cultural settings

### *Confucianism and gender roles*

For the majority of the Viet (Kinh ethnic) population, their beliefs and everyday practices are heavily influenced by the principles of Confucianism, especially regarding familial relationships and gender roles (see, for instance Jamieson 1995; Taylor 2007). Vietnamese culture stresses the central role of a (heterosexual) family in an individual life, but also in the creation and maintenance of society, which is already enshrined in the National constitution and various national laws (see Rydstrom 2017). A multigenerational family unit with grandparents, parents, and young children living together is a common arrangement in the society (Perkins, Cotrel-Gibbons, and Nguyen 2016). There are general expectations that parents sacrifice their own needs and prioritise the well-being of their children while children should take care of their parents in their old age and beyond through ancestral worshipping rituals (Bélanger and Barbieri 2009).

With respect to familial relations, orthodox Confucianism disciplines the hierarchy between generations and genders. Accordingly, sons, as they can carry on the family line, are preferred over daughters (Bélanger and Barbieri 2009). Throughout her life course, a woman should conform to “*tam tông*” (three obediences) that is: to obey her father during

childhood; her husband after getting married; and her son during widowhood. She should also maintain “*tứ đức*” (four virtues) which consist of: *Công* (Labour); *Dung* (Appearance); *Ngôn* (Speech); and *Hạnh* (Behaviour). In the first half of the twentieth century, the eradication of feudalism, the establishment of the Indochinese (later Vietnamese) Communist Party along with the Vietnamese Women’s Union transformed the concepts of gender and gender status in Vietnam (Que 1996). As millions of Vietnamese women actively participated in the decade-long wars in the local guerrilla and militia forces, as well as in other professional capacities, the roles of women were redefined from a domesticated life to a battlefield in order to fight for their country (Anderson 2010; S. C. Taylor 2007).

Following the declaration on the formation of New Democratic and Republic State of Vietnam, the CPV introduced the first Constitution in 1946 which officially stated “equality between men and women” (Fahey 1998, p. 225). Those principles enshrined in the 1946 Constitution were maintained in the 1980 Constitution - the first Constitution of the reunified Socialist Republic of Vietnam and the goal of gender equality was highlighted throughout the CPV’s gender and political agendas (Eisen 1984). The introduction of *Đổi Mới* provided women with unprecedented opportunities for educational, political, and economic advancement (Drummond 2006; Schuler et al. 2006). However, Confucian-inspired discourses that promote women’s essential roles as mothers and carers still dominate public discussion surrounding the modern image of womanhood in the post-socialist state (Hoang 2020; Khuat, Le, and Nguyen 2010). The Women’s Union, a governmental mass organisation and a grassroots movement tasked with representing Vietnamese women and advancing the Communist Party’s priorities directed towards women, has launched the “Happy Family” or “Cultured Family” nationwide campaigns which reinforce core ideals that centre around domestic femininity, thereby regulating women’s gendered behaviours and perpetuating gender inequalities (see Hoang 2020; Nguyen-Vo 2012; Rydström 2016). For instance, they are expected to play their pivotal role in realising national family planning programs and maintaining harmonious family relations (Leshkovich 2014; Rydström 2016) by demonstrating “good morality,” that is living with sentiments or emotions (Rydstrøm 2017, p. 1058) and to show their devotion, selflessness, endurance, and hardship-bearing ability in everyday life (Gammeltoft 2018; Pettus 2004; Rydstrøm 2017). Motherhood is underscored as a vital part of every girl and woman’s life and fulfilling a woman’s “heavenly mandate” of

childbearing and breastfeeding is not only important to self-identification but also the development of the society (Rydstrøm 2004, 2006). Such ideals profoundly impact women's illness perceptions and their practices of seeking care as we see later in this thesis.

### ***The role of Buddhism***

Only less than 5% of the total Vietnamese population officially claim Buddhism as their religion (General Statistics Office 2019). Nevertheless, Buddhism still undergirds moral codes for the Vietnamese population (Shohet 2013) and plays an important role in the people's worshipping practices along with ancestor and spirit worship (Salemink 2008; Soucy 2012). The past decades since *Đổi Mới* has particularly observed the blossoming and vigorous renaissance of Buddhism throughout Vietnam which has gained increasing popularity among people of diverse backgrounds as well as the Communist Party. The CPV has officially endorsed Zen Buddhism as a national tradition and adopted important tenets of Buddhist movement such as the attack on superstition and the endeavour to foster an enlightened citizenry (P. Taylor 2007a). Since *Đổi Mới* the government has called for public-private cooperation in the provision of social services and in response to this call, Buddhism-based organisations have become the most active alternative actors in the country, providing shelter, meals, clothes, medical care, and basic education for disadvantaged people such as hospital patients (Hoang, Nguyen, and Reynolds 2019; Swenson 2020).

In most parts of Vietnam, Buddhism is not usually practiced in a systematic, formal, and orthodox way and people can pray to Buddha while simultaneously embracing the practices and rituals of other religions (Soucy 2012; Taylor 2004), even those deemed as un-Buddhist as they are aimed at supernatural forces (Soucy 2017). Prior research suggests that bearing a resemblance to elsewhere in Asia (Ikels 2004; Menon 2012), religious practices such as Buddhism are more common among elderly Vietnamese people, especially women whose financial support is essential to the flourishing of Vietnamese Buddhism (Soucy 2017). In their old age, people in Vietnam practise Buddhism to spend their free time more meaningful and get prepared for death as they believe the merits they cultivate through their practices will help them bring blessings to their family and transform their physical suffering as they transition to a new and better life (Le 2017; Soucy 2012).

However, the city of Hue where my ethnography was based is usually regarded as a “Buddhist Kingdom” (*miền đất Phật*) since the land is home to renowned Buddhist monks and a great number of ancient sacred Buddhist pagodas and has observed the uprising of various Buddhist movements throughout the history of the Vietnam (see also (P. Taylor 2007a)). The practices of Buddhism are popular among its residents, both young and old. When I visited and interviewed my informants at their home, I often noticed an altar of Buddha or the Goddess of Mercy placed at the centre and most respectful place in their house. Placed behind these are the ancestral altars (to worship deceased family members), usually at lower position. Different from many regions in Vietnam, people in Hue have additional altars for protective Gods inside their house from the beginning of their adulthood until old age (often at 60 years old). The altar’s position and the worshipped God varies and depends on the gender and birth year of the adult persons in that house. There is also an altar outside each house which people in Hue and some neighbouring districts set up to worship the wandering spirits, believed to belong to those who were killed, for instance, in street accidents, during the past wars, or famine. People burn incense and place fresh fruits, flowers, and elaborately prepared meals on those altars as part of their worshipping rituals on the first, fourteenth, fifteenth, and last days of the Lunar month, or on special occasions, such as during Lunar New Year, or at the death anniversary of their ancestors. Hue people whom I talked to during my ethnography reported to regularly attend Buddhist *dharma* talks at local pagodas and make charitable donations to Buddhist-based organisations. Many strictly follow vegetarian diets as part of their Buddhist practice at least two days a month. Buddha’s Birthday and the Ghost Festival (falling respectively in April and July in the Lunar calendar) are also widely celebrated across the city.

## Health beliefs

Buddhist cosmology and concepts, such as the laws of karma and reincarnation, continue to determine the belief system related to different forms of disease and how people manage and live with their illnesses in Vietnam (Gammeltoft 2014; Swenson 2020; Vu 2014). In this worldview, ill health is perceived to result from moral failure or misdeeds accumulated in the present or past lives by the person who bears the disease or their family members. After death, each sentient being is reborn, and the rebirth is dependent

on karmic seeds from past lives. Therefore, to live a happy and healthy life and achieve higher levels of rebirth, one must strive to generate good deeds (Swenson 2020; Tran et al. 2019). As noted by Swenson (2020) in her 18-month ethnographic study with Buddhist charity volunteers at an Oncology Hospital in Ho Chi Minh City, her informants often drew on the laws of karma to explain the causes of cancer and in view of this, they considered their merit-creating acts or altruism as a form of cancer prevention. In their belief, by engaging in charitable programs, such as meal donation and financial subsidies to cancer patients, they were able to cultivate Buddhist virtues, which brought benefits to the health and well-being of not only the donors and recipients but also all sentient beings.

Also central to understanding Vietnamese health beliefs is the concept of *âm-dương* or yin-yang balance. The yin-yang system originated from ancient Chinese philosophy (for a summary of these concepts, see Hsu et al. 2009) and continues to play an important role in Vietnamese culture, especially when it comes to understanding of health and illness (see, for instance, Gammeltoft 2012; Wahlberg 2006b). Accordingly, a disease is caused by the disequilibrium of the humoral forces of yin (“*âm*”) and yang (“*dương*”). According to this structure of thought, the physical human body comprises different organs, each of which is either yin or yang and yin-yang balance is required for maintaining good health (Hsu et al. 2009). Vietnamese traditional medicine holds that the two vital elements of the body are “*khí*” (energy, of yang principle) and “*huyết*” (blood, of yin principle). Those two are interrelated: “*khí*” drives the circulation of “*huyết*” (Hoang 1999 as cited in Wahlberg 2006b). As the internal dynamics of yin-yang within a human’s body also interacts with that of the external worlds, maintaining good health requires the harmony within the individual body, but also with the outside social and natural environment, for instance, wind, temperature, food, and drink (Jamieson 1995; Marr 1987).

Yin-yang harmony can be maintained, restored, or disrupted through diet because food can be of yin or yang nature depending on its humoral characteristics. Foods in popular knowledge are broken down into four categories: cold (e.g seafood, fish, and snails); hot (e.g spices like ginger, chili, or garlic, alcoholic drinks, tropical fruits like mango, jackfruit, and western medicine); cooling (e.g green vegetables, lemon, orange, and vitamin C); and neutral or warm (e.g rice, pork, beef, and eggs). Food of hot or warm nature are yang while cold and cool food are yin (e.g Craig 2002; Jamieson 1995). Popular Vietnamese beliefs emphasise food as a central element in maintaining good health which is considered curative care in every household. It is widely held that a person’s ability to

eat with a good appetite primarily denotes their bodily strength and vice versa, the lack of a good appetite or dietary excess is believed to cause illness (Craig 2002, pp. 90-92).

Easy-to-digest foods and many dietary restrictions need to be followed at the most vulnerable times, such as during sickness, and especially during pregnancy, childbirth and the post-partum (Craig 2002) because during these particular periods, women's bodies are believed to be most susceptible to external forces (Gammeltoft 2012). Childbirth is believed to engender the strongest state of yin and in order to balance the yang effects and prevent maternal illnesses postpartum, a woman should consume yang or hot foods (that are rich in protein and energy) while restricting foods of cold (yin) nature so that she can resume her strength after the loss of blood and opening of her body during labour (Morrow 1996; Poh, Wong, and Karim 2005). In addition, a woman is advised to observe strict postnatal dietary practices due to the nutritional benefits on her breast milk which directly affects her infant's health during lactation. Certain nourishing foods that are believed to rebuild bodily equilibrium as well as increase the production of breast milk include, for instance, rice, ginger, lean pork, soup with pig nails or pork ragout and green papaya, (black) chicken soup, and warm water. Meanwhile, raw vegetables and seafood should be avoided during lactation because it is understood to cause allergies and other ailments in the infants (Lundberg and Thu 2012; Morrow 1996). Such dietary precautions and practices are consistent with those adopted by mothers in other Asian countries, such as Thailand (Liamputtong 2004; Whittaker 2002), Malaysia (Manderson 1981; Poh et al. 2005); and China (Liu et al. 2006; Raven et al. 2007).

The rapid process of neoliberal market liberalisation, modernisation, and urbanisation since *Đổi Mới* have transformed Vietnam's food system as well as the patterns of food consumption among Vietnamese people. Growing agricultural production, increased volumes of imports, the proliferation of modern retailers, and higher living standards have offered the people a wider range of products while simultaneously reducing their self-production and self-consumption practices (Figuíé et al. 2019). As people increasingly depend on external food supply, there has been mounting reports exposing the rampant use of chemical inputs in agricultural production, notably related to pesticides in growing fruit and vegetables, growth hormones in animal feeds, and the overuse of preservatives in food processing amid a failing regulation system (Figuíé et al. 2019; Pham, Mol, and Oosterveer 2013). Feeding the bodies with

contaminated food has therefore become a widespread source of anxiety for the public in Vietnam (Ehlert and Faltmann 2019; Wertheim-Heck, Spaargaren, and Vellema 2014).

Considering the vital role of food in everyday life in Vietnam, it is unsurprising that people often turn to food in the first place to explain the occurrence of ill health, ranging from cholera to infertility, birth defects, and various types of cancers (for instance, see Gammeltoft 2014; Lincoln 2014; Swenson 2020). Likewise, such knowledge dominates the understanding of my research participants when they search for the causes of breast cancer (Chapter 5). As I elaborate in the following chapters, traditional health beliefs related to food, specifically the yin-yang principles and the importance of postpartum practices heavily influence the way people make sense of breast cancer and their interpretations of abnormal breast symptoms (Chapter 6), as well as the decisions of seeking medical attention, for instance, the avoidance of interventions that require antibiotics post-surgery (Chapter 8). The perceptions and behaviours to seek care in relation to breast cancer should also be viewed within the context of the current health system. In the section that follows, I describe how the health system in Vietnam is organised, its recent changes, and the relevant regulations regarding national health insurance that are fundamental to our understanding of people's care-seeking practices and the delivery of healthcare services.

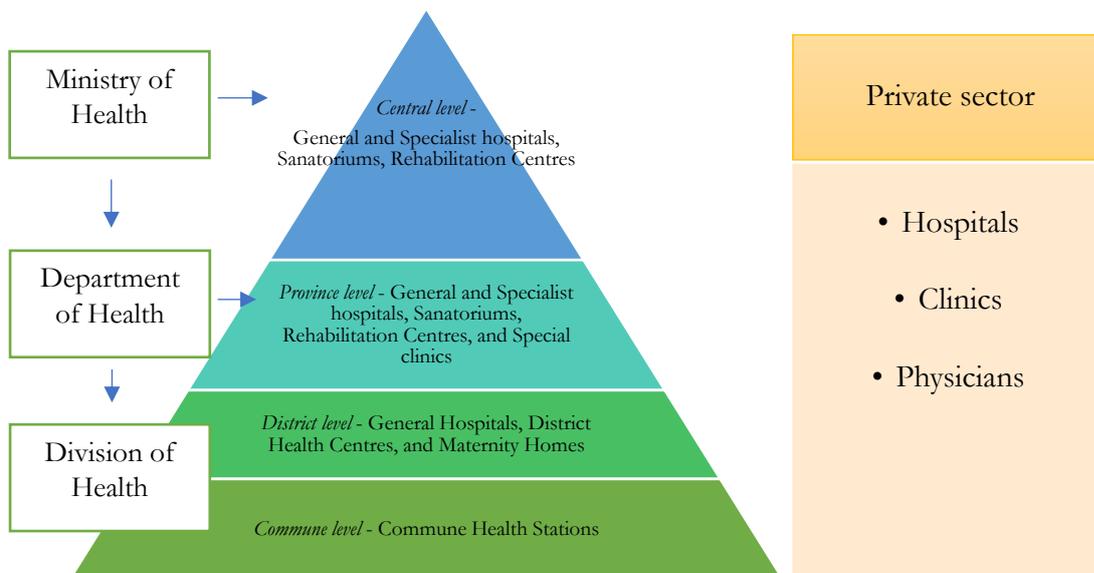
## **Health system of Vietnam**

### ***Health system structure***

Viet Nam's government-owned health system (public healthcare) comprises four administrative levels: national (Ministry of Health - MOH); provincial (Department of Health - DOH); district (Division of Health); and commune health station (CHS). At the *national level*, general hospitals, universities and colleges, and national research and institutes are under the management of the MOH. These are the highest points of referral in the whole system (Figure 3. 1). By 2018 there were 47 facilities at this level with 31,436 beds. The 12,517 facilities at local level are categorised at three hierarchical levels: commune, district, and province. The DOH manages *province-level* general and specialised hospitals. The organisation of provincial specialised hospitals depends on the population in each province. At the *district level*, health centres – the first level with in-patient hospital

services - offer both medical and preventive services (Ministry of Health 2018; World Health Organization 2016). CHS serves as the entry-point of care from which referrals are escalated to district centres, provincial hospitals or specialised clinics, and national hospitals as the final point (Duong 2015). In addition, there are a network of 755 health facilities managed by line ministries other than the MOH with more than 9,000 beds in 2018 (Ministry of Health 2018).

In parallel with the government sector, private health facilities came into operation in the 1990s. The latest statistics from the Ministry of Health (MOH) suggest that 228 private hospitals operated nationwide by 2018, housing a total of 21,122 hospital beds. The traditional (folk) sector continues to co-exist with biomedical hospitals and clinics. These comprise traditional medicine hospitals, clinics, and healers which are managed either within the government (at central national or provincial level) or within the private system (Ministry of Health 2018).



**Figure 3. 1.** Vietnam's Biomedical Health System

*Source:* Adapted from Ministry of Health (2018) and World Health Organization (2016)

## **Đổi Mới, privatisation, and the growing burden of medical expenses**

Vietnam's transition from a subsidised to a market-based economy with socialist orientation in the mid-1980s has brought about profound changes in its health system.

Until 1989 when the country was hit by a fiscal crisis, Vietnamese hospitals had been largely funded by the state. To cope with the impacts of decreasing budgets, while maintaining the central role in ensuring well-being for the people, the state called for mobilising private resources and stressed the involvement of non-state actors in care and welfare provision, including education and healthcare (Nguyen 2015, 2018). The principle of socialisation (*xã hội hoá*) – that is the state of being under the responsibility of the whole society – was formally set out in a 1997 government decree to guide the provision of public goods and social services (Nguyen 2018, p. 631), implying a turn towards self-governance and the individualization of responsibilities of public goods (Nguyen-Marshall 2008; Nguyen 2018). The government started to restructure the health system by permitting measures for greater hospitals’ autonomy, such as user-fee collection and partial retention of their revenues, formalising the pharmaceutical industry, deregulating retail drug sales, and legalising private hospitals (London 2013; Morooka et al. 2017; Stalford 2019). “Patient-requested services” or “service treatment” have been made available within public hospitals (London 2013) which offer patients faster services and better-equipped private rooms in public hospitals, although they cannot be reimbursed through health insurance or at lower rate than standard services (Nguyen 2018).

These rapid privatisation and socialising reforms prevented the whole system from collapse and contributed to expanding consumers’ choices and increasing the quality of healthcare services as hospital’s resources were allocated in a more efficient way (London 2013). In addition, the emergence of a private health system comprising hospitals, medical, and maternity clinics in parallel with the public system has allowed for greater availability of services. Since *Đổi Mới* 1986, Vietnam has seen a rising number of private medical practices which are estimated to account for 11% of all hospitals in Vietnam (Cheng 2014). Nevertheless, the segregation between private and public provision of care is not always clear. As my ethnography later demonstrates, many doctors at public hospitals are also employed by private clinics on a part-time basis or themselves own one where they work after official working hours. Those private arrangements provide better-off patients with greater access and well-catered services while compromising the quality of treatment for those who can only afford overcrowded services at public hospitals where health insurance can be reimbursed. The socialisation and commodification of healthcare has also prompted increases in medication and treatment costs as many services previously subsidised by the state are no longer provided while revenue

maximisation has been sought among healthcare providers and fees at public hospitals are constantly rising (Nguyen 2015). Since 2017, state budget no longer covers salaries of doctors and other public hospital staff who start to be paid out of health insurance and out-of-pocket payments (Nguyen 2018). The situation resulted in increasing stratification of the system and exacerbated health access inequity across different population groups and regions (Lincoln 2014; London 2013; Priwitzer 2012; Su and Hoang 2015).

### ***Health insurance***

To offset the financial burden resulting from rising healthcare costs post-*Đổi Mới*, the government of Vietnam introduced social health insurance in early 1990s, of which the coverage reached 86.8% of the total population in 2018 (Ministry of Health 2018). This is an approximate five-fold increase as compared to 2001 when below 15% of the population was insured (Ministry of Health 2013). Vietnam's health insurance comprises *compulsory* and *voluntary* schemes. When first introduced in 1992, the mandatory scheme only applied for public servants and formal sector employees who then enrolled as contributing groups and social beneficiary groups (such as pensioners, war veterans and their families) who received state subsidies to participate in the scheme. The coverage of the compulsory scheme was later extended to more non-contributory social beneficiaries, such as poor households, ethnic minorities and families in socio-economically disadvantaged regions, as well as children under 6 years old and elderly people aged 80 years and over. Regarding the voluntary scheme which was first implemented in 1994, workers employed in the informal sector, students, and dependents of those who have already been covered in the mandatory scheme can enrol.<sup>1</sup> Certain groups, for example, near-poor households and students also benefit from a partial state's subsidy of insurance premium (see Le et al. 2020; Palmer 2014 for summaries on the development of Vietnam's social health insurance). Responsibilities for formulating policies regarding the insurance premiums, benefits, and co-payment rest with the MOH; meanwhile, Vietnam's Social Security Agency is tasked with implementing related policies (Le et al. 2020).

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<sup>1</sup> According to the Government's Decree 46/2018/ND-CP, as of 2021 the monthly premium applied in the voluntary scheme for household is set at 67,050 VND for the first member in the household and decreases for each additional family member. The total premium for a 4-member household is approximately 190,000 VND/month or 2,250,000 VND/year (~US\$97.0).

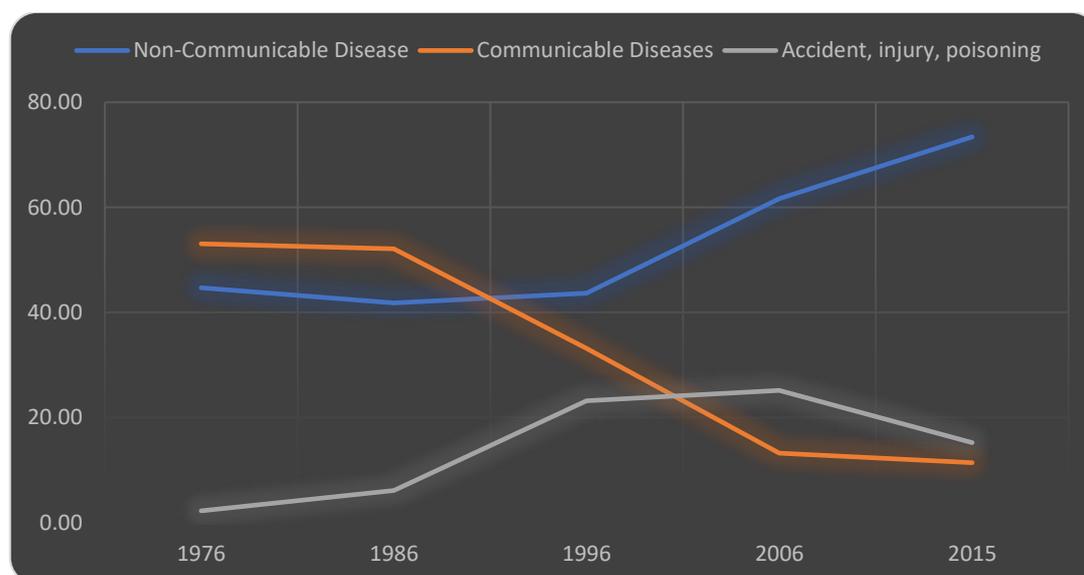
Since 2015, amendments of the Health Insurance Law (Law No. 46/2014/QH13) provide a mandate of health insurance for all citizens whereby an uninsured person can enrol in the voluntary scheme if all members in their household purchase insurance altogether. Despite this, unlike the compulsory scheme where the government can enforce the participation and contributions of formal sector employers (Palmer 2014), there is no direct penalty for not participating in the other scheme (Dao 2020). The household business sector is the largest employment provider in Vietnam, generating job and income for one-third of the total working population. Two-thirds of the household business sector belongs to the informal sector with no business registration (Pasquier-Doumer, Oudin, and Thang 2017). Workers employed in the informal sector and agriculture are uninsured by default and if they want to be covered, they must purchase insurance as a voluntary contributor (Dao 2020). It is estimated that half of the household business employees work without a contract and less than 25% are covered with health insurance. Those who are covered tend to be through the entitlements of their family members rather than their own employer (Pasquier-Doumer et al. 2017). A recent study with rural workers in the informal sector suggests that the majority only choose to enrol in the scheme when they are ill or in poor health (Ho et al. 2020). This resonates with the situation for many of my informants who were not covered by any kind of insurance at the time of their cancer diagnosis since they were farmers or casual workers without a long-term labour contract, or self-employed and could not afford to enrol the whole family in the voluntary scheme.

There is ample evidence showing an increase in healthcare utilisation among insured populations (e.g Palmer 2014). In the context of breast cancer, a quantitative study in Central Vietnam reveals that the likelihood of uninsured patients forgoing treatment is over four times higher than that among those covered by health insurance (Nguyen, H. L. et al. 2013). Nevertheless, insured patients still face significant out-of-pocket expenses. As per existing regulations, people with a social health insurance card are covered at all public and a small number of private hospitals. Insured people need to register their primary point of receiving care, usually at a commune or district-level health facility, where they are entitled to the highest rate of coverage. By the time of writing, the co-payment rate for inpatient care ranges from 0% (applicable for children under 6, people who have lost working capacity, are unemployed, or receive a social allowance, such as the poor, people with a certain level of disability, or veterans) to 20% (for the remainder, including

those enrolled in the compulsory scheme) (Le et al. 2020). The coverage is different for high-technology procedures and there are expenditure caps for certain patented medications as I later analyse in my main finding chapters. At higher-level facilities such as provincial and national-level hospitals, insured patients need to obtain referrals from local-level health facilities to retain their entitlements (Dao 2020).<sup>2</sup> As can be seen in Chapter 6 and Chapter 7, most patients had to pay 100% of examination costs and over 60% of treatment costs due to their practice of bypassing local health facilities and moving directly to tertiary care without an approval letter.

### An epidemiological transition in Vietnam

Vietnam, like other developing countries, has been undergoing a sweeping epidemiological transition (Dibley et al. 2013) in which the overall patterns of morbidity and mortality shift from communicable diseases to NCDs (Figure 3. 2).



**Figure 3. 2.** Mortality trend in Vietnam by category from 1976 to 2015 (%)

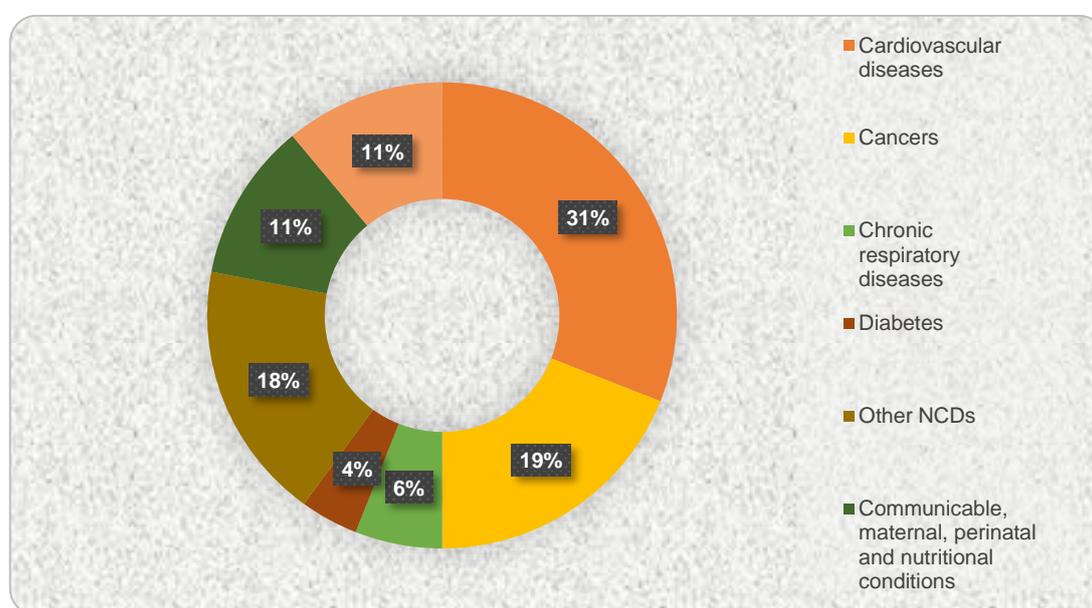
Source: Ministry of Health (2017)

Twenty years since *Đổi Mới* 1986, hospital admissions due to NCDs increased from 39% to 69% and deaths due to chronic diseases rose from 42% to 63% of total deaths in

<sup>2</sup> From January 1, 2021, insured people are allowed to have inpatient treatment covered at provincial health facility without a referral.

2008 (Ministry of Health 2009). In 2016, 424,000 deaths (77% of total deaths) were attributable to NCDs (World Health Organization 2018, p. 218). NCDs collectively accounted for 6.7 million years of life lost (56% of total YLLs), and 14 million disability adjusted life years lost (66% of DALYs lost). The probability of dying between the ages of 30 and 70 among the four NCDs is 17% (WHO 2014).

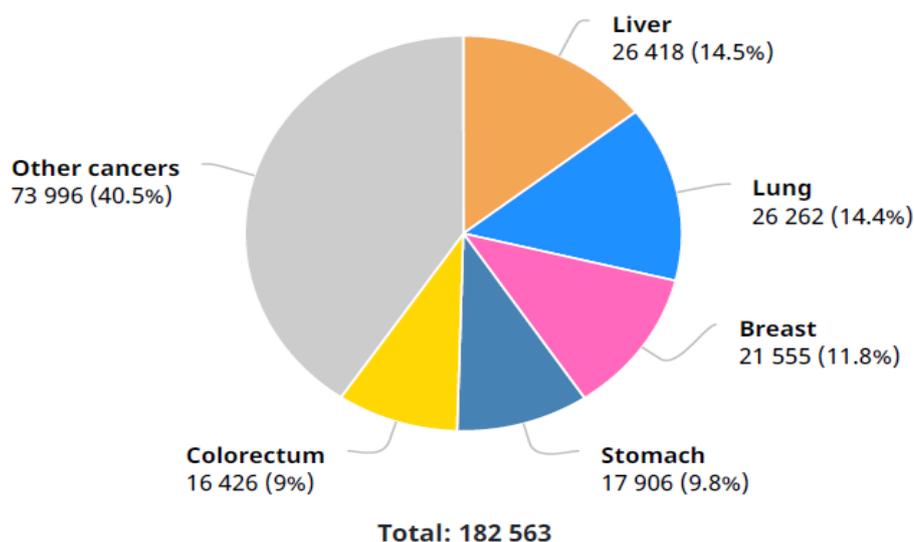
Among four main NCDs, cancer has become the leading cause of YLLs and the second leading cause of death. As can be seen in Figure 3. 3, cancers claimed more than 100,000 or 19% of total deaths in Vietnam in 2016 (WHO 2018, p. 218) and 2,320,000 YLLs (34% of total YLLs) (Institute for Health Metrics and Evaluation 2013; Ministry of Health & Health Partnership Group 2015).



**Figure 3. 3.** Mortality causes in Vietnam in 2016 (%)

*Source:* World Health Organization (2018, p. 218)

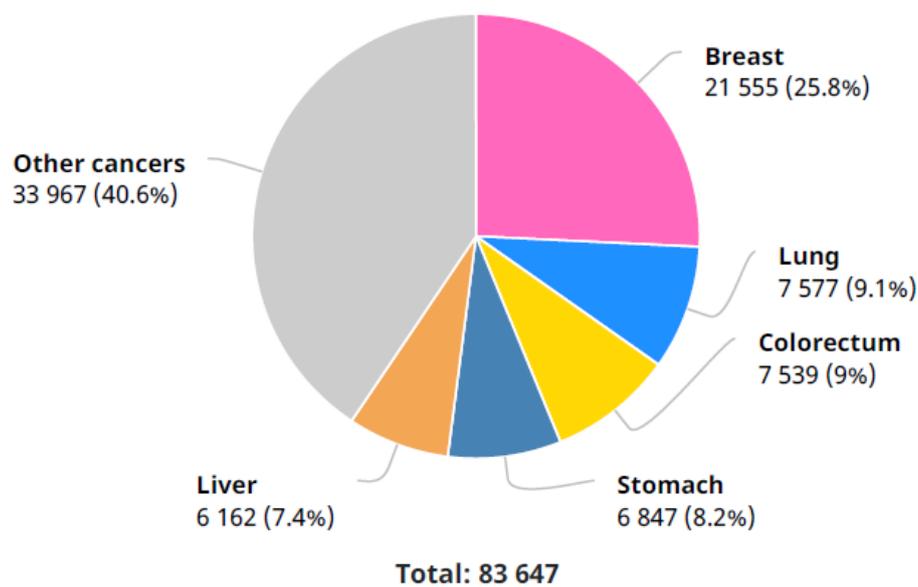
Latest data show that 182,563 new cancer cases (Figure 3. 4) were detected in 2020 alone (98,916 males and 83,647 females), accounting for 0.19% of the total population (GLOBOCAN 2020a). As compared to 30 years ago, these recent statistics have more than tripled the figures released in the 1990s when there were approximately 50,000 new cases a year (Anh and Duc 2002)



**Figure 3. 4.** The number of new cancer cases in Vietnam in 2020 (both sexes)

*Source:* GLOBOCAN (2020a)

There exist gender variations regarding cancer patterns in Vietnam. Men account for a remarkably larger proportion of total cases than women (54.2% versus 45.8%). For women, the most common types of cancers are breast, lung, colorectum, stomach and liver cancers (Figure 3. 5) while for men, liver, lung, stomach, colorectum, and prostate are the most prevalent (GLOBOCAN 2020a). Breast cancer incidence is dramatically increasing in developing countries like Vietnam where the age-standardised incidence of breast cancer has drastically risen from 13.8 per 100,000 women in 2000 to 23.0 per 100,000 women in 2012 (IARC 2012). In less than ten years, the number of new cases has almost doubled from 11,067 in 2012 (IARC 2012) to 21,555 in 2020. These latest figures suggest that breast cancer has now become the most common female cancer in the country, comprising 25.8% of all cancer cases newly detected among Vietnamese women and claiming 9,345 deaths nationwide (GLOBOCAN 2020a).



**Figure 3. 5.** The number of new cancer cases in 2020 among women in Vietnam

*Source:* GLOBOCAN (2020a)

### **National policies on NCD control and prevention**

The government of Vietnam's commitments to managing NCDs dated back to the early 2000s with the promulgation and approval of policies that promoted healthy diets and physical activities. Since then, a spate of national legislation had come into existence, including the Law on Tobacco Control (2012), policies on control and minimization of the harmful use of alcohol (in 2014), and the Environment Law (Ministry of Health and Health Partnership Group 2015). Moreover, National Target Programs for the prevention and control of NCDs covering hypertension, cancers, and diabetes mellitus have become effective since 2006 (Nguyen and Hoang 2018). In the latest national strategy for NCD prevention and control from 2015 to 2025, MOH set several specific objectives to address the growing burden of cancer, including a target of 40% of individuals with common cancers being diagnosed at an earlier stage; and another to reduce 20% of premature deaths (aged <70) resulting from NCDs (Ministry of Health 2015b). As part of the national strategy to combat NCDs, Vietnam first implemented the National Cancer Control Program (NCCP) in 2008 which focused on raising community awareness on cancer prevention and early detection, promoting screening and early diagnosis, and

enhancing the health-system's capacity, as well as monitoring and creating a cancer registry (Tran, Pham, and Dao 2016). However, the results of the NCCP appear quite limited, which is due to inadequate public investment. It was reported that less than 3.5% of the government's health budget was allocated to NCCP and four programs on controlling other NCDs (see Pham et al. 2019).

### ***Oncology infrastructure and capacity***

Specifically on oncology care, as of 2014 there are six public specialist oncology hospitals in cities of Hanoi, Ho Chi Minh City, Danang, Hue, Can Tho, and Nghe An. Additionally, there are 43 oncology centres operating at national, provincial, and specialist hospitals along with private oncology hospitals that have been recently opened. Forty out of 63 provinces have oncology treatment facilities in place (Ministry of Health and Health Partnership Group 2015). However, disparities regarding diagnostic and treatment capability still prevail across regions and between national- and lower-level health facilities. For instance, regarding cancer diagnosis, patients can only access modern techniques for immune histo-chemistry and molecular examinations at a minor number of comprehensive cancer centres (Tran et al. 2016). And even at specialised cancer centres, there are concerns over the accuracy of pathological testing where the exact or complete diagnostic concordance was found at only 50% or below (Dayton et al. 2017). Access to radiotherapy is also limited for patients residing outside major cities. The 51 radiotherapy machines in Vietnam, similarly to other health resources, mainly concentrate in Hanoi and Ho Chi Minh City where the two largest national cancer centres (i.e the National Cancer Hospital or “K hospital” and Ho Chi Minh City Cancer Hospital) are situated. This situation inevitably leads to the overcrowding status of major oncology hospitals (Ministry of Health and Health Partnership Group 2015). Inadequate palliative care is another hurdle facing the country. Although the majority of cancer patients in Vietnam are diagnosed at an advanced stage and therefore, critically require hospice care, palliative care units only exist at the National Cancer Hospital, Ho Chi Minh City Cancer Hospital, and three other hospitals in urban cities (including the Central Hospital where my ethnography was based) (Tran et al. 2016). There is also a shortage of opioids and other essential drugs at CHS. It is estimated that the existing oncology infrastructure in Vietnam can only meet approximately 30% to 40% of population's needs for cancer-related services (Ministry of Health and Health Partnership Group 2015). As can be seen later in my thesis, this

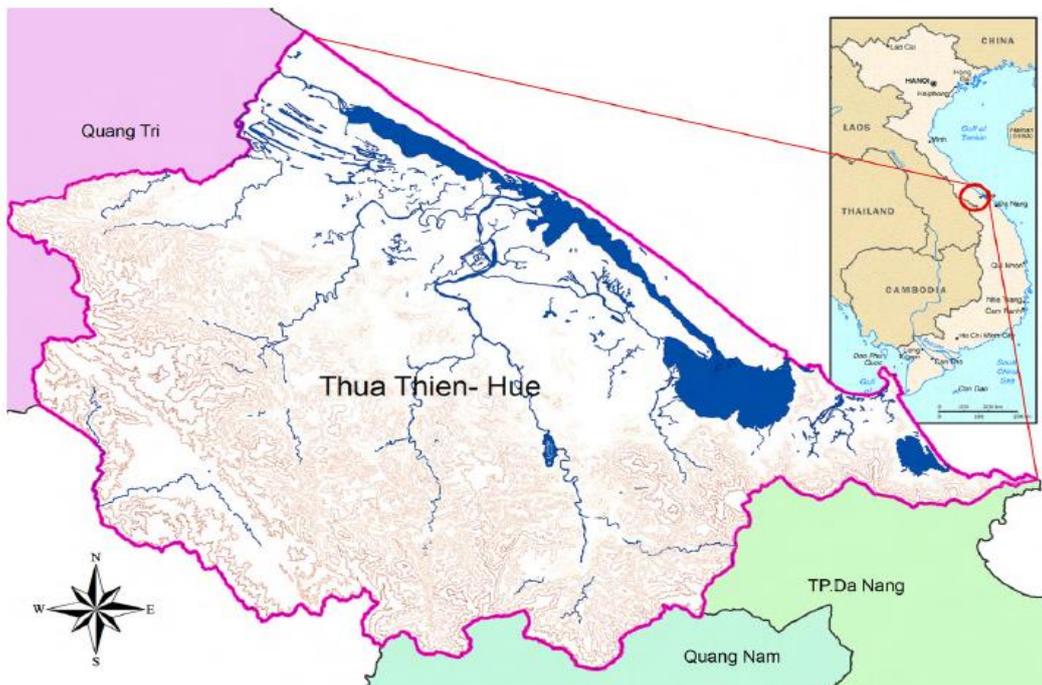
situation renders medical travel to obtain cancer diagnosis and treatment inevitable among patients residing in rural areas or small urban cities because such services are non-existent or of substandard quality in their hometowns.

## **Introduction to the field sites**

### ***Thua Thien Hue province***

The province of Thua Thien Hue is located in the central region of Viet Nam, bordered on the east by the South China Sea (also known as East Sea) and on the west by Laos (see Figure 3. 6). Thua Thien Hue has a population estimated at 1,149,800 (with an approximate of 235 persons/km<sup>2</sup>) in 2016 (General Statistics Office of Vietnam 2016). Thua Thien Hue is divided into nine administrative units with Hue being the province's capital city. Nearly 49% of the province's total population reside in rural areas (Thua Thien Hue Government n.d.). A majority of the province's infrastructure and industrial compounds lie in the coastal plain and most of the population lives within 25 km of the coast (Tran and Shaw 2007).

The city of Hue is the former capital city of Vietnam, once home to the Nguyễn dynasty – the last imperial monarchy – throughout the 19<sup>th</sup> century until 1945 when Emperor Bảo Đại abdicated and transferred power to the Vietnamese Communist Party which later became the ruling party and established the Democratic Republic of Vietnam (the early foundation for the current Socialist Republic of Vietnam). Hue was constructed along the lines of the Forbidden City by Emperor Gia Long, who was the first Nguyễn emperor ruling the country from 1802 until 1820 and was home to the imperial court, mandarin, and army. The area encircled by the city's walls also accommodated a large civilian population, comprised of artisans and merchants, who later set their residence further to the east (Logan 2005). Nowadays, Hue is the capital city of Thua Thien Hue province with an estimated population of 358,754 (as of 2018), housing the province's highest government agencies and departments and has become one of the busiest cultural and economic centres in the Central region. Hue is famous among local and international tourists for its ancient citadel which was the first in Vietnam to be recognised as an UNESCO's World Heritage site (Thua Thien Hue Government n.d.).



**Figure 3. 6.** The province of Thua Thien Hue

*Source:* Tran and Shaw (2007)

### ***Hue Central Hospital***

Hue Central Hospital in the City of Hue, Thua Thien Hue province was the main site for my observation and interviews with medical staff and patients. Established in 1894 during the Nguyen's Dynasty in the sixth year of Emperor Thanh Thai's reign according to His Majesty's Decree, Hue Central Hospital was originally called "*nhà thương bệnh sở*" (medical hospital) and was the first biomedical hospital in operation in Vietnam. Throughout its history, it is also referred to the people informally as "*Nhà thương lớn*" (Grand Hôpital) (Hue Central Hospital 2019). By the time of its establishment, the hospital consisted of two structures built by the French on an area which had been previously used by the naval army. The front structure comprised three rooms while the five-room structure was situated at the back, along with a kitchen. In the following years, additional structures were erected of which separate areas were designated for admitting and treating Western (mostly French) official and Western patients. Nguyễn's royal family members and officials were the first Vietnamese people to receive treatment at the Hospital. According to *Dai Nam Nhat Thong Chi*, in 1895 Emperor Thanh Thai called for Doctor Henry, the then director of the hospital, to attend the birth of his two babies,

which marked the feudal monarchy's official endorsement of Western medicine. From 1915 to 1921, the hospital treated from 150 to 250 local Vietnamese patients while maintaining a separate area or room for admitting European patients. It was not until 1945 that the hospital appointed its first Vietnamese Director (Duong 2014; Ton n.d.).

In 1944, the hospital's name was changed to “*Bệnh viện Trung Ương Huế*” (Hôpital Central de Hué or Hue Central Hospital) given its region-wide prestigious reputation for its quality of expertise and treatment. From 1955 to 1975, the hospital was the largest hospital in the Central area of Vietnam within the management of the Southern Vietnam's MOH. Since the 1975 Reunification, the hospital was transferred to the government of the Socialist Republic of Vietnam (Hue Central Hospital 2019; Ton n.d.).

Nowadays, the Central Hospital operates two units and comprises 76 clinical departments, 10 centres, and 24 pharmaceutical departments. The headquarters are situated inside the city of Hue overlooking the Perfume River (*sông Hương*). The second unit operates in the district of Phong Điền, about 20 kilometres from the main unit. The hospital employed a total number of 3,056 staff in 2019. In 2018, the hospital had a capacity of nearly 4,000 beds, treating 150,000 inpatients. The hospital as a whole performed 38,000 surgeries and assisted 9,000 births (Hue Central Hospital 2019).

As one of the three largest general hospitals in the country and the only special-grade hospital (the highest tier that the MOH assigned to Vietnamese hospitals) serving the Central region, Hue Central Hospital is famous nationwide for housing modern technology and high-quality experts with the capability to attend to complicated medical procedures, such as lung and heart transplant, stem cell transplantation, and oncology treatment (Hue Central Hospital 2019). Situating my hospital ethnography within Hue Central Hospital therefore allowed me to study a patient population from diverse socio-economic backgrounds across different provinces in the region. In the following chapter, I describe in detail the methodology deployed for my research, as well as the various issues I was faced with when gaining access to the field sites during my nine-month ethnography.

## Chapter 4.

# Undertaking Ethnography of Breast Cancer in Central Vietnam

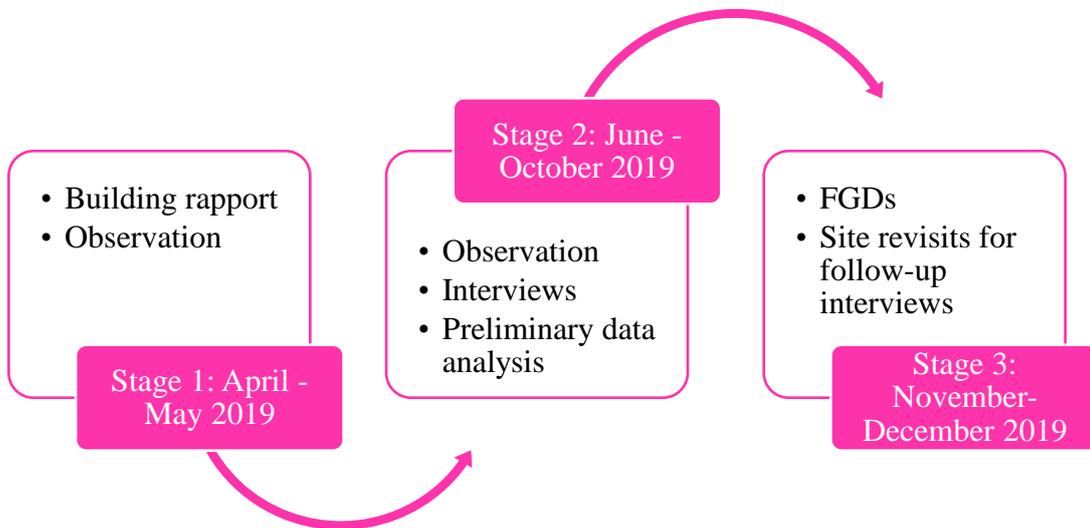
Our interview ended and I switched off the recorder. Aunty Lan wrapped up her belongings. She was about to leave. She said goodbye to me, rising from her chair. But she then sat down again and kept chatting with me about her son and asked me about what I was doing for the rest of my time at the hospital. She laughed a lot. That moment she made me forget how emotional our interview had been. I reminded her to check the time so she would not miss the last bus back to Quang Binh. I thanked Aunty Lan again and suggested we would meet up in her next appointment. She then told me: “I also want to thank you. I like talking with you. I feel like I can tell you about many things. I feel lucky that I’ve met you this afternoon.” (Fieldnote, 2019)

This excerpt was taken from my field diary which I wrote after my appointment with Aunty Lan in the second month of my ethnography. In contrast with the chatty mood she had at the end of our first encounter, Aunty Lan remained quiet when we started our conversation. Like many other informants I interviewed, Aunty Lan was at first very confused about my role. She had thought I was also a doctor because her oncologist introduced me to her when she came to have her quarterly examination and I had a private room like other consulting rooms where we had our interview. But the doctor and I confirmed to her that I was not a clinician. And I was not like any doctor she had ever met because I wanted her to tell me about her life. Staff at the hospital sites were equally confused, or perhaps, skeptical about my presence and my study. They were not familiar with an anthropologist who did research at a hospital by observing and chatting. In this chapter I describe the various stages of my ethnographic fieldwork in 2019 and the issues I confronted throughout the nine months spent in the field. I discuss how I gained access to the hospital spheres and addressed the concerns of gatekeepers, as well as how I built

rapport with my informants. I also provide a description of data collection methods I used during my ethnography, ethical issues emerging from this research, and the process of data analysis.

## Ethnographic setting

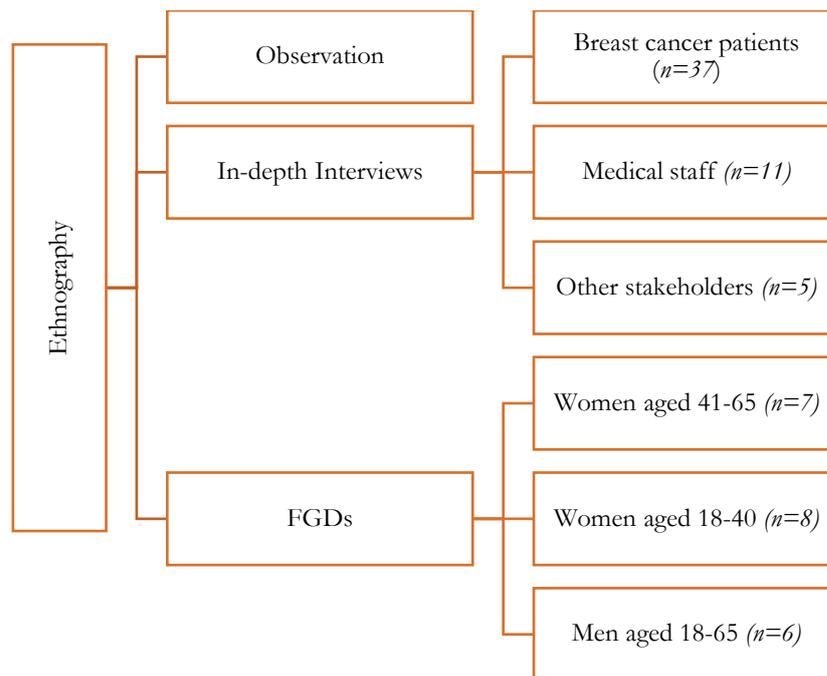
Over a nine-month period from April to December 2019, I conducted multi-sited ethnography using multiple methods of data collection, including participant observation, focus groups discussions (FGDs), and interviews (Figure 4. 1). I deployed ethnography as the methodology for my research as it enables the researcher's immersion into the social space and day-to-day lives of the population under study (Singer & Baer 2007; Creswell 2007). In healthcare research in particular, ethnography allows for the study of cultural, economic, and social circumstances that shape health-seeking behaviours and the practice of healthcare delivery (Manderson and Hoban 2006).



**Figure 4. 1.** Ethnographic procedure

The ethnography took place across multiple sites at both medical and community settings, including hospital inpatient and outpatient departments, periodic events of the local breast cancer peer support group, and home visits to a subsample of respondents. I

also conducted part of my ethnography at Bô Đô<sup>3</sup>, a rural commune lying to the north-west of Thừa Thiên Huế province and home to 4,500 people where one of my patient informants resided. There I observed the daily life of the community, interviewed several informants at the local authorities and commune health station, as well as conducted focus groups with villagers of various backgrounds. Figure 4. 2 below summarises the number of participants involved in my in-depth interviews and FGDs throughout my ethnographic fieldwork.



**Figure 4. 2.** The number of participants by data collection method

## Negotiating access to hospital sites

Within the hospital setting, a significant part of my ethnography took place within the Oncology Centre of Hue Central Hospital. The Centre consisted of two administration offices and five departments: (i) surgery, (ii) radiation, (iii) chemotherapy, (iv) palliative care, and (v) consulting. By 2019 it employed a total number of 94 staff among whom there were 25 medical doctors and 49 nurses (Oncology Centre 2019). I also undertook observation at the Oncology Department of a province-level hospital for a short period

<sup>3</sup> All names of participants quoted in this study are pseudonyms. Name of this small commune is also changed to avoid revealing identifiable details of any persons participating in my research.

of time where I interviewed several physicians and patients with the referrals of my key informants.

I first contacted the Oncology Centre at Hue Central Hospital via the formal introduction of my local supervisor and the National Cancer Hospital in Hanoi where I had tested my research tools before officially setting my foot “in the field.” The Centre first requested me to submit my research proposal, my research instruments along with Monash University’s ethical clearance to their managerial board and two weeks later, asked me to come to their office and present about the scope of the work that I was planning to implement at their Centre. At that initial meeting, I received a large number of concerns regarding my position at the Centre and particularly the methodology that my research deployed. They gave me examples from previous research studies conducted in their discipline which clearly stipulated a sample size and entailed structured questionnaires. They were unfamiliar with research that was qualitative in nature or with an ethnographic study. One manager who was also a teaching Associate Professor commented that my indication of “data saturation” as a criterion for determining the number of patients to be interviewed did not sound scientifically grounded. In addition, he wanted me to adjust my interview guidelines for both patients and medical staff since the open-ended questions that I was outlining in my research instruments would (1) disallow medical staff to participate due to their busy working schedule; and (2) complicate data analysis process as I would be unable to “generate beautiful numbers and models”. Instead, the managerial board suggested I should develop a self-administered questionnaire for medical staff to fill in as well as clarify a specific set of questions for patients.

I was not surprised by their recommendation given the dominance of quantitative studies in cancer research in Vietnam (Jenkins et al. 2018). As my ethnography progressed, I often encountered staff who were doing biomedical research with cancer patients and came to ask me “which scale are you going to use to measure the experience of the patients?” even after I had already described my anthropological study.

To defend my unfamiliar methodology, I first spoke about the benefits of qualitative research that was going to “supplement,” not replace biomedical studies in a sense that it would provide a thick description of what cannot be explained in numbers. I persuaded them that I was not going to survey several hundred staff and patients over

the course of my ethnography, so the feasibility of data collection would not be threatened. I also talked about the software for managing qualitative data, an unknown tool among the board which would facilitate the process of analysing “too many open-ended questions” as they believed. Further, I highlighted the fact that my ethnography would last for a 9-month period, so it would enable me to follow my informants in more than one appointment and by so doing, would accommodate the busy working schedule of participating healthcare providers. I received the Centre’s approval a week after my presentation with a requirement that I would work under the monitoring of a Deputy Director, the Associate Professor aforementioned, with whom I was responsible for reporting my observing schedule and holding a monthly debriefing session.

### **Building rapport with medical staff**

Being granted the approval to conduct my research at the Oncology Centre did not give me the acceptance of their staff as well as patients. As prior literature indicates, hospitals are not familiar with the observation work that anthropologists adopt during their research (Mulemi 2010). At the hospital sites where I conducted my fieldwork, cancer ward managers, medical and non-medical staff were confused about a researcher who was not medically trained but requested to attend their medical practice with a notebook on which she kept jotting down unknown content as she walked by or talked to people.

During my first weeks at the Centre, while the medical staff were overall intrigued by my presence, I could sense some alertness among the Oncology Centre’s workers whom I encountered. Later on, I found out that many of them associated me with someone “close” with the board of directors, being assigned a task of supervising and reporting back to the management team. The nurses in particular were both curious and cautious about my presence and tended to keep their distance with me when I was first introduced into the Consulting department. To gain the trust of those staff, I made extra efforts in selecting appropriate ways of communicating with them in order not to appear as an intruder or a threatening force to their practice. I avoided posing many questions and instead, tried to be as open and candid as I could whenever they had concerns and asked about my involvement, where I came from, why I was there, and what I wanted from them.

Whenever my time allowed, I joined doctors and nurses over a tea in the staff room or lunch after consulting sessions. I took this time to learn more about their job, patients, and personal life. I also had frequent chats with non-medical staff, such as the Centre's receptionist and cleaner, and listened to their accounts of daily routines or personal stories. In this informal setting, I also shared stories of my own life and work. I asked them for advice about settling down in Hue, for instance, a good neighborhood for renting out accommodation or dining places that were popular among the locals, and we often made jokes about cultural and linguistic differences between the North where I come from and the Central region.

Once the staff there were familiar and comfortable with my presence, I requested to attend their practice and observed their interaction with patients at different consulting inpatient divisions. Additionally, I expressed my interest in interviewing them in later phases of my ethnography, and as soon as a provider agreed to participate, we would schedule an interview at their office. Many of the physicians and nurses I met helped extend my sample by introducing me to other colleagues working in or out of the Oncology Centre.

My interaction with the medical staff was not limited to the context of their medical profession nor my PhD research. Throughout my ethnography at the Centre, I received several requests for helping with translating several handbooks on oncology practice from English to Vietnamese, or proof-reading research articles or reports. Some young residents approached me to seek advice about learning English or searching for an opportunity to study overseas. Others consulted me on the design of their research with breast cancer patients. I accepted these requests when my time allowed and considered it as an opportunity for reciprocity.

## **Methods of data collection**

### ***Observation***

In the first week after I obtained permission to enter the ward, the Deputy Director educated me about the Centre's structure and functions of different departments operated within the Centre. He introduced me to the head of each division with whom I later

discussed my research and arrangements for my observation. My first weeks were mainly spent at three consulting rooms of the Centre's Consulting Department. This area was the first point that received patients coming to the Centre after they completed the administrative registration (see Appendix 3). Newly registered patients came to consulting rooms to seek doctors' diagnostic examinations while outpatients<sup>4</sup> came to receive their medicines and/or follow-up examination tests. Patients who were about to be admitted to hospital also had to present at the consulting room to receive approval from a doctor before they could proceed with administrative procedures. Physicians from different departments of the Centre took turns to attend one of the consulting rooms and during their shift were assisted by one to two nurses. Their appointments were set at the end of each month and a monthly schedule was publicly listed in each room so that other staff and patients were informed of those who were in charge. There was also a board hung at the front door of each consulting room indicating the name of the doctor who attended the room on that day along with his contact number and the nurse's name.

Inside the consulting room I sat behind the doctor or next to the nurse who helped input the patient's personal details and processed documentation as required by the doctor's prescription. The doctor introduced me to the patient when one entered to have their examination. With the permission of the patient I would stay with them during their consulting session. I did not ask any questions or interfere with the patient-doctor exchange and only wrote down in my notebook about how the consultation went on. Because there was no consulting room specifically designated for breast-related issues, I attended consulting sessions of patients who visited the hospital to be screened or treated for various diseases. For these sessions I sometimes stayed inside the room to record information so that I could later compare these with records from patients having issues with their breasts as long as the patients felt comfortable and provided verbal consent to my presence. Otherwise, I would leave the room and go out to chat with patients waiting in the benches along the corridor of the Consulting department.

During each consulting session I wrote down details in my notebook to describe the first impressions I had about the patient, time and duration of the encounter, the conversation between the patient and the doctor, any physical examination if one occurred, as well as any other interaction the patient had with the in-charge nurse or other

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<sup>4</sup> Cancer patients who came to the cancer ward for follow-up care every month, 3 months or 6 months, depending on their treatment status after they had been previously hospitalised for primary treatment.

events happening when the session took place, for instance, the sudden visit by other patients who had not been called in.

In addition, I also observed at diagnostic (mammography, ultrasound room) and inpatient departments (Chemotherapy, Radiotherapy, Post-operation, and Palliative Care) at the permission of the Oncology Centre's board of directors. At the beginning of my visit, I was often accompanied by a doctor who was in charge of the sector. The staff gave me some statistics about their sector, their operating schedule and informed me where I could find breast cancer patients. Later they walked me to inpatient rooms and introduced me to the patients and left me with the patients.

I tried to divide my time between different departments and settings within the Oncology Centre so that I could talk with patients and their caregivers as much as possible.<sup>5</sup> I moved from one area to another to make people feel familiar with my presence and joined a conversation with patients and their accompanying caregivers whenever they felt comfortable and welcoming. I often chatted with their caregivers on the waiting benches during the hours when caregivers were not allowed to enter the inpatient divisions, or attended a communal lunch/dinner inside a patient's room with patients and their families. At times, I also observed at other settings outside the Oncology Centre, such as in other specialising hospitals of Hue Central Hospital, canteens, pharmacies or service centres.

Outside the medical setting, via my personal contact in Hanoi I was introduced to the Courageous Women Club (*Câu lạc bộ Phụ nữ Kiên cường*) – a peer support network that operates across more than 20 provinces in Vietnam. The network is run by a group of executive members based in Hanoi and some nearby Northern provinces. Their main platform is a Facebook fanpage named *Companions of Breast Cancer Patients* where any member can post questions and receive responses from the executive members, as well as other peers. By the time of writing, this page reached over 7,500 members. Every year the network holds several offline events for members across the country to gather and meet in person. The network is run voluntarily and not registered as a non-governmental

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<sup>5</sup> At hospital in Vietnam each inpatient is often accompanied by at least a caregiver who is a member in their family or extended family. This person stays with the patient inside inpatient room during the visiting hours during the day. At night, they usually sleep on a foldable bed they carry to the hospital. The caregivers help the patient with daily activities, such as preparing or buying meals (which is not often provided by the hospital), washing and bathing (for seriously ill patients), administering treatment or paperwork. I further analyse the patients and their caregivers' experience of hospitalisation in Chapter 6.

organisation nor social enterprise. Funding for its activities mainly comes from its members. In each province, the network supports the establishment of a “branch” comprising a team leader and patients residing in the province. Via the executive members in Hanoi, I was connected with its branch in Hue which named itself “*Đội Áo hồng*” (the Pink-shirt team) and was allowed to participate in their monthly gathering and activities. I accompanied the peer support group in various hospital visits when a group of five or six group members came to inpatient divisions, meeting women with breast cancer and shared with them their own stories of surviving cancer and provided information about the group in case anyone wanted to join. From this network I could identify participants and key informants of my study.



**Plate 4. 1.** The peer group gifting handmade chemo-hats to inpatients as part of the Pink October Month events

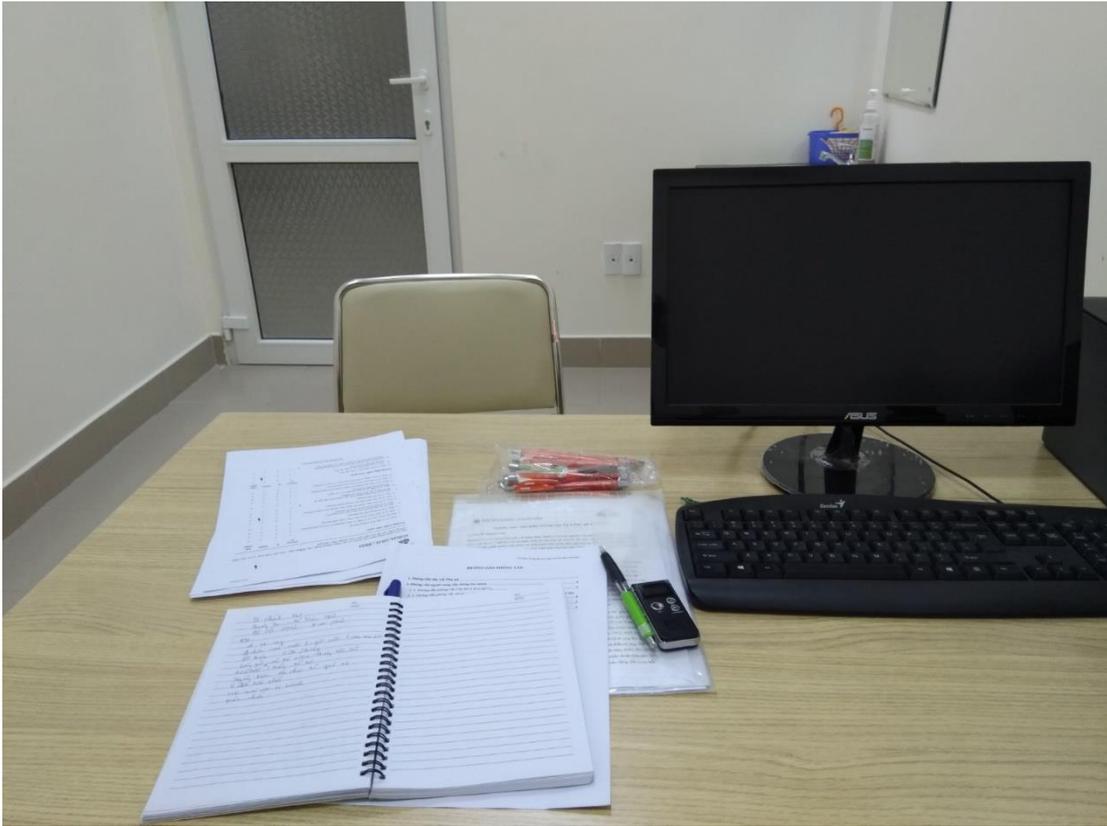
I gained a lot of information by simply “hanging out” with my participants. As Bernard (2006, p. 368) writes, “Hanging out builds trust, or rapport, and trust results in ordinary conversation and ordinary behavior in your presence.” I came to appreciate the informal nature of my data-gathering process, of becoming a participant in the women’s lives, and more importantly, the confidence that they had for my involvement. Many of my participants made me a trusted friend during and even after my time in the field. Some invited me to stay with their family or very often invited me to share a meal with them at weekend or during special occasion such as their birthdays. I had several opportunities to visit my participants at home. When possible, I would also accompany them in their daily activities, such as to the hospital on their routine care appointments or to obtain

medications, in the market to do grocery shopping, or meet with their relatives and neighbours.

### ***Interviews***

#### *Interviews with breast cancer patients*

Whenever I identified a patient who might be a potential participant of my study (breast cancer patients or those who came with concerns about breast health), I would approach them at the end of their consulting session or at their inpatient room to introduce myself and my PhD research in greater detail. I would ask them for their consent to participate in my research. When they agreed to talk to me, I tried to have a short interview which was like an informal conversation to learn about the demographic background of the women, their illness history, and contact details. These short interviews often took place on the bench in the waiting area outside the consulting or inpatient rooms. If their time allowed, I would request an in-depth interview later that day in a private closed room which the Oncology Centre assigned to me or in one of the cafeterias of the Hospital (see Plate 4. 2). If the patient could not stay longer because they had tests to complete that day, I scheduled another meeting either at their home or in their nearest follow-up appointment. I would usually call my participants by telephone within a week since our first encounter and again before their upcoming appointment at the hospital.



**Plate 4. 2.** My interview room at the hospital

The in-depth interviews with the patients were flexible and often unstructured and on average lasted from 45 minutes to 120 minutes. Three main open-ended questions were used to maintain the narrative flow and allow for the understanding of the context (Squire et al. 2014), including: (1) How did you find out about your cancer? (2) How have you been treated? and (3) How do you think your life has changed since you were diagnosed with breast cancer? By the end of the ethnography, a total of 37 informants participated in my in-depth interviews, including 33 women (see Table 4. 1) from provinces in the Central region (mean age was 46 years old; range: 26-62) and four from the North (aged 36 to 48).<sup>6</sup>

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<sup>6</sup> Aside from patients from Central regions, I also interviewed four patients from Northern provinces who came to Hue Central Hospital to have their breast reconstructed. For these patients I only used their interviews to analyse the data for the write-up of my chapter on patients' decision-making of breast reconstruction. Data on which I analyse for this whole thesis was drawn from the 33 patients whose background information I present here. Among the four Northern women, three had cancerous tumour in their left breast and one in the right. Two were diagnosed at stage II and the other two at stage III. All were married. One lived in rural area. One woman had a post-graduate degree, two had university/college degree, while the other had completed high school.

**Table 4. 1.** Characteristics of patient informants from the Central region (n=33)

<b>Province of residence</b>		<b>Marital status</b>	
Dak Lak	1	Single (never married)	5
Ha Tinh	1	Married	24
Khanh Hoa	1	Divorced/Separate/Widowed	4
Nghe An	1		
Quang Binh	10	<b>Age</b>	
Quang Nam	1	Below 30	2
Quang Nam	1	30-39	7
Quang Tri	5	40-49	12
Thanh Hoa	1	50-59	7
Thua Thien Hue	11	60 and above	5
<b>Rurality</b>		<b>Cancer stage (when first diagnosed)</b>	
Rural area	19	I	7
Urban region	14	II	15
		III	3
		IV	1
No schooling or not completing primary degree	3	Unknown	7
Primary	9		
Lower secondary	7		
Upper secondary	3	<b>Location of the cancerous tumour when first diagnosed</b>	
Vocational training	1	Right	14
College/University or Higher	10	Left	19

Among these 33 patients, I carried out follow-up interviews over the course of two to five visits with 16 patients to validate the information I obtained in the first interview. I usually started with summarising the key points of our previous encounters and asked if the respondent wanted to revise or add further points. I chose a few topics previously brought forward by the informants to elaborate. In those follow-up interviews I also inquired into new areas which recurrently emerged from my interviews with other informants.



**Plate 4. 3.** An inpatient's room

*Interviews with medical staff*

I interviewed eleven healthcare providers at different hospitals in both Hanoi (National Cancer Hospital) and Thua Thien Hue (Hue Central Hospital, provincial hospital and commune clinic), most of which were recorded and conducted at the respondent's office. Respondent's age ranged from 27 to 59 and four of the respondents are female. My medical informants had different areas of expertise and included one general practitioner, two surgeons, five medical oncologists, one radiation oncologist, one radiation cum palliative care oncologist, and a nurse. These interviews contained open-ended questions and mainly focused on five areas (1) their working experience in oncology; (2) explanatory

models of breast cancer; (3) participation and evaluation of existing cancer screening schemes; (4) participation and evaluation of cancer treatment at their institutions; and (5) perceived challenges in their work. At the end of each interview I often asked my informants if they knew some colleagues with whom I might talk to about the same issues.

*Interviews with other stakeholders*

I also conducted five interviews with local government officers (Women’s Union and Social Protection officer), a researcher, and executive board members of the peer support network in both Hanoi and Hue. Informants were recruited based on snowball or convenience sampling and included those who were either familiar with the implementation of government policies regarding public health insurance or social security, as well as the socio-economy, demography, culture, and traditional healthcare practices of the locality.



**Plate 4. 4.** People’s Committee of Bộ Đới commune

*Interviews with other patients, and families/relatives of breast cancer patients*

At the Consulting department I also interviewed women who came to visit the hospital to be screened or have a breast lump treated. These interviews were often informal and unstructured, centred on the reasons for their medical visit, screening and breast self-

examining practice, access to screening services, and perceptions of cancer and breast cancer. I did not record these interviews but took notes during and after our conversation.



**Plate 4. 5.** People waiting in the corridor of the consulting department

When I interviewed the women patients at hospital or their home, I also met and informally interviewed their accompanying caregivers in order to understand the influence they might have upon the patient's care-seeking decisions, but also the impacts of the illness on their life. My appointment with the patients at home often involved the participation of their (extended) family members and occasionally neighbours. Conversations with those people were informative in a way that they contributed to my understanding of locally and socially constructed beliefs regarding health and illness, and the experiences that the patient and their families underwent since the occurrence of breast cancer.

### ***Focus group discussions***

I conducted three focus groups with laypeople (two groups of women: one group with women aged 18-40 – FGD 01 and another with women aged 41-65 – FGD 02, one group of men – FGD 03) in Bộ Đội commune to elicit their views towards health, healthcare and illness. I used convenience sampling to recruit participants. Three weeks before the focus groups via the commune's mass organisations, I advertised my research study,

recruitment criteria (men and women aged 18 above living in the commune), with an interest in discussing health-related topics, and tentative time and place. The recruitment process ensured that participants came from different occupational and income backgrounds. Two focus groups with women were held in a village's communal house while the one with men took place in the meeting room of the Farmers' Union. Each lasted for an average of two hours and was digitally recorded.



**Plate 4. 6.** A village's communal house where focus groups took place

At the beginning of my focus group, I introduced myself as a research student from Australia studying health and healthcare rather than specifically on the narrow topic of breast cancer, which enabled me to derive their perspectives on health and illness in the broadest sense. I often started with questions about existing health issues that concerned the community and how villagers responded when a member in their family got sick. Particularly during women's focus groups, I explored locally constructed concepts of healthy breasts and practices regarding breast care, their understanding of and experience with breast examination, and access to breast care services. Later, our discussion shifted to the topic of breast cancer. Meanwhile, in discussion with men, we began talking about health issues in general and it was not until some participants

mentioned their concern about cancer that I began to elaborate on related topics (for instance, cancer prevalence in the community, their meanings of cancer, and perceived causes of cancer) to maintain the natural flow of our discussion.



**Plate 4. 7.** A focus group at Bộ Đội commune

I developed five vignettes (see Appendix 4 for detailed description) for my participants to discuss during the three focus groups, which were based on real stories I collected during my interviews with the women patients I had met in my fieldwork. These vignettes covered wide-ranging scenarios to allow for the exploration of participants' perceptions and responses to different circumstances (Whittaker 2002), which would provide the contextual understanding to my informants' beliefs and decisions throughout their illness trajectory. Participants were requested to give their opinions imagining themselves as family members, friends, or relatives of the patients told in these stories.

### ***Recruitment of key informants***

After two months into my ethnography I created a pool of “key informants” (Bernard 2006, p. 196) comprising two doctors and three women patients whom I would meet

regularly for the remaining time of my fieldwork. I usually identified them after our first or second interviews based on the amount of information they could provide and their extent of openness to my research. With those people I recorded our first interviews whereas our follow-up appointments usually took place less formally, either over a tea/coffee, lunch or dinner, and were not digitally recorded. For that reason, it was more appropriate for me to take notes during or immediately after our conversation. Over the course of my fieldwork, those key informants helped clarify topics that I was not familiar with and verified themes emerging from the interviews with other informants. Additionally, they suggested or introduced me to other potential participants whom I later approached to elicit their interest in participating in my study.

## **Ethical issues**

Doing ethnography offers medical anthropologists unique opportunities to gather rich data to generate thick description about health and illness experience because it allows them to study their target population over an extended period and gives them adequate time to build researcher-participant relationships. Such approach enables in-depth understanding of the research context and basis for people's behaviours. Researchers carrying out ethnographic research, on the other hand, always face a continuum of ethical tensions they need to address before and during the time they get in the field. Particularly in a qualitative research project with an unstructured and unpredictable nature (Liamputtong 2013) which was concerned with very intimate accounts of women's illness experience and occasionally, their painful memories, every question might pose "a moral dilemma" (Clegg and Slife 2009, p. 24). In view of this, ethical responsibilities were seriously and carefully considered from the beginning of the research design and throughout every stage of my ethnography to protect my participants' freedom and privacy. Participants were informed about their involvement in the research and made aware of the whole procedure as well as any risks that might arise from their participation. They were provided with a detailed statement and explained in plain language about the research and their rights to participate, disengage, or withdraw at any stage of their participation. My informants had the right to choose the time and space where the interviews took place, which made them feel comfortable and protected the confidentiality of the data they were to share with me. I also paid greater attention to

“implicit dissent,” taking into account that there were possible cases when the women disagreed to participate but did not explicitly articulate their opinions. This is not unusual in a culture like Vietnam where women, especially those from rural areas, often act in a modest manner and tend not to refuse to a request. For instance, when women did not show up for a scheduled interview or focus group, remained silent during when asked any question, or showed discomfort during an observed consultation such as appearing reluctant to answer a question asked by their doctors when I was around. When such signs were detected, I would pause the interview/focus group or refrained from observing the participants in the consultation room. I would look for a later time to resume my research or withdraw the data from those participants should they not be willing to continue. This thesis and all related publications only use pseudonyms and unidentifiable information. All photos used in this thesis were produced at the permission of my participants. They were either taken by myself or my participants. Some pictures had already been posted in the participants’ social media accounts. Otherwise, the sources would be acknowledged. Those considerations and arrangements helped avoid any possible harms and minimise the risks of being in a stressful situation (Liamputtong 2007) as my participants took part in this kind of sensitive research. In the sections that follow I describe in detail ethical issues associated with the implementation of my ethnography.

### ***Implementing procedures***

I obtained the approval to conduct this ethnographic study from Monash University Human Research Ethics Committee (Project 14130, approved on 29 November 2018). Prior to my fieldwork, all explanatory statements, consent forms, leaflet, and research tools were translated into Vietnamese and adapted to be more culturally and linguistically appropriate in the context where my ethnography took place. These documents were later reviewed and approved by the Internal Review Board in Human Subject Research of the Institute for Social Development Studies (Vietnam – approved on December 21, 2018), as well as by the various hospitals’ boards of directors and peer support group leaders. At the hospital, I observed consulting sessions and inpatient rooms only with the permission of the medical staff in-charge on that day who introduced me to the patients as a student from Australia who wanted to learn about the life of cancer patients. I would stay at the consulting room only if the patient gave a verbal consent to my presence. I prepared a short introductory leaflet (attached in Appendix 5) summarising the explanatory

statement to give to the patients and always wore a Monash University ID card whenever I was at the hospital to clarify my independent role.

In the explanatory statement provided to potential participants, I clearly set out that participation was voluntary and participants had the rights to withdraw or not answer any questions they did not feel comfortable with, and that all information was confidential and would not affect their treatment status or relationship with the medical staff. The possibility of using or not using a recorder was also communicated at the beginning of each interview. I also provided the contact details of the “*Đội Áo hồng*” executive members who had previously agreed to be listed and offer help to any patients who experienced any distress from recalling their illness trajectory or simply wished to join a network with other fellow patients. Members of the peer support network in Hue had received training on providing peer-to-peer counselling organised by Hue Central Hospital in collaboration with the Global Focus on Cancer, an international non-profit organisation whose mission is to support the development of locally sustainable cancer support groups.

All personal names used in this thesis and the name of the commune, are pseudonyms. All FGDs and most of the in-depth interviews were digitally recorded. When informants indicated their preference for not using a recorder, I wrote down extensive notes during and immediately after the interview. I transcribed around half of the recordings myself and hired two research assistants to work on the remaining tapes. Both assistants come from the Central region, so they are familiar with the culture and could understand the dialects that my participants spoke. I generated a unique code without any identifiable information for each informant. If any names were accidentally recorded, they would also be removed before I sent out the recordings to the research assistants.

### ***The position of a hybridised anthropologist***

In the context of the study, I consider myself to be a hybridised anthropologist. Being a Vietnamese woman from the North of Vietnam, I have experienced a history, culture, and society which is distinct from the Central region. I have gone overseas to pursue higher education in Western countries and exposed myself to multicultural and multinational environments, which has provided me a different background from most

of my participants. The majority of participants in my fieldwork are from families who mainly rely on farming for their livelihoods and most have not had post-high school education. Many have lived in rural areas for most of their lives. Such differences render me equivalent to a non-native anthropologist, allowing me to observe and evaluate the situation as a non-participant. On the other hand, I am able to conduct my research from emic perspectives. From 2011 to 2017, I worked in a number of development projects as a social researcher or practitioner in the Central provinces of Vietnam. Therefore, I am familiar with the area and understand their traditional norms and rituals, as well as the local language. However, my ethnography took place in sites where I have never worked before, and in that sense, there were no previous relationships that could affect participants' expectations of me in my role as a researcher.

### *Gifting and volunteering*

All participants involved in my in-depth interviews and FGDs received a gift as my token of appreciation for their time, such as a notebook with a Monash USB stick (for medical staff and other non-patient informants), a scarf or an insulated water bottle (for patients). When I visited informants in their homes, I often brought fruits or sweet treats for their young children. In certain cases, such as in FGDs with villagers in Bội Đội commune where participants were requested to gather at the communal house, they were covered for their cost of transportation with money (50,000 VND or approximately US\$2.20<sup>7</sup> per person). When interviews took place at a cafeteria, I offered to pay for my participants' drinks or meals. In a few cases when I learned that my participants were facing economic troubles, I offered them financial assistance after all the interviews had finished and via a third person, usually “*Đội Áo hồng*,” in order to ensure my anonymity and importantly, avoid incurring any sense of indebtedness to the recipients. I myself also received gifts from my participants. Some of my participants brought me fruits or other produce they grew in their farms when they came to see me again in regular follow-up appointments at the hospital or when I visited them at their home. I was also invited to share a meal with my participant's family when I visited them or on special occasions. In such cases, I would accept their offers because they symbolized their trust in our relationship and also because it would cause offence not to accept. In addition, I did not want to burden them with

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<sup>7</sup> 1 USD is equivalent to 22,800 VND at the time of writing

carrying the gifts in a long journey back to their hometown on different modes of transportation.

Within “*Đội Áo hồng*,” members first perceived me as a student and a researcher. Some thought of me as a journalist who wanted to record their life after breast cancer diagnosis. Later on, they embraced me as a member of their team and invited me to every formal and informal event that took place during my ethnography, including a series of Pink October events, charity hospital visits, and their monthly birthday group celebrations. At the end of my fieldwork, I volunteered to raise funds for their community events on raising breast cancer awareness although I was not involved in the funding reimbursement nor event organisation which took place after I had returned to Australia. I view these diverse roles as beneficial to enhancing my rapport with participants, allowing me to gain emic perspectives, and providing me an opportunity of reciprocity, similar to what I experienced with the medical staff at the hospital.

#### ***Reaffirming my role as a researcher, not a medical doctor***

During my observation, sometimes patients were confused about my role at the hospital. They saw me on the bench in the waiting corridor, inside the consulting, mammography, and inpatient rooms. They watched me exchange words with doctors and nurses, as well as guarding officers. Many first thought I was also healthcare staff, despite the fact that I did not wear a white coat. They also spotted me talking to patients and their family members, sometimes with a recorder and most of the time with a notebook.

To clarify my role, I prepared an information sheet at the consulting room where I was allowed to attend. This document described me as a researcher from a university in Australia who is not a medical doctor and explained that there was no connection between my observing practice and the treatment patients were going to receive at the hospital. This was again re-confirmed by the doctors when they introduced me to incoming patients. In the waiting room or at various events for breast cancer patients, at the very moment when I first approached patients and invited them to participate in my study, I always introduced myself as a research student and not a medical doctor.

However, very often I faced situations when my respondents “interviewed” me in search for advice on their diagnosis or treatment. For instance, HỒNG, whose story I mention later in my thesis, met me at Hue inpatient room while waiting to receive

chemotherapy, showed me her cancer pathological report and asked me to explain to her about the meaning of Estrogen-positive (ER+) and Progesterone-positive (PR+) cancer. Or in another circumstance, a woman I interviewed at her home wanted to know about the stage of her breast cancer. She could not understand her test reports that list T2N1M0 and none of the medical providers had ever explained them for her. Her result sheet read “not metastatic” but she was confused about the information stating that she had a tumour of 1.7 centimeter in diameter. Very often during or after my interviews, my informants asked me about whether or not they should take some complementary medicines sold online that other patients had said would be able to “cure cancer.”

As my rapport with patients became deepened, I increasingly received requests for treatment advice. Some of them required immediate and urgent response as in the case of 36-year-old Thu. She was prescribed Herceptin for the treatment of HER2-positive which would cost her approximately 400,000,000 VND (~US\$17,543.86) – three times higher than the value of her family’s total savings. She told me a couple of days after her diagnosis that she was unlikely to continue the treatment because one of her relatives had reassured her that it was unnecessary for her early-stage cancer and wanted me to provide her with the same confirmation. In such circumstances, I could have shared with them the knowledge I learned from reading medical research or from conversations I had with the oncologists and by doing so, helped them avoid the fear and anxiety when seeing a medical specialist. However, being an anthropologist with no prior training in health sciences I never took on such a role.

On the other hand, I could not simply ignore their requests, especially after lengthy hours they had helped me with my research or entrusted me as a close friend or a family member. More importantly, the information that they were told by someone without a medical background possibly led to a delay or treatment opt-out, which would be detrimental to their treatment outcomes and survival. I took this opportunity to pose additional questions about their relationship with their doctors and found out about the barriers in their communication. Accordingly, I would persuade them to speak about their concerns with their doctors and when possible, referred them to appropriate contact points.

***“I never told anyone my stories” - A researcher’s role as a bosom friend and a companion***

While sharing their intimate accounts of living with a malignant health condition, many informants could not hold back tears recalling how their life had flipped upside down, how the earth underneath their feet shook, or how they felt that the sky over their head was falling down when they received their cancer diagnosis. We shared tears as they revealed the financial burden the illness had brought; the fatigue resulting from the medications that made them feel like they were living in the body of a person with a disability; about the disruptions and non-bodily losses outside the operation rooms. Women talked emotionally about how their children had served as their buffer in the worst days, boosting their recovery and determination to carry on, or about their devastated feelings when relationship breakdowns occurred to them in the post-cancer life. We also shared laughs over stories of their creativity in self-tailoring their own cushion to replace the missing breast so that they looked the same as before their mastectomy. Like Aunty Lan whose conversation I shared at the beginning of this chapter, many of my informants admitted that they could confide the most sensitive parts of their life during our interviews, such as changes in their sexual life with their husband. When I thanked them at the end of our encounter, very often they came to tell me that they felt much relieved. They appreciated our interviews because during our conversations, they could express the feelings they had stuffed deep down inside and had never been able to tell anyone in their close kinship group or network. Many women told me they had pretended to act strongly and courageous in front of others even though they had constant fears over cancer relapse, metastasis, and death. In that sense, I see my interviews as carrying some cathartic benefit for my participants, a situation that has been shared by many other researchers doing research with different vulnerable groups because their participants are able to reveal their concerns and have someone interestedly listen to their stories (for summary, see Liamputtong 2007). On the other hand, the situation also suggests the absence of professional services for patients to access so that they can safely disclose about their psychological distress and emotional needs while seeking oncology care at public hospitals in Vietnam.

## **Data management and analysis**

During the interview I used a digital voice recorder after obtaining the consent of my informants. In case they did not feel comfortable with recording, I would resort to taking extensive notes during my interview. Even when the interview was recorded, I still attempted to generate notes right after the interview to describe the setting, how the participant appeared and responded, as well as notable themes emerging from our conversation. I compared these notes with the transcripts of the interview during the analysis process to better document and understand the surrounding context where the interview had taken place.

Given the lack of knowledge regarding the lived experiences of cancer in Vietnam, I analysed the data using a grounded theory approach (Charmaz 2014). Grounded theory allows for the understanding of the social processes and context upon which women's lived experiences are predicated. Using this approach requires paying greater attention to the informants' narratives and perspectives rather than already-established assumptions, thereby enabling the generation of original insights and theories (Strauss and Corbin 1997). Data analysis began simultaneously during the data collection phase to allow for the identification of patterns and themes that needed to be further validated. This also enabled me to remain open to emerging themes, as well as to refine my interview guidelines. Throughout my fieldwork, I generated a memo to describe my first impressions with the data and noted recurrent and emergent themes and concepts, and then translated all these notes into English and regularly discussed with my supervising team who also advised on areas I should pursue further.

All recordings were later transcribed verbatim in Vietnamese, the original language in which they were conducted, in order to preserve the subtlety and nuances of my informants' accounts. These transcripts along with observation and interview notes were then organised into separate folders by type of informants (healthcare providers, patients, laypeople, and other stakeholders), loaded and analysed using NVivo 12.0 software. I initially identified broad concepts by applying open coding to analyse a subset of transcripts, including ten patient, five healthcare provider interviews and one focus group. I selected this subset to ensure variability in patient's age, living region (rural and urban), and cancer stage. Emergent codes derived from the open-coding stage were refined through constant comparison within and between transcripts, and later collapsed into broader codes. These broader codes with selected samples of quotes were translated into English so that I together with my supervisors could develop a consistent code structure

and agreed on a codebook. Upon the codebook's completion, I conducted focused coding (Charmaz 2006) on the entire dataset by synthesising larger data segments using the codes established earlier. Given the nature of grounded theory, I remained open to unexpected ideas that emerged from this coding stage by moving across transcripts and comparing data to data, and data to my codes. Categories were then developed out of the focused codes and the relationships between them were eventually identified.

### ***Internal validity***

Data validation was undertaken in the form of triangulation. There are three types of triangulation (Miles and Huberman 1994) used in my research to enhance the findings' internal validity, including from: different sources of data (patients, healthcare providers, community people, and other stakeholders); by using different methods (observation, interviews, and FGDs); and at different points in time (spanning across three stages of the ethnography).

## **Conclusion**

In summary, this chapter describes the methodology I have deployed to answer my research questions and outlines the constraints I was faced with while attempting to gain access into the hospital facilities. Most notably, I confronted the reservations and scepticism of the medical staff over the ethnographic nature of my study. This was owed to the fact that the presence of social scientists was rare and social science research of this type is unfamiliar in Vietnamese hospitals. While I was able to solve the initial misunderstanding, my present study also identifies the potential room to foster the collaboration between medical and social sciences. Hospital-based ethnographic research can contribute to enhancing the knowledge of patients' perspectives of the care they receive, but also the subjective experiences of healthcare professionals in relation to the provision of care. In view of this, it is mutually beneficial to both the researchers and the host hospital.

Recruitment of healthcare providers was a noteworthy limitation of my research. Considering the overcrowding situation at public hospitals in Vietnam, there is a shortage of staff in large urban hospitals where doctors and nurses are usually overloaded and

constantly required to work overtime. This posed challenges in finding healthcare provider informants who were willing to commit an hour of their time to participate in my interviews. In many cases, I had to meet doctors during their evening or early morning shifts for an interview. It was also usual that an interview was rescheduled several times due to the time constraints of my informants. In a few cases, I had to cut short an interview because the interviewee had to attend to an emergency case or had an unexpected meeting and thus, had to drop out. That situation resulted in a small number of healthcare professional informants recruited for this research.

My research did not include women patients who had just received their cancer diagnosis and those who were seriously ill and receiving end-of-life care because I was concerned about their psychological distress. In addition, there is a lack of representation of young women under 30 years of age among my participants. While my sample reflects the current age pattern nationwide where over 60% of breast cancer patients belong to 40-60 age group (Nguyen, L. H. et al. 2013), it has been recently suggested that the trend is changing and Vietnamese women are diagnosed at younger ages (see Jenkins et al. 2018). Future research could consider including these groups to capture their varying concerns and wide-ranging experiences when living with breast cancer, for example issues related to fertility needs among younger women and palliative care among critically ill patients which remain largely unexplored in many LMICs' research agendas.

Due to the nature of my research which involved participants who lived with a life-threatening condition, from time to time I met women diagnosed at a late stage of their illness, or those whose health condition deteriorated during the course of my ethnography. Some women passed away while I was still in fieldwork or after I had returned to Australia. Listening to their stories about the struggles between life and death and mourning the loss of my participants was traumatic not only as a researcher who had documented their narratives but also as someone who had considered many participants as her friends. Every stage of my ethnographic fieldwork, from data collection until analysis and writing was a replay of traumatic events, which is often captured by other scholars who conduct this type of emotionally demanding research (e.g. Wray, Markovic and Manderson 2007). Prior to my fieldwork, I had not been mentally prepared to deal with such devastating news and the feelings of powerlessness, sadness, and grief usually invaded me post-fieldwork. I am immensely thankful for the network of supervisors, friends, family and especially many of the women in the peer support group whom I could

lean on and helped me cope with those feelings. On the other hand, I also strongly believe that the availability of professional counselling services tailored to support researchers would be critically needed to help them overcome the distress resulting from studying highly charged topics.

The findings from this nine-month fieldwork are presented in the subsequent chapters. Each chapter begins with a review of relevant literature in Vietnam and elsewhere to provide a background to the topics of focus. This is followed with the analysis of my ethnographic data. In each chapter, I provide the perspectives of my participants to support an argument or a prominent theme emerging from my fieldwork. At times, I choose several case studies in which I quote participants at length and describe the context within which their understanding and experience of breast cancer is embedded. I also discuss how my findings reconfirm or advance the knowledge that has been existing in the respective fields.

## Chapter 5.

# Making Sense of Breast Cancer: Explanations of Cancer Aetiologies

### Introduction

The search for what causes an illness may be seen as an attempt to bring order to a disordered situation, providing a meaning to traumatic events and maintaining a sense of meaningfulness (Das 1995; Harris 1989). A cancer diagnosis triggers an “existential plight” for persons with cancer, leading them to look for “meaning in life” by seeking to understand why they have cancer (Kernan and Lepore 2009, p. 1176) and through this process to establish a credible aetiology, people also seek to “re-establish agency” (Manderson, Markovic, and Quinn 2005, p. 324). This chapter provides insights into how different perceptions about cancer causation are constructed within the intersection of biomedical, epidemiological explanations, and social experiences. Examining what Davison and colleagues (1991) term “lay epidemiology”— the process through which health risks are understood and interpreted by laypeople — contributes insights into the ongoing social-structural circumstances which shape the way patients and their families make sense of their illnesses. Throughout this chapter I draw attention to the broader contexts that ordinary people blame for causing their illness and contributes to the growing body of literature suggesting that the notion of risk has come to express social and political concerns (Nelkin 2003; Petryna 2013). In non-experts’ search for causation, a cancer risk is always shaped by specific environments and only made meaningful through long-standing popular and contemporary ideas about embodied vulnerability to exogenous influences (Gibbon 2018). Biomedical concepts alone do not suffice in explaining why a particular person experiences cancer. In my study, popular accounts do not exclude prominent biomedical knowledge regarding cancer risk factors. Nevertheless, people reinterpret and reconstruct their understanding by locating such knowledge in a framework that is meaningful for their life circumstances. My findings that follow

challenge the assumptions that view risk merely in objective terms by revealing how the understanding of cancer causation in Vietnam is mediated through the particular historical social contexts of warfare, a transitional market economy, poverty, and cultural configurations of gender roles.

As Dorothy Nelkin (2003, p. viii) observes, “people perceive risks through different ‘frames’ that reflect their values, world views, and concepts of social order. These frames can influence definitions of risk, allocations of responsibility and blame, evaluations of scientific evidence, and ideas about appropriate decision-making authority.” This chapter’s analysis is built on this conceptualisation to reflect on the varying “frames” that patients and their families rely on to assemble their explanations in response to the question of “what causes breast cancer?”

Most studies adopting social science perspectives on lay aetiologies of cancer have emerged from non-Western developing countries in the last two decades. In those studies, lay explanations of cancer causality are often combined with epidemiologically established risk factors, and the two are not mutually exclusive. Factors identified by scientific evidence such as heredity or genetics, exposure to environmental pollution or radiation, as well as consumption of food that contains carcinogenic chemicals are pervasive in lay explanatory models across various settings from Asia to Africa (cf. Dumalaon-Canaria et al. 2014; Manderson 2011). Lifestyle risk factors such as smoking or alcohol drinking are also incorporated in lay aetiologies of cancer but often in a dissimilar way to Western societies which often place the blame on individuals for their risky behaviours. For instance, in her research in rural China, Lora-Wainwright (2013) finds that Chinese families employ aetiologies such as smoking and drinking in explaining cancer. However, these families do not blame the sufferers for engaging in smoking or drinking because these behaviours constitute masculinity and are important to social life – they are parts of normalised habits (2013, p. 27).

Embedded in lay explanations of cancer are people’s interpretations of biomedical views in individually meaningful terms. For example, women in Southern Mexico understand cancer as partly caused by excessive parity combined with a lack of practical support, rather than focus on its physiological consequences (Hunt 1998). Similarly, Martínez (2018) notes that patients’ explanatory models of cervical cancer in Venezuela

are drawn on biomedical risks such as sexually transmitted diseases, but frame these within their own life experiences, such as the male partner's role in risk aetiology.

Among recent scholarship on breast cancer aetiologies, a study in Southern Thailand by Liamputtong and Suwankhong (2016) demonstrates that while some laypeople invoke biomedical risk factors such as genetic inheritance or hazardous food to explain their illnesses, Buddhism greatly influences the understanding of causation among most Thai women. In their worldview, bad karma, accumulated through previous acts such as an abortion, is considered the underlying cause of breast cancer. Similar beliefs linking cancer with one's previous actions are present among Indian and Iranian women who attribute its occurrence as a form of punishment for sins (Howard et al. 2007). Meanwhile in China, breast cancer is believed to result from a woman's fate or bad luck (Simpson 2005). The aetiological association between negative emotions such as stress and cancer is often found in research eliciting lay epidemiology. For example, Nelson's study (2017) shows that stress emanating from unmanageable demands of a modern life is a widespread causal belief among South Korean women and through this aetiology, they consider breast cancer a sign of prosperity gone wrong.

## **Local constructions of women's breasts and cancer knowledge**

While breast is " *vú* " in Vietnamese, in daily conversation people often use the word " *ngực* " (chest) interchangeably with " *vú* ." For instance, a woman tends to say "I had a lump on my chest" when discussing breast lumps in public places to maintain her modesty (See more in Chapter 6 on the initial discovery of a breast lump). Referring to " *ngực* " rather than " *vú* " also signifies greater politeness because in certain circumstances, " *vú* " is considered to have an erotic meaning. In Central Vietnam, people deploy the word " *bụ* " to refer to a woman's breast as a whole, or " *trái trôm* " when describing the inner hard structure of the breast, excluding the nipple.

The meanings given to the female breast are always closely connected to societal values and cultural norms (Yalom 1997). Contemporary Vietnamese society continues to celebrate women's heavenly mandate (" *thiên chức* ") of childbearing and breastfeeding (Rydstrøm 2006). It is, therefore, unsurprising that participants in my ethnography

primarily discussed the maternal role of women's breasts when asked about the meanings they attached to this intimate part of a woman's body. They believed that the most important role of their breasts was to produce milk and nurse their children. Standards for beautiful breasts were also shaped around this nurturing role. For instance, according to the women villagers in my FGDs, in the old days, a groom's mother preferred having a daughter-in-law with round, blooming breasts (*"bụ nở nang"*) and large buttocks (*"mông bự"*) with a belief that she could give birth easily and produce a lot of milk. Having this in mind, the shape and look of one's breasts could affect a woman's marriageability because those who had small, flat, deflated (*"xẹp lép"*) breasts were not desired due to a belief that she lacked the ability to produce sufficient milk, nor milk of good quality to her children.

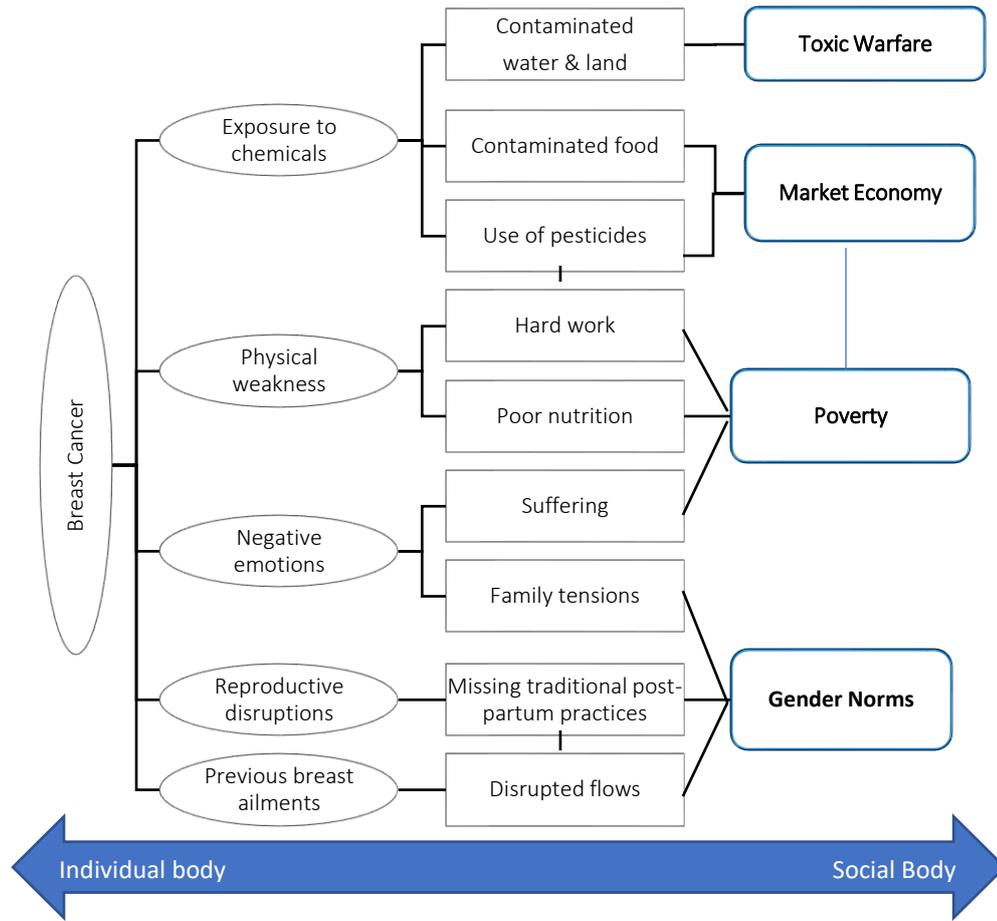
Aesthetically, women stated firm breasts were highly desired and during lactation they were advised to protect their breasts from turning flabby (*"chấy xệ"*), firstly by recruiting a senior experienced woman to help with "milk squeeze" (see more detailed description about this practice later in this chapter) in a gentle manner that caused little pain to the breasts and preserved their forms. Having medium-sized breasts was more ideal than large or flat breasts. Different from published literature in Western countries which often regard women's breasts as a visible site of sexuality or eroticism (for example, Lupton 1994; Saywell, Henderson, & Beattie 2000; Yalom 1997), my research participants were reticent in discussing their breasts as a sexual object. Given the primary link between women's breasts and women's heavenly mandate of motherhood, many informants interviewed in my fieldwork often explained the origins of cancers by referring their maternal and nurturing obligations as I elaborate further in this chapter. Additionally, such constructions regarding the meanings of women's breasts also influence women's decision-making in relation to their mastectomised body which is explored further in Chapter 8.

In terms of cancer language, in Vietnamese, cancer is translated as *"ung thư,"* (breast cancer is *"ung thư vú"* which is a universal term used across different regions of Vietnam) and a malignant lump is called *"u ác,"* as opposed to *"u lành"* (benign lump). Both adjectives *"lành"* (malignant) and *"ác"* (benign) are often used to describe the characteristics of a human or an animal – a movable subject with thoughts and emotions — reflecting an understanding of cancer as having an agentive nature acting upon the body. My informants could refer to a non-exhaustive list of terms to describe the various sub-categories of a benign lump, for instance *"bướu"* (a lump which grows visibly on the

skin), “*u nang*” (a fluid-containing lump), “*u mỡ*” (a fat lump), or “*u bã đậu*” (a bean-residue lump), and often describe various traditional methods, mainly using medicinal herbs that were available in their local regions, to treat those “*u lành*” (which I describe in detail in Chapter 6). Meanwhile, people tended to deploy relatively broad terms for malignant lumps, such as “*ung thư*” in formal settings, or “*u ác*” and “*K*” (read as /ka:/, a short form borrowed from the Latin word *karkinōma*). In most participants’ opinions, “*ung thư*” vitally required the interventions of biomedicine. The limited knowledge of “*u ác*” as contrary to “*u lành*” partly indicates the foreignness of cancer in local knowledge and for that reason, people often depend on modern frames to understand and interpret the disease.

### **Varying frames of cancer causations**

Within my interviews and FGDs, I asked about the perceived causes of cancer in general and breast cancer in particular. Most participants were familiar with biomedical discourses of the carcinogenic potentials of hazardous food and chemicals or exposure to contaminated environments in their accounts of what caused cancer. For non-patient participants, the distinction between aetiologies of cancer and breast cancer often became blurred. Most non-patients believed these factors were associated with cancer in general, not particularly breast cancer. However, these risk factors alone provided insufficient explanations for patients and their families for their particular experience of breast cancer. Rather, patients tended to draw on their specific life circumstances for their explanations and perceived breast cancer as a gendered manifestation of their vulnerability created through warfare, market economy, and poverty. Women also referred to their maternal and nurturing obligations to search for the source of their cancer. Figure 5. 1 depicts the relationships described by my research participants between the broad social settings that affect the collective social body, to the more specific effects they experience in their personal lives which they believe responsible for their experience of breast cancer. Breast cancer is understood as one form of embodied mediation of the effects of a rapacious market economy, contamination, and social distress. These are discussed in detail below.



**Figure 5. 1.** Lay constructions of cancer aetiologies: varying frames of causations

## The Market Economy

The market economy figured in women’s narratives as the source of a number of harmful effects upon their health including the use of pesticides in agriculture to ensure higher production and increased consumption of food that is contaminated with chemicals and pesticides.

### *Exposed biologies*

Exposure to farming chemicals was widely held among my participants as a direct cause to various health problems. Like many informants, Trà (aged 56, Quang Tri) suggested an association between pesticides and her breast cancer. Her exposure came through her work as a farmer and she admitted to having used “a lot of pesticides” for her 1,000

square-meter paddy field, and therefore to have fallen a victim of her own hazardous practice. But she saw herself not as a perpetrator but also a sufferer.

(...) I lost three babies because of my destitution. I also had to use a lot of pesticides. The doctor said I was poisoned. I had three miscarriages continuously. He said it was because of it [the use of pesticides] (...) People told me to use pesticides, but I did not know how. I filled and carried the whole big bottle. Whenever I carried it and stood up, it spilled out of the bottle and spread to my shirt. It penetrated my body. I did not realize soon enough to get a shower then... You know, my disease was because of that.

Writing in rural China, Lora-Wainwright (2013) maintains that in perceiving chemicals used in the farm as a cause of cancer, farmers in her study construct aetiologies vis-à-vis the current market economy and morality. Wahlberg (2018) also notes how subfertility is blamed upon the “exposed biologies” of the population from contaminated foods, water and air pollution as a result of post-reform China’s industrial growth. Likewise, in Trà’s account, her commentary articulated the indispensable role of farm chemicals in a transition to the market economy in which producers must compete with one another by finding ways to boost their productivity and enhance their products’ appearance by using pesticides because “everyone else used that in their own fields.” While Trà was fully aware of the dangers of using chemicals which were blamed for her past miscarriages, she felt she had no other choice but to use them due to her sole responsibility to provide for her family.

### ***Contaminated food***

The use of pesticides and chemicals in farm production is understood to lead to contamination of food. My informants described this as a factor beyond their control rather than one’s choice of lifestyle, as in the case of **DƯƠNG** illustrated below.

#### *Case Study - DƯƠNG*

I went to visit **DƯƠNG** at her home at the very end of a quiet road south of Hue. **DƯƠNG** was 47 years old and was diagnosed with stage II breast cancer in 2015. I met her several times at the hospital and the peer support group and she became one of my key informants during the time of my ethnography. I was sitting by the window in their living

room. From there I could see half of the room's space was used for worshipping: on the higher altar sat the statue of Guan Yin Goddess of Mercy (*Phật Bà Quan Âm*) while on the lower smaller one was wooden-framed pictures of deceased family members. In the remaining space were a high desk and a couple of plastic chairs to the left end and **Dương's** knitting materials and machine to the right. Her mother, Aunt Huynh (83 years old), walked out of her room and sat with me while her daughter went to serve a client who wanted to buy a pot from her plant-shop in the front yard of her house. Lighting a cigarette, Aunt Huynh saw my surprise because it was not common for a woman in my country to smoke. "I had been smoking since I was 16 or 17 until now. Everyday I have 1 or 2 cigarettes. I learned it from my father. He worked for the Nguyen Dynasty and sometimes I accompanied him to see his friends from whom I learned how to smoke." She explained to me that smoking made her feel awake and happy ( *vui*). While looking skinny, Aunt Huynh moved very fast and spoke in a clear, precise tone. "She was fit and active, not having any severe illness," as **Dương** told me about her mother. She still prepared meals for the whole family, including **Dương's** husband and two sons, and her younger brother who suffered from a psychiatric disorder.

As **Dương** came back talking to me, Aunt Huynh joined our conversation about cancer causation. She believed that the alarming growth in cancer cases in recent years had resulted from toxins introduced into body through food and explained it as a consequence of excessive use of pesticides in agriculture:

Now everyone sprays pesticides to make their plants grow faster, bigger. And then after only one day or two, they take these plants to sell in the market. It is them who kill us, not anyone else. In the past, to make the plants grow and flourish there was only a way by using manure. We blended pigs' manure with straw and soil. It was non-toxic. Now that they use it [pesticides], it caused cancer. We buy them, eat such chemicals and develop disease. But we could not just stop eating.

For Aunt Huynh cancer was a new phenomenon that only occurred in modern times. She contrasted the present situation with that in the past and found the discrepancy regarding farming methods (use of pesticides rather than manure made in a traditional, "organic" way) and consumption patterns (eating hazardous foods) as playing a role in determining the occurrence of cancer. She emphasised the one who should be blamed (people selling chemically contaminated food) for "killing us" and at the same time,

maintained the lack of control among people like herself, her daughter, and other cancer patients who were aware of the hazardous situation but became powerless: they had no alternative but continued to consume the food in order to survive.

Another patient described the consumption of unsafe food as an inevitable requirement of a modern woman's highly pressured working life. My, a 29-year-old woman from Phong Điền, a semi-rural district about 20 kilometres away from Hue, was among the youngest patients interviewed in my ethnography who was only 26 years old when she received her histologic report indicating the cancerous status of her breast lump.

In the old days my husband and I lived on our own, so we often ate out. We rarely cooked. Because there was only the two of us. We made some good money while we both worked so we did not have time. I keep asking whether it was because of that I had this disease (...) The food, I don't know what kind of food they cooked for us.

In My's opinion, her long exposure to food that contained unsafe preservatives was the possible cause of her cancer at a young age. The consumption of market food attested to a "modern life" demanded by the market economy which was characterized by living independently as a nuclear family and women's increased engagement in the labour market. After her marriage, My and her husband lived on their own in a rented flat near her factory rather than staying with the husband's family as is customary. With this living arrangement she lacked support from her in-laws when it came to household chores such as meal preparation. The consumption of food which was not home cooked was an essential part of her daily life when she worked long hours, starting from 8am to 6pm at the textile factory, striving to offset the high cost of living for a newly-wed couple.

In recent decades, food safety has become a mounting social and political issue in Vietnam (Wertheim-Heck et al. 2014) where the media has been replete with reports of food scandals regarding the overuse of chemical inputs in agriculture and food processing. The situation has intensified the public's anxiety over the food they consume, as well as diminished their trust in food producers and regulators (Figué et al. 2019). People's concerns over the causal link between the toxicity of food and illness are increasingly present in anthropological accounts studying health issues in Vietnam (Lincoln 2014b; Swenson 2020). For instance, Tine Gammeltoft (2014) illustrates that pollution of food, air, and working environment pervades people's explanations for infertility, spontaneous

abortions, and birth defects. Her informants believe that the increasing exposure to toxic food and environment is the price of Vietnam's rapid economic growth and transition to a liberalised market economy.

In my particular study, I would argue that the price is felt not only among rural poor women like Trà who had few choices but to continue using pesticides to produce a better rice yield in her attempt to fulfil the breadwinner's role in her family. The price of modernisation, of economic growth also takes its toll on urban residents such as the case of Dương and her family whose intake of toxic food was completely out of their control because of what they viewed as irresponsible or immoral food producers. Or as in the case of My, vulnerability is perceived to be the result of "eating out" and therefore being prone to food contamination because of the requirement to work in a job with long hours and high pressure to produce a sustainable income to offset the high cost of living for a young couple. The way patients and their families try to understand the causation of their illness through their ingestion of hazardous food and pesticides conveys as much about the social conditions in which they live as it does their understanding of the "exposed biologies" (Wahlberg 2018) of their bodies as permeable and vulnerable to outside carcinogenic toxins. They consider it is the demands of a market economy in which producers must compete with one another by finding ways to boost their productivity and enhance their products' appearance by using pesticides in their field and through their practice, they place both their health and that of consumers at risk of cancer. It is the demands of an open market economy that provides unsafe foods in the market rather than less contaminated home-cooked or home-grown foods as people used to eat in the subsistence era because of the requirements that people engage in highly demanding work outside their household context. Their causal ontology can therefore reveal much about their perceptions of the present social conditions that give rise to their chance of developing cancer.

## **Poverty**

The liberalised market economy has also brought a greater sense of economic inequality and poverty. Poverty is understood to precipitate cancer by exerting an aggregate effect on other causal factors. Those who live in economically stringent situations are considered more vulnerable because they have no alternative but to live and work in hazardous

conditions. In that sense, poverty magnifies people's vulnerability to the market economy's forces. Patients and their families also explained their failing psychological and physiological health as resulting from economic hardships in their lives which in turn causes excessive "worry" that ultimately results in the occurrence of breast cancer.

For instance, Trà (from Quang Tri), the farmer reporting the use of pesticides in her farm who was mentioned earlier, ascribed her cancer to the use of pesticides but maintained that the ultimate explanation lay within the destitution facing her family which made such practices necessary. Despite being cautioned about the effect that pesticides inflicted on her previous miscarriages, Trà continued this strenuous work in order to earn a living for her whole family because her husband and son were both very sick. By equating her illness with chemical exposure and the physically hard work she had endured, Trà diverted the blame from her individual responsibility (her past act of using pesticides), thereby making the social circumstances surrounding the behaviour accountable.

Additionally, her narrative shifts the illness discourse of breast cancer from a stigmatising condition to a positive attribute marking the social ideals of hard work, diligence and self-sacrifice for one's family. Previous scholarship on the cultural meanings of illness in Vietnam suggests clear evidence of a Buddhist karmic interpretation of a disease or disability as resulting from a past demerit committed by the sufferers, their immediate family, or ancestors, which draws considerable stigma towards those living with such conditions (Gammeltoft 2014; Vu et al. 2014). A recent media analysis also notes the challenge that social stigma and discrimination present for patients undergoing breast cancer treatment in Vietnam (Jenkins, Ha, et al. 2020). In view of this, by positing an aetiology that places responsibility away from the sufferer to socially valued attributes such as hard work and ensuring her family's well-being, patients such as Trà form an attempt to counter the negative stigma of living with cancer.

Likewise, Nhàn, a 39-year-old woman living in Quang Binh province who was undergoing treatment for her metastatic cancer by the time of this study, related her illness to the hardships she suffered since her childhood. Her difficult life was exacerbated after she got married and had to care for a disabled brother-in-law. The accident which caused his disability forced her family into financial hardship and with the birth of her two daughters, she hardly had enough money to buy nutritious food for herself. The economic constraints took its toll on her health by leaving her body in a physically weakened status: "You know when I had the surgery [mastectomy], I weighed only 33 kilograms (...)

Sometimes when I had a bit of money, I bought something delicious home for me to eat. But then my daughters saw the food and they said they had never tasted it before. Then I would give them all... What else could I do?" The struggle to make ends meet also caused her emotional suffering ("worried a lot"), which altogether entered her explanations for the development of breast cancer.

As similarly noted in previous ethnographies studying lay explanations of ill health, suffering and its resulting worry is seen as a characteristic of contemporary social life in Vietnam where women state that poverty exhausts their bodies because they are given little rest and poor nutrition while having to work too hard and worry endlessly (Gammeltoft 2012). The case of Xuân (from Khanh Hoa) also reflected on the link between suffering, family tensions and breast cancer.

*The case of Xuân*

Xuân, a 46-year-old woman with three children, found out she had a breast lump in 2015 and went to Hue Central Hospital which is approximately 12 hours by bus from her home for an examination. There she underwent a lumpectomy and when the biopsy test indicated that Xuân's lump was cancerous, she needed an immediate mastectomy for which she had to pay 100% of the operation and hospitalisation fees as she was not covered by any health insurance. Prior to her diagnosis, Xuân lived with her three children and husband but he was often away and she knew that he was having an extramarital affair. After she returned home with only one breast, her husband moved out and never came back to see her and their children. Talking to me about his mother's illness, Bình, her 24-year-old son blamed it upon the psychological distress Xuân had endured throughout her poor life and broken marriage: "Women who fell ill with that disease [cancer] were always those living in hard situation (*hoàn cảnh khó khăn*). They had too many worries in their lives. I thought it was because of overthinking. Like my mom, she fell ill because of that too. She thought a lot, especially about my dad. Since he ran away, ever since, he no longer visited and cared about me and my siblings." (Fieldnote, 2019)

In this account, Bình attributed his mother's illness to the distress she had endured throughout her economic constraints and marriage breakdown. He placed the responsibility not onto his mother's temperament but the poverty facing their family, as well as his father's extramarital affair and child neglect which prompted a cancer-causing emotion in his mother. Articulating the carcinogenic potential of Xuân's stressful

thoughts was a means through which Binh condemned his father's socially unacceptable behaviour. Binh's narrative also frames the experience of cancer within well-established values of family cohesion: his mother fell ill because a family breakdown stripped from her the precondition for maintaining good health - that is, orderly, balanced and harmonious social relations (Gammeltoft 2012; Rydstrom 2017).

The aetiological association between negative emotions such as stress and cancer is often found in research eliciting lay perceptions of cancer explanations. For an example, studying cancer villages in rural Sichuan (China), Lora-Wainwright (2009) finds out that lay perceptions of cancer highlight its causal link with anxiety and anger: cancer sufferers are those who undergo unbearable conflicts and hardships, which arouses prolonged anxiety and later precipitates cancer. Likewise, South Korean women in the study by Im et al. (2002) believe that breast cancer results from physical hardships in their life, as well as the stress grown out of conflicting interpersonal relationships with their mothers-in-law and husbands. The belief that negative emotions, including stress, anger, and aggression are contributing factors to cancer is not only typical in Asian populations but can be found across disparate settings.

For instance, an early study on lay epidemiology among rural Australians demonstrate that their participants, both men and women, use stress in an idiomatic way to make sense of various health problems (Whittaker and Connor 1999). With that they also reflect the embodiment of social and economic circumstances. In their study, men use the term "stress" to speak of workplace tension while women use "stress" to refer to their distinctive gender roles as mothers and housewives. As the authors argue, people's descriptions of stress are powerful illustrations of the bodily experience of social inequalities or exploitation. Stress is therefore a mode to link the body with mind, and body with society. While examining how gynecological cancer is understood among Australian women, Manderson, Markovic and Quinn (2005) propose that by relating the occurrence of their cancer to stress, the women in their study connect the external world which is beyond their control, and the lack of control over their diseased bodies. Stress is then seen as a characteristic of contemporary social life, and for those women it can result in physical vulnerability that eventually causes them to develop cancer.

By attributing cancer to negative emotional states, we may understand the illness as having a public meaning, an expression which Paul Farmer (1988) employs in Haiti

where he attributes “bad blood” to malignant emotions resulting from physical abuses. As in the case of Bình, Nhân, and many other informants, blaming the worries due to financial hardships for their experience of cancer, they implicitly condemn other people held responsible for a family tension, such as unfaithful husbands, as well as the broader social structures placing pressures upon them. In that sense, by ascribing cancer to negative emotions as a consequence of poverty and suffering, people do not simply understand the illness as pathology, but rather, recognises its social origins.

### **“There are still chemical toxics the American left” - Toxic warfare**

Rural informants living close to the once demilitarised zone along the 17<sup>th</sup> Parallel related the development of their cancer to the historical legacies of the American War (1955-1975, known elsewhere as the Vietnam War). Some of the rural communes in the Central region constitute one of the most heavily Agent Orange-exposed regions in the country (Palmer 2005). Agent Orange is a mixture of two herbicides containing a dioxin-by-product (10–80 Organizing Committee; 1993) and was used extensively by the American military troops during the Vietnam War for defoliation and destroying crops supplied to the Northern Communist forces (Stellman et al. 2003). It is estimated that around 15% of land cover below the 17<sup>th</sup> Parallel, and as many as 4.8 million people were directly sprayed with Agent Orange from 1961 to 1971 (Stellman et al. 2003). Approximately 19% of the land in that region is still polluted by unexploded ordinance (UXO) and landmines - in some regions one-half of all land remains contaminated with over 100,000 tonnes of UXO and mines, and efforts to remove them is slow (Stellman et al. 2003; Tuoi Tre 2018).

#### *The case of Minh*

My Tuesday morning was usually spent at room 303 in the Chemotherapy Department which was designated for breast cancer and other female cancer inpatients. I chose Tuesdays to observe the department because it was the preparation day for a new chemotherapy cycle when some patients received a “*kích cầu*” infusion that helped boost the count of red and white blood cells. Most patients were still conscious before chemicals deeply infused into every blood vessel and caused exhausting side effects over the following two days. Then on Friday morning patients would do the check-out procedure,

including some injections, examinations when necessary and administrative work. This week, as usual, Dr. Thi walked me to the room and introduced me to the new patients. Some patients went to ask her about their blood test the day before. She skimmed through their test result and spoke to Sister Thủy, the in-charge nurse. After that Dr. Thi withdrew to her office on the same floor, leaving me alone with the patients. I moved toward the centre of the room and greeted everyone. I recognised some faces. Nine out of 11 beds were occupied. I noticed many of the patients carried an electric fan to their bed in a hope to cool down the summer heat in Hue.

I walked towards Minh who was lying on her bed, talking to her fellow patient Hồng. Both of them stopped their conversation and smiled with me, Hồng quickly turned back to her bed, taking out a colourful flowery scarf and wrapped around her head while Minh rose up, leaning her back against one end of her bed. She looked poised and left her baldness visible, which I assumed was due partly to the unbearable heat in this 40-square-meter room where there was no air-conditioner but only a ceiling fan and three others on the wall to providing ventilation for the whole room. Today Minh was about to receive her seventh round of chemotherapy. She had already got familiar with the whole procedure and told me that the side effects had diminished in her most recent cycle and she hoped this time she would feel even better. “Do you know what causes this disease?” Hồng asked me after a while. Knowing I would not be able to provide them satisfying answers, I redirected the question back to them. This time Minh no longer remained silent:

I live in an area where the Americans heavily bombarded and sprayed herbicide, so I see there are many cancer patients in my commune. In my village alone, there is a family with three members diagnosed with cancer. For the men it is lung and liver cancer. For women the most common are cervical and breast cancer... It is a war legacy. It made water infused with lethal chemicals (*chất độc*). The authority has carried out the test which proved that. The whole commune was affected. Women are more likely to develop cancer because they have to cultivate [in the field], so they are more prone to herbicide and pesticide. (Minh, 53 years old, Quang Tri)

Living and working with war veterans at a commune’s mass organisation, Minh was convinced about the carcinogenic effects of toxic warfare while witnessing a rise in all

forms of cancer in her community in recent years. Minh asserted that her aetiology did not lack scientific grounding. It was verified by her local government's test which had indicated the contamination of the water source in their commune. Residents in her locality were also convinced of the risk: "Some households bought water filters. There is a dark contrast between water samples before and after going through filter. Unfiltered water is very muddy."

Apart from Agent Orange, bombing or war toxins in general were among the factors that were frequently mentioned by my informants. More specifically, the idea of the cancer-causing role of war's toxic residues was pervasive among residents in the commune of *Bộ Đới* where part of my fieldwork occurred. *Bộ Đới* is a rural commune to the north-west of Thừa Thiên Huế province, home to around 4,500 people. After an hour-motorbike-ride from Hue, along the concretized main road leading to the busiest morning market, one could easily spot lines of rubber and acacia plants - the key forestry livelihood of residents in *Bộ Đới*. Looking at the greenery of those plantations and listening to the noise from the bustling trading activities of the market, I could not imagine *Bộ Đới* was a residence-free area just 40 years ago and had only attracted emigrants from Hue city and other districts in the province following the state's call for building new economic zone post-Reunification 1975. Itself being trapped among mountain ranges and layers of tropical forests, *Bộ Đới* served as the military base for former South Vietnam's troops during the American War because of its remoteness and topography. Since the fall of the US-supported regime, the Communist North took over the whole region and started its political and economic transformation. When the first wave of migrants began to settle in the commune, the only dirt road connecting *Bộ Đới* to Hue city used to get blocked for months during rainy season. It was now upgraded to an asphalt road which could carry trucks collecting rubber and acacia timber from *Bộ Đới* to factories in and out of the province. The once military base had been turned into sites where villages, markets, schools and a commune clinic rose up. Nevertheless, *Bộ Đới*'s transformative outlook at present was not devoid of pieces brought back from one of world's most intense wars of the twentieth century.

When I met Bình (aged 35) an officer at the People's Committee of *Bộ Đới*, she communicated her views about the increased incidence of cancer among her fellow villagers:

It is a part left from the war (...) Here the majority of people, they used to collect war remnants [to sell to recycle]. There are many [unexploded] ordinance (UXO) and landmines. Many people went collect those things. They went to the forest and stayed for several days. There they had to drink stream water which contained some residue [from Agent Orange] for a long time. Later they developed the disease. I think it is the reason.

Bình shared similar assumptions with Minh, a patient I presented earlier, regarding the way people got affected by Agent Orange through the absorption of contaminated water. In her aetiology, Bình brought forward not only the issue of Agent Orange, but she also elaborated on the situation associated with UXO and landmines. In regions like *Bộ Đội* commune where former South Vietnam troops were concentrated, it is evident that there was a high level of bombing and the planting of landmines (Palmer et al. 2019). Bình recalled how her commune was struck by a number of accidents associated with UXO and mines ten years ago. While the situation was improved with a declining number of UXO accidents, people still bore the brunt of it. Chemicals in bombs and mines disrupted the people's present lives by not causing visibly deformed bodies as they used to, but have become "gradual and silent killers," attacking war survivors and their families according to some male villagers whom I met during a focus group I held there to learn about the lay epidemiology of health and illnesses. For them, members in their families or fellow residents developed cancer because of their exposure to "chemical toxins (*chất độc hóa học*) the Americans left" during their early days relocating to *Bộ Đội* to build up the economy and revive a war-torn region.

War is the reason. Sometimes there are still chemical toxins the Americans left... In the previous days because there was nothing, they [peasants] had to mine gold [to make a living], there they used water from the pond, sometimes they used the water to cook. Then the disease developed inside their body through the food they cooked.

People's accounts that I illustrate in this section confirm what Gammeltoft (2014) describes as an unsettling aspect of Vietnam's war-torn past. In her work on reproductive misfortune, Gammeltoft (2014) shows the widespread understanding of the war's effects upon the aetiology of deformities, disabilities, and miscarriages in Vietnam. However, there are differences between the way her informants and those in my study explain the links between their illnesses and toxic warfare exposure. She explains how several families

of returned soldiers attempt to circumvent the stigma that might haunt families who suffer from genetic anomalies and reproductive losses due to previous exposures to Agent Orange, especially when living in Northern cities that were not exposed to the herbicide. They do this by blaming their reproductive misfortunes on the mother's experience of "a cold" during her pregnancy. In contrast, among my informants in the Central region, my study found little stigma associated with exposure to carcinogenic toxins that remain from the war—they consider themselves not as individual cases but parts of a collectively exposed population. Through their aetiologies they remind themselves and others of the collective losses, disruptions, and sufferings in that region that linger some forty years after the horrible conflict ended.

The lay attribution of cancer to toxic war chemicals as found during my ethnography is unsurprising given the fact that the most brutal battles between Communist North Vietnamese troops and US-supported South Vietnamese troops broke out in the Central region. Survivors who were born and grew up during the 1960s, such as those making up the majority of my respondents, maintained agonising memories of the war regardless of their former political views and support. While there is evidence elsewhere pointing out the established link between Agent Orange and cancer (for summaries see Fox 2007; Gammeltoft 2014), or the long-lasting impacts that wars generally inflict on human health (Palmer et al. 2019), I do not attempt to supplement those with any epidemiological proof from the popular accounts I present here. This task is not within the scope of my ethnography, nor does it fall under my capacity as a social scientist. These war-related health narratives as I demonstrate here contribute further evidence of the war's effects and support a form of bio-citizenship (Petryna 2013) for the exposed population. These causal perceptions of chemical warfare constitute a "symbol of innocent suffering" (Fox 2007, p. 254) and in response to US. denials of responsibility, assert a moral judgement demanding those responsible to be accountable and to recognise and compensate the sufferers.

## **Gendered Norms**

The next group of themes that emerged in the narratives of breast cancer aetiologies relate to gender norms, including the observance of specific practices for women to ensure their health and appropriate roles in the family. As I described in Chapter 3, contemporary

Vietnamese society continues to celebrate women's "heavenly mandate" (*thiên chức*) of childbearing and breastfeeding (Rydstrøm 2006). To this end, being able to produce a child is considered crucial to fulfil a woman's social identity. Normative gender ideals also emphasise how it is vital for a woman, as a citizen, to realize the expectations of providing life and nurturance, as well as fulfilling the state's imperative that women protect the country's population (Gammeltoft 2014). As already noted, harmonious family relations are also largely seen as the responsibility of the wife and mother of a household and failure to ensure family harmony is a further source of worry for women.

### ***Failure to observe postpartum practices***

Physicians and some lay people in this study based their explanations for the causes of breast cancer upon cultural concepts of women's duties. For them, the cancer was caused by deviations from the culturally defined ideal role of a woman as a wife and a mother. In particular, getting married and giving birth at a late age, bearing no child, or refusing to lactate were behaviours considered related to the rise of breast cancer. Physicians often interpreted biomedically established risk factors in ways that reflected the local and cultural views of women's ideal roles. For instance, Dr. Truông, a male oncologist, firmly believed that the most important cause of the increased rate of breast cancer identified in Vietnam in the last decade was:

First of all I think it [increase in breast cancer cases in Vietnam] was a social matter when many women have decreased normal sexual activities. What I mean here is that many choose not to get married, they accept to be single moms raising a child on her own but not getting married. They are more easy-going (*dễ dãi*) when it comes to sexual relationships. Many follow a school of thought in which they are not getting married, never, it might be a trend, or a religion. It is those who do not have proper sexual behaviours, not getting married, not having sexual activities. They have higher risk [of developing breast cancer]"

Dr. Truông's comment reflected a conservative expectation that a mature woman should marry a man and have sexual activities within wedlock. While placing his view of the causal link between breast cancer and improper sexual behaviours, he implied a moral judgement against those who fail to obey with traditional concepts of women's role. He blamed modernisation whereby women are increasingly postponing or avoiding getting

married and being more independent. His remarks held modern women responsible for the development of their breast cancer and blamed an individual for pursuing a modern life.

Likewise, my informants also explained the cancer in terms of a woman's failure to fulfil her womanly destiny as a mother. For example, not having ever given birth or breastfed or the experience of conditions that block or inflame the breast are believed to make a woman vulnerable to breast cancer. For instance, Lam (aged 56, Hue city) drew on her niece Hiếu's inability to bear a child to explain the occurrence of her cancer. Lam precluded the onset of Hiếu's cancer to heredity because none of her sisters, nieces, daughter, nor herself had developed any cancer. According to Lam, by giving birth to at least one child each they were spared the disease. Hiếu was seen as a deviation because she was the only woman in the extended family who had not given birth to any children.

After breakfast, I joined Lam and her husband over tea. We continued our chat about Hiếu when I asked Lam about Hiếu's first day at the hospital prior to her first round of chemotherapy. Our conversation quickly turned to Lam's commentary on the causes of her niece's cancer. Lam said, "After she [Hiếu] got married she moved to Saigon to live with her husband. But she could not have any child, so her husband had an affair with another woman. She found out and they got divorced and returned to Hue. You know what? My parents had 10 children, and none has the disease. After she was diagnosed, her twin sister also went for a screening, but she only had a benign lump." She continued, "She never has given birth, never breastfed so has never got her breast squeezed. Because of that, '*trái chàm*'<sup>8</sup> is still there, and it causes her [breast] cancer)." (Fieldnote, November 5th, 2019)

In this account, Lam's aetiologies were predicated on the socially established expectations about gender roles similarly to the views expressed by Dr. Truong. But her understanding was loaded with more cultural ethnomedical explanations. In pathologising Hiếu's failure to comply with a traditional postpartum health practice that has been in existence for many generations in the region, Lam voiced her attitude towards endorsing the importance of cultural values in protecting against modern diseases. Because Hiếu did not

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<sup>8</sup> This term is used to refer to inner round hard structure encompassing the whole breast, excluding the nipple.

have a child, she did not undergo the practice of “*bóp sữa*” (milk squeeze), a traditional practice that is undertaken for women in a belief that it helps “cook” breast milk (*làm chín sữa*) and makes it flow fluidly in order to protect the child from catching any disease during breastfeeding period.

While the aetiological link between breast cancer and a woman’s nulliparity was more likely articulated among women in middle-age range and above, the perception towards the importance of traditional health practices was shared with younger informants. Throughout my ethnography I noticed that younger women in both urban and rural settings continued to practice some methods of traditional confinement postpartum (see also Whittaker 2002), which is consistent with findings of other research on maternal health practices among women in urban cities in Vietnam (cf. Lundberg and Thu 2012), or among immigrant Vietnamese overseas who value the protective importance of traditional postnatal rituals (for instance, see Groleau, Soulière and Kirmayer 2006).

“Milk squeeze” was one which was especially common among women in Hue. Following a childbirth, usually the mother, mother-in-law, or an experienced woman senior in her age, practiced squeezing milk for the new mother. To prepare, the helper first got a pot of sticky rice with two or three shallots which was believed to bring out the aroma of the breastmilk. She then blended the two ingredients together and bring them to steam. After the sticky rice was cooked, the helper placed them onto two pieces of clean cloth, wrapped up the cloth, and started to squeeze and press them until got into two rice balls, each the size of an adult fist. As soon as the rice was still very hot, the helper grabbed two balls and rolled around one breast of the mother. She pressed downward and then placed the whole breast between the two rice balls and started to squeeze hard until the milk came out. At some point, the helper moved the two rice balls closer to nipple and pressed it. She finished with one breast and repeated the whole procedure with the other one. While the rice cooled down, she reheated it in the steamer and redid the squeeze several times on each breast. The whole practice takes nearly an hour and is repeated over two or three days and the procedure might cause a lot of pain to the mother as 29-year-old My commented: “It was so painful that it even made me cry”. Some women even recalled instances where women felt as if their “*trái chàm*” had been broken due to the squeeze.

However painful it might be, most of the informants who told me about the practice never questioned its benefits. If a new mother did not practice “milk squeeze”,

as *Dương*, a 47-year-old patient believed, her milk would become “fishy, not cooked”<sup>9</sup> and her new-born child might suffer from stomach-related diseases such as diarrhoea. She claimed that her two sons stayed healthy because she had her breasts squeezed by her mother-in-law right after she returned home from the hospital: “They [her sons] were strong and defecated normally. Their stools were in gold colour, yellowish during the twelve months I breastfed them.” In addition, she thought that the practice helped protect a woman from developing breast ailments such as blocked ducts because it promoted the flow of breastmilk, and cleared any clots accumulated by the consumption of too much nutritious food during gestation. During lactation, the mother was also encouraged to eat certain food to enhance her milk production, for instance, cooked rice with salt and pepper, unripe or green banana, and figs slowly cooked with pork or pig’s legs, and sweet potato leaves. Dried dish, that was dish without or little water, such as braised fish and pork was thought to aid in the production of breastmilk while certain food such as morning glory, vegetable soup, or sour fruits were deemed unhealthy and should be avoided.

In addition to “milk squeeze”, women in Hue and neighbouring Central provinces continued to practice many postpartum health practices. These includes the practice of “mother roasting” such as lying on a bamboo bed or sitting on a chair over a charcoal fire in the first month following childbirth which is practiced across East and South East Asia (Liamputtong 2004; Manderson 1981; Whittaker 2002). These would help recover the woman’s body, heal her vagina which had been opened wide and bruised during birth, and shrink and flatten her womb and belly. The mother also applied sea salt mixed with lemon to her face and dried over the fire to rejuvenate her skin. During the first month, the new mother refrained from taking a shower or washing her hair for fear of catching a cold. Instead, she used humorally “hot” rice vodka with ginger to apply onto her whole body to relieve her fatigue, as well as remove dirt off her body. Further, many women also had a steam bath, or home sauna every day with a big pot of boiled herbs derived from various plants, such as mint, guava, lemon grass, lemon, grapefruit, or star apple. Women were also advised to refrain from having sex with their husband in the first three

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<sup>9</sup> One of the benefits of “milk squeeze” is to make the breastmilk “*chín*.” In Vietnamese language, “*chín*” can be “ripe” or “cooked.” In my conversation with *Dương*, she usually used the latter word and compared the practice as bringing the milk to boil.

months and ten days after childbirth because it was generally believed that sex would cause tremendous injury to the cervix.

Women whom I interviewed perceived these postpartum practices as essential to rebalance body humors, boost their health and speed recovery after birth, and spare women any ailments as they age. In particular, these practices ensure the flow of bodily humors through the breast, resulting in both an ability to breastfeed successfully but also ensuring long-term breast health. Those who had not had the opportunity to fully comply, whether because they had never given birth, or not undertaken these practices correctly, were considered vulnerable to long term health problems. For example, **Dương**, attributed her ill-health to missing this practice. She gave birth by caesarean sections for both of her sons and so was unable to go through “mother roasting” and only conducted home saunas 20 days later after her birth. She contrasted her mother’s health condition with hers, as well as generalised about the differences she observed between women in her region with others who did not practice these healthcare rituals.

It was not until the 20<sup>th</sup> day or later after my son’s birth that I had a steamed bath. Because of that, women like me, only 40, 50 years-old but [we] already feel tired, feel exhausted, have so many diseases. We are not like the elders in Hue. They followed all [the practices] and when they get to their 90s they are still fit, active.... Here people are very strict, not like in Hanoi or Saigon. There they [women] take a shower only a couple of days after they give birth... You know sometimes we feel the first month [after childbirth] was like a torture. Women from elsewhere who get married into this region cannot bear it... But if we do them all, we will not get any disease when we are older. Like elder women here in Hue. You see my mom? They are thin but very strong (*mạnh mẽ*). They can do this, do that, not like old women in Hanoi or Saigon. They [Hue women] do not have any disease at all.

**Dương** reemphasised the link between one’s experience of traditional healthcare practices and the ability to withstand any disease. For her, those long-held rituals, despite their toughness which she described “like torture,” played as protective factors for a woman’s health not only in the immediate period following her childbirth. They also carried a long-term impact on her physical health later in her old age. Her account reflects the general attitude from many women I met during this ethnography. While appraising and adopting many medical achievements resulting from the era of modernisation, women like **Dương**,

My, and many others did not desist from traditional practices. In their attempt to making sense of their illness, they believed failures to follow traditions would cause poor health for women.

*The case of Châu*

The discourse that blames women who failed to obey to traditionally constructed gender ideals as presented in this section was popular among patients I interviewed except for Châu. Châu was a 41-year-old teacher working in Hue city and an outpatient diagnosed with stage I hormone-positive breast cancer. On an afternoon in June I met Châu when she came to the counselling department to get her monthly hormonal therapy and was particularly intrigued by her conversation with Nurse Diệu after the ovary-suppression injection. She talked to Diệu: “Sister Diệu, I always want to know if this fatal disease (*bệnh hiểm nghèo*) is because in the old days, my husband and I had a lot of sex. I always wanted him to hold me, touch me. Every time when we had sex, we did it for a very long time until we reached climax.”

Châu was concerned that her sexual desire was unusual, associated with a lack of virtue in women (Hoang 2005). Social discourses of appropriate sexuality for Vietnamese women is that they take a passive, submissive role in sexual activities and this differs from men. This is considered a biological principle in popular discourses on sexuality in Vietnam. Initiating sex with her partner or revealing her thoughts about sexual desires is constructed as threatening to the gendered order in a woman’s family and the society (Khuat, Le and Nguyen 2010; Vu 2008). Châu’s fear pointed to a long-held belief that “too much” sex comprised a risky behaviour that was deemed detrimental to one’s health (Santillan et al. 2002):

Is it because of [my sexual life] that my hormone level was increased? It was too high and it caused this disease? I find that my ova was very active (*rất nhạy*). The evidence was that right after I got married, I got pregnant immediately. Some rumoured that I had been pregnant before the wedding but it was not true.

Châu’s fears did not, however, resonate with the remaining patients I encountered who may have been reticent to openly speak of their sexuality. They tended to base their explanations on the responsibility for and exercise of gender roles in other ways, such as childrearing, nurturing or maintaining femininity.

### *Disrupted flows*

Apart from a failure to undertake appropriate postpartum practices, many informants stressed that difficulties with lactation precipitated their breast cancer. To construct their aetiologies, they revived accounts of any past ailments in their breasts – the site where the malignant tumour was diagnosed. Some traced it to any external forces inflicted on their breast such as wearing a tight bra, which resonated with the cultural view of healthy breasts having no restrictions on flow. More frequently, patients grounded the causal concept between their cancer and a former breast lump or ailment, such as a blocked duct (*tắc tuyến sữa*). The relationship between health and maintaining flows within the breasts (whether through the practice of “milk squeeze,” postpartum heating, successful breastfeeding and no restrictions that may cause clots or lumps) thus depicts women as especially vulnerable to cancer, either because they do not reproduce or because they do.

In forming their aetiologies in relation to disrupted flows, women also referred to womanhood as a form of suffering and self-sacrifice. For example, Khanh, a 61-year-old single mother, attributed the development of her advanced cancer to a breast ailment that had not been diagnosed and treated in a timely fashion. When Khanh first identified a lump in her right breast, her daughter was entering Grade 12, so she decided to put the well-being of her daughter ahead of hers by delaying a screening test: “I did not want to interrupt her study. I always wanted her to pass the exam to university.” This framing positioned Khanh as a good mother and by tracing culpability of her cancer to the circumstances beyond her control, she avoided blame due to her failure to adhere to popular health promotion messages urging women to attend to early symptoms of breast cancer. It was her role as a mother who prioritised the care of her children above her own and the hardships confronted by a single mother and female breadwinner that were deemed responsible for her late presentation and illness.

The women’s narratives as revealed in this section give significance to the location of cancer as a direct result of antecedent ailments in their breasts such as blocked ducts or a sore breast which disrupt the flows of blood, milk, and humoral heat through the breast. This explanation presents a versatile set of meanings which fit in with public health discourse promoting an individual’s responsibility for early detection and regular breast screening. But it also identifies the source of women’s cancer as located within women’s maternal responsibility and nurturing roles. The local understanding related to pre-

existing breast ailments might be considered what Hunt refers to as “a conceptual bridge” in her analysis of the imagery of a *golpe* as a cause of cancer, linking women’s diseased bodies and the external social world (1998, p. 304). Given that breasts are intimately associated with a woman’s lactation, breastfeeding acts as a potent metaphor illustrating the women’s domestic roles. By incorporating previous ailments caused by breastfeeding, or the lack of childbearing and breastfeeding (hence disruption or failure of normal flows), or delays in treating a breast lump because of their childrearing in their explanatory frameworks, these women attributed the physical illness they were suffering to the values and ideals that are socially and morally expected of a virtuous woman. Finally, the failure to follow traditional postpartum practices, such as breast squeezing and mother roasting, or infertility anchors the experience of poor health to contemporary values and biomedical interference in traditions and lifestyles, thereby increasing women’s vulnerability to diseases. Talking about causation in this case was an idiomatic way reflecting their critique of gender ideals regarding their maternal and nurturing roles.

## Conclusion

This chapter has focused on the wider social, political, and historical circumstances through which laypeople frame the sources of their pathology. Lay understanding, biomedical knowledge, and cultural specificities together constitute what cancer “is” in any given setting (Broom et al. 2018, p. 49). As this chapter has illustrated, lay understanding such as those related to karma or fate as described in the existing literature on illnesses in Vietnam (Gammeltoft 2014; Vu et al. 2014) are less prevalent. For most participants, cancer is considered a modern disease that was not recorded in the past; therefore, cancer requires modern frames of interpretation. This may be attributable to recent spikes in cancer prevalence in Vietnam (Ministry of Health and Health Partnership Group 2015), making it a topic of familiarity to the public in their everyday life and the media. It is also worth noting that most patients had received one or several types of hospital-based treatment by the time of my fieldwork and many of them were members of the peer support network. The primacy of the biomedical discourses upheld throughout those experiences may have a notable role in my participants’ adoption of biomedical knowledge in their aetiological models.

The predominant view among my informants emphasises the role of chemically contaminated food, agriculture and the environment in the development of breast cancer. This is partly due to public health education transmitting epidemiological findings on the relation between diet, the environment, and cancer, which calls for the general public to minimize their risk factors by adopting a healthy diet, doing regular exercise (Jenkins, Ha, et al. 2020), advising women to undertake pregnancy at a young age and to breastfeed (Ministry of Health 2015a). My laypeople informants, however, interpreted these messages through different frames. They rejected the notion of hazardous food or toxic chemicals as an individual lifestyle-related factor while constructing their aetiologies based on such messages. Instead, they emphasised collective vulnerabilities caused by structural factors such as the market economy, poverty and the legacies of war.

People are not oblivious to the elevated harms inflicted by toxic substances in everyday use of food and water; nevertheless, they feel exposure to toxins and pollutants goes beyond their own control. Such ideas about cancer causation are reflexive of people's lack of power at different levels (Whittaker 1998), from their inability to control their daily food consumption, to their powerlessness when living in contaminated villages after a recent war. In this regard, I turn to Margaret Lock's notion of "local biologies" which accounts for how biological difference - sometimes obvious, at other times very subtle - moulds and contains the subjective experience of individuals and the creation of cultural interpretation (1994, p. 39). This concept illuminates the interplay between the socio-cultural environments and biology, allowing us to approach the significance of local biologies that reflect the varying social and physical conditions of human lives across societies (Lock and Kaufert 2001). In his work on the rising concerns about the health effects of pollution upon fertility in China, Ayo Wahlberg (2018) draws upon Lock's notion to describe the "exposed biologies" that figure in Chinese aetiologies, the side effects of modernisation, industrialisation, and urbanised living. Similarly, my informants conceive their "exposed biologies" as the outcome of social structural forces, thereby shifting the responsibility of the disease from personal behaviours to a vague group of irresponsible "others" (Singer 2011, p. 156) related to profit-driven food producers within the market economy, the authoritative failure to monitor and ensure food and water safety, and poor living conditions.

In their attempts to trace the causes of their breast cancer, participants build their own meaningful frameworks which embody their understanding based on biomedical risk

models interwoven with a range of meanings that resonate with the historical and contemporary circumstances shaping their life experiences. For my participants, a serious illness such as cancer is a moral event as much as a biological event (Gregg 2003; Hunt 1998), and throughout the process of searching for illness explanations, people simultaneously form their moral commentaries on established and modern values, be it an absence of traditional healthcare practices, a failed marriage, strenuous work, or poverty. Cancer causality has in this way become a means to articulate a complex range of attitudes towards the ongoing context of social (dis)order, modernisation, market economy and warfare, and to reflect critiques of traditional gender roles.

This chapter's findings have implications for public health messaging regarding breast cancer prevention. Firstly, it reminds us that biomedical information is mediated by situated experiences and cultural understanding. It is notable that family genetic risk factors were rarely mentioned by women, possibly due to the stigma this would bring to the entire family line. The general public brings a range of sources of information to their questions regarding why they have developed breast cancer at this point in their lives. My participants were unlikely to recognise themselves in biomedical narratives of breast cancer risk that focus upon individual responsibility and lifestyle factors. It needs to be acknowledged that such messaging carries its own biases and may not reflect the lived realities of women. Rather, they may conflate such prevention messages regarding risk with causality and feel they have little control over limiting their risk, given their social situations and feel blamed for their misfortune. There needs to be recognition of local explanatory models of the body and its flows and reassure women that failure to undertake local postpartum practices is not a major factor in the development of breast cancer. Rather than approach laypeople as ignorant and in need of "correct" education, public awareness campaigns must meaningfully engage with the situated social and cultural specificities of breast cancer.

## Chapter 6.

# From a Black Bean-sized Lump to a “Life Sentence:” Trajectories to a Diagnosis of Breast Cancer

### Introduction

In the previous chapter I analysed the various frames that patients and their families draw on to explain the causation of breast cancer which is often perceived as a modern disease that was not recorded in the past and foreign in their local knowledge. People often construct their aetiological understanding based on dominant biomedical concepts regarding cancer risk factors while simultaneously locating such knowledge in a framework that is meaningful to their situated life circumstances. In this chapter I explore women’s early experiences with breast cancer after a breast lump is discovered and how women attend to their symptomatic breasts. The women’s narratives that follow reveal their search for diagnosis and the various factors shaping and influencing this journey. Once a symptom growing in the breast is suspected to be cancerous, the women’s accounts emphasise the vital role of seeking medical attention in detecting and confirming its malignancy status. However, their diagnosis-seeking decisions and trajectories are hardly a simple process but involve multistage complexities, whereby one’s urgency to having medical attention, in many circumstances, is subject to and circumvented by structural barriers regarding the absence of a national screening program and constraints regarding oncology services and capacity in the country. This chapter describes women’s interpretations of and responses to breast symptoms, but also illuminates the broader context of their encounters with healthcare services.

Early detection of breast cancer has been well established to reduce mortality and morbidity associated with advanced stages of the disease (for summaries see Dey 2014; Steiness et al. 2018). In light of these results, providing early access to effective diagnostic

and treatment services plays a central role in any strategy aimed at decreasing breast cancer mortality (Lauby-Secretan et al. 2015; Panieri 2012). Screening for breast cancer is a procedure involving tests and examination that are performed to identify abnormalities before the occurrence of any signs or symptoms. According to the latest breast screening guidelines recommended by the American Cancer Society (ACS), women at an average risk should have regular screening mammography from 45 years of age. Screening should be conducted every other year for women aged 55 and older (Oeffinger et al. 2015). Meanwhile, women who are at a high risk for breast cancer should get an annual mammogram and breast MRI (magnetic resonance imaging) starting at age 30 (American Cancer Society n.d.). Apart from screening mammography, several studies reveal that clinical breast examination (CBE) and self-examination, and other imaging techniques also provide rigorous scientific evaluation (see, for instance, Lauby-Secretan et al. 2015). While breast cancer has become a health priority in lower-middle income countries (LMICs), screening programs and breast cancer control strategies in these settings generally remain lacking (Dey 2014). This results in women presenting at advanced stages and lower breast cancer survival rates than in high-income countries (Anderson et al. 2011; Sankaranarayanan et al. 2010).

To date there has not been a nationwide screening program in place in Vietnam and women have to pay for screening services entirely out-of-pocket. Data about how screening programs have been implemented and the rate of participation in screening activities is largely deficient (Jenkins et al. 2018; Nguyen, C. P. and Adang 2018). As suggested by a MOH's report, over 120,000 women have been screened from 2008 to 2013 (Ministry of Health and Health Partnership Group 2015), accounting for roughly 10% of eligible women (Harper 2011, p. 6). Meanwhile, within the National Cancer Control Programme implemented between 2008 and 2015, an estimated 100,000 women aged 30 to 54 were screened for breast and cervical cancer (Tran et al. 2016). Those screening interventions included CBE, ultrasound, and mammography (Tran et al. 2016), or primarily focused on CBE (Nguyen, L. H. et al. 2013). As noted by a review of recent screening programs, only 2% of the target population participated in pilot programs where they were screened for cervical, breast, oral, and colorectal cancers (Pham et al. 2019). Most pilot screening programs are delivered to urban populations, mainly in large cities such as Hanoi and Ho Chi Minh City (Jenkins et al. 2018). In addition, despite the implementation of various national policies to control cancer, screening services remain

uncovered via the national health insurance and for that reason, people have to privately pay for their participation without any reimbursement even when they have already enrolled in the scheme (Pham et al. 2019).

## Discovery of a breast symptom

In my interviews and discussions with women on health and illness, participants often agreed on the frequent exposure of women's breasts to various ailments throughout their lifetime, from puberty to menopause, which was mainly associated with their womanhood and the "heavenly mandate" of childbearing and nurturing. Nevertheless, how participants responded to breast symptoms was vastly different, which in the first place depended on their appraisal as to whether the condition was normal or a cause for concern, which determined how urgently to seek help. There are different and sometimes conflicting notions of symptoms as shown in Table 6. 1 which lists the varying conditions my participants used to differentiate between benign and malignant symptoms.

**Table 6. 1.** Classification of breast symptoms

Benign symptoms	Malignant symptoms
<ul style="list-style-type: none"> <li>• Feeling tense in the breast prior to or during menstruation</li> <li>• Not feeling pain when having a breast lump</li> <li>• Blocked duct during lactation</li> </ul>	<ul style="list-style-type: none"> <li>• Sore breast</li> <li>• Inverted nipple</li> <li>• A solid lump in the breast which means the lump has roots that cling onto the breast</li> <li>• Unusual discharge from the nipple</li> <li>• A breast lump growing fast</li> <li>• A lump in areas close to the chest</li> <li>• A movable breast lump</li> <li>• An appearance of breast lump and co-occurrence of other ailments (fever, fatigue, etc)</li> <li>• Inflamed breast</li> <li>• Reddish inflammation in the breast</li> </ul>

### *Treating a benign lump*

On identifying a symptom which they perceived to be benign, the common response reported among my participants was either using traditional healing methods or simply ignoring it. As I mentioned in the previous chapter, local knowledge regarding benign lumps is abundant, particularly in terms of the vocabulary people use to describe various forms of lumps, as well as the self-treatment options. In this aspect, my participants often referred to a range of herbs that was locally available at no or little cost, or easily grown in one's own garden. The most popular medicinal herbs cited by my participants in focus groups and interviews include “*trinh nữ hoàng cung*” (*crinum latifolium*), “*rau má*” (*Centella asiatica*), “*bồ công anh*” (dandelion), or “*long tu*” (aloe vera) which can be used raw or after being boiled as a form of medicine to treat various types of benign lumps, including those in the breasts. These plants are easily found across the Central region and most are also used in their everyday diet, especially “*rau má*” which is locally known to be non-toxic and categorised as humorally ‘balanced’ (“*tính bình*” that means neutral - neither hot nor cold) with healing properties and anti-carcinogenic potential (for instance, see Mai Hoa 2010). In Thua Thien Hue, “*rau má*” is a cheap type of vegetable (Plate 6. 1), easily grown and has versatile usage in everyday cuisine, suitable for use in a salad or a hot soup.



**Plate 6. 1.** *Rau má*, a popular traditional herb in Thua Thien Hue

*Source:* [thuocdandoc.org](http://thuocdandoc.org)

The popularity of self-grown herbs mentioned among my participants is not surprising given Vietnam's post-colonial public health strategies that aimed to revive traditional medicine and encourage self-sufficiency in using herbal treatment for the most common illnesses (Wahlberg 2006). Such healing methods are well recorded in traditional medicinal texts that are widely accessible for the general public. For instance, the book *Using Southern herbs ("cây thuốc Nam") to treat a disease* published by the Culture and Information Publishing House (Mai Hoa 2010) – one of the largest state publishers in Vietnam - describes the respective uses of medicinal herbs to treat various benign breast ailments (Table 6. 2):

**Table 6. 2.** Using medicinal herbs to treat post-natal ailments

- Use glutinous rice and coriander to make porridge when breasts cannot or produce insufficient milk.
- Bring red beans, coriander seeds or dried “*cỏ bợ*” (*Marsilea quadrifolia*) to boil and drink or eat roasted sesame seeds with salt, to treat blocked duct.
- When experiencing pain or inflammation in the breast or nipple, use a bunch of “*cỏ bợ*”, clean well, grind it and add some boiled water, drink twice a day. Use the residue to apply directly onto the inflamed area. The symptom will disappear in two or three days. Other herbs can replace “*cỏ bợ*” which have the same benefits include roots of “*rau má*” (*Centella asiatica*) or “*bồ công anh*” (dandelion).
- Grind a bunch of “*mồng tơi*” (*Basella alba*) leaves and apply onto the inflamed breast area or the skin that is cracked. The symptom will disappear after a couple of times.
- When experiencing breast inflammation or sore breast due to a blocked duct after giving birth, apply ground sesames directly onto the area. A blocked duct causing sore breast can also be cured by bringing 50 gram of “*đinh lăng*” (*Polyscias fruticosa*) leaves and small branches to boil and drink.
- When there is a red spot growing around the breast, it should be treated immediately. Use white radish with its leaves, grind altogether and apply onto the spot.

*Source:* Mai Hoa (2010, pp. 212-225)

Bearing in mind that a benign lump can heal itself or be treated with traditional medicines with long-known therapeutic benefits and minimal side effects, most of my participants agreed there was no need for any biomedical interventions:

Trang: So do you all mean that for a benign lump, there won't be any surgery needed?

Woman #1: Absolutely not. Having surgery is so scary. For that you only need one like that, applying [medicinal herbs] onto the lump and after some days, it is cured.

Woman #2: No surgery, we all fear it. Only using herbs to feel peace of mind. (FGD 02)

## **The urgency to seek care**

When a woman recognised a breast symptom or in combination with other bodily changes, she faced a decision as to how to attend to it. Her appraisal or intuition was often mentioned as the most important factor that determined her care-seeking behaviour. If she perceived a symptom's development as normal, she was likely to leave it unattended or resort to self-medication as previously described. However, when a change in the body was appraised as abnormal ("*bất bình thường*") or severe ("*nghiêm trọng*") which matched their knowledge of breast cancer, most participants emphasised the urgency to seek biomedical advice, as summarised by 54-year-old Thi (Hue City): "The lump often grows very fast, getting bigger instantly because it has legs. So we need to treat it at the hospital. We need to remove it immediately. If you use the Southern medicine [herbs], it cannot be treated quickly."

### ***The initial recognition of malignancy***

A woman's own interpretation of a breast symptom's acuteness was based on a variety of factors in relation to the common knowledge of cancer as a condition that rapidly developed and deteriorated a patient's physical state. In this regard, women tended to distinguish a malignant symptom on the basis of the timing of its discovery, its location, persistence/duration, or the shape and movability of the lump. For instance, in my

interview with Hay, a 47-year-old patient from Quang Tri province, she recalled the discovery of a breast lump in 2018. She was convinced about its severity after her own research and communication with other women. Based on the pointy shape of the lump - a suspected form of malignancy, she decided to go directly to the Central Hospital to have an examination rather than visiting a hospital in her province. Later in that visit she was diagnosed with stage II breast cancer.

I accidentally found a node (“*cục hạch*”) while taking a bath. Its upper part could move (“*nhúc nhích*”) [when being touched] but the lower remained static. I read about lumps and asked many people who often said that if the lump was fixed at a place, it meant that it had legs and contained toxics, so it could hold on tightly and did not move nor run. Meanwhile, a moving lump was often a benign one. In my case it was pointy at the top. At first I did not think it was malignant because it could move, but then I examined more closely and found out only the upper part could. So I suspected [its malignancy]. (Hay, aged 47, Quang Tri)

In many cases women could not describe in detail the characteristics of the lump at their first discovery. Rather, they used general terms, mainly “*u*” or “*cục*” (a lump), or “*hạch*” (a node) to refer to a breast symptom or some bodily changes that made them “feel tired”, or “not right,” and often focused on the *sudden* nature of their first discovery – the moment marking the beginning of the cancer journey. In such cases, it was the abrupt growth of a lump which prompted them to seek immediate help. Tuyến, who had never been hospitalised except for her two births, travelled 170 kilometers to Hue to have her breast examined without any delay after her identification of a lump on her right breast at the age of thirty-three:

It was very accidental. At night, I remembered around ten o’clock, I was about to go to sleep. As a routine I moved my hands around the breasts, you know, do an exam for myself. Then suddenly I found a small, very small lump, the same size as a black bean. I felt a bit abnormal. (...) The next morning I still felt bothered. So I went to a private clinic where they sent me out for an ultrasound. The result was not very positive. They only did a physical examination and could not conclude anything. So I arranged my work and went to Hue right away. It was only 10 days since I first discovered the lump to the day when I had the first surgery. (Tuyến, aged 36, Quang Binh)

Not all breast lumps were considered equally significant and those identified at special times or occurring at the same time as other bodily changes, or with the advent of other illnesses often triggered greater fear among women. For instance, the account of Chi, whose cancer was diagnosed in 2015, entailed the smallest detail on the remarkable events at the time she started to notice changes in her body. She found the lump two years after she had retired from her teaching job at a high school:

My story I know is similar to many others', that was a lump discovery after a funeral. Many knowledgeable people explain that a cancer patient has a weak body even though the disease has not yet manifested. When the patient attends a place such as a funeral venue, the deadly atmosphere ("tư khí") exhausts her body and from that moment, many people find out they have cancer. In my case in 2015, my brother-in-law passed away. On the day that we held the funeral, I went to help organise it. After everything was finished, I went back home on my motorbike. When I crossed the bridge, I suddenly felt very cold even though it was in the mid-summer when the weather was extremely hot. Not long after that, I found a lump in my chest [which later turned out to be breast cancer]. (Chi, aged 62, Hue city)

During my fieldwork I often encountered lively discussion regarding the influence of attending a funeral on the well-being of cancer patients. Many patients like Chi narrated their stories of identifying a cancerous lump after a funeral. The debate as to whether or not a cancer patient should attend a funeral was also frequently brought forward in everyday conversations among patients themselves or with their doctors. While there is no established scientific findings suggesting the impact of funeral attendance on expediting a cancer diagnosis nor on a patient's health status, my informants and some healthcare providers often drew on the yin-yang principles (see Chapter 3 on the Vietnam's traditional health beliefs) to explain the association. In viewing death as having a yin nature, my informants often explained that funeral sites are filled with yin or cold element, which would lead to an imbalance in attendees' vital energy. As a patient with cancer is considered to have an excess of yin, exposure to more of this principle would therefore exacerbate their disorder, rendering symptoms worse and in such cases, making them more easily detected. For those who have already been diagnosed, it is also advised that they avoid attending a funeral or visiting a cemetery in order to protect their health.

In the present study, Chi's story resembles many others' illness narratives which framed the first symptom identification along with the receipt of their cancer diagnosis as defining moments in their life. Towards this end, though many of my informants could only describe the subtle characteristics of the bodily changes or symptoms they had experienced, most of them could often vividly recall the exact timing, the contexts surrounding their discovery, or a specific, often traumatic event that led to their discovery. These included, for instance, a fever following a lump discovery, severe fatigue following stressful events like a funeral or accident of a family member, or at the completion of their house construction. This should be considered in relation to the widespread notion that worry and physical weakness precipitates breast cancer as demonstrated in the previous chapter. While they could not identify a symptom until that specific moment in their life, the women usually maintained that a cancerous lump had already been "hidden," "constantly growing inside the body." The advent of those important events served as a catalyst to their identification: they exhausted their already weakened body and rendered visible symptoms of cancer.

### ***Interaction with the social network***

A woman's help-seeking behaviours were also impacted by a variety of external factors, notably the interaction with people in her social network. In my FGDs, women participants believed that female breasts were prone to various ailments throughout their life course due to women's roles in childbearing and breastfeeding. In view of this, many women, including the patients in my research, tended to convince themselves that a change in or around their breast was a common illness that was non-severe and thus, did not require medical attention. It was only when they were encouraged by other people, mainly a female member in their social network, that they sought a professional examination.

In this regard, knowing another woman who has had breast cancer prompted women to present for a medical examination after they discovered some symptoms. Many patients often mentioned how their personal communication with an existing patient was vital to their appraisal of a symptom or bodily change because they were able to compare their own symptoms and find the similarities and were encouraged to seek medical advice early. Trà, whose use of pesticide I discussed in the previous chapter, recalled that when she first identified a breast lump, she thought it was associated with her fever and fatigue

due to her hard work and lack of rest. She did not intend to visit a clinic because the lump was not sore and Trà thought it would disappear after she took some over-the-counter medicines as she had always done when feeling sick. At that time, she had a neighbour who had been recently diagnosed and treated for breast cancer. When Trà came to visit the neighbour and told her about the lump, the woman urged her to go to a hospital to get examined and reassured Trà about cancer manageability:

That woman, she asked me: “Why did you dare not to go? There was a woman here named Lan, she died because of a similar lump. Now you have a lump, why not go for a check-up? If necessary, they will remove it, why do you leave it like that?” She offered to help me watch over the motorbikes [Trà’s income-making source in addition to her farm work] so that I could go for a check-up. Then I followed her advice. (Trà, aged 56, Quang Tri)

Additionally, knowing someone in their close network who has suffered from any form of cancer can act as a trigger to care-seeking because it provokes the fear of having cancer. Studies in various settings suggest that a woman’s fear and anxiety about diagnosis and treatment might prompt her to seek help or provoke procrastination and delay in order to avoid a confirmation of cancer (Shaw 2019; Unger-Saldaña & Infante-Castañeda 2011). In the case of my study participants, such fear had served to motivate them to seek medical diagnosis and treatment as early as possible at the discovery of any symptom in their breast. This was frequently mentioned by the women I met at the consulting rooms:

38-year-old Giang from Gia Lai was waiting for her turn to enter the mammography room after having her ultrasound and clinical examination results. As we were chatting on the waiting bench, she told me that she feared the lump she sometimes discovered in her breast could be cancerous. It was the first time she had ever had her breast clinically checked. When I asked her about breast cancer communications she received at her commune, Giang told me there was nothing like that provided at her commune clinic. She sought medical attention immediately after discovering about the lump because her brother-in-law had recently passed away because of lung cancer and that she knew too many cancer patients in her village. In her belief, if detected early, “there was still hope” for breast cancer patients. She told me that she knew some women in her village who had undergone mastectomy, “they lost their hair, felt terribly exhausted, but then they recovered.” Meanwhile, there were some whose

cancer had already been acute, “they would die with or without a mastectomy even when they went to big hospitals in Saigon.” (Fieldnote, 2019)

Immediate care-seeking behaviours might result from the fears of observing a cancer spike in the community, but also from public health messaging which often emphasises the importance of timely early detection in a patient’s survival. A common message transmitted in public communication campaigns on the prevention of breast cancer in Vietnam is: “Early detection of breast cancer leads to curability.” In my interviews with the women, many could narrate this phrase when I asked them about their perceptions of breast cancer treatment. Some went to add an additional statement: “Lateness turns [it] into an incurable disease (*bệnh nan y*).”

The care-seeking decisions were notably influenced by the information the women received from a person with a medical background. In their narratives of care-seeking trajectories, the women often placed emphasis on the advantage of knowing someone who worked as a healthcare professional as a critical driving force to their early presentation at a hospital, such as the case of Tuyến (aged 36, Quang Binh) mentioned earlier. Her decision to visit a clinic instantly in the morning after she found an abnormal symptom resulted from her own appraisal, but also due to the insistence of her husband who was a doctor at a provincial hospital. In the case of Duờng, her friend encouraged her to seek a second opinion after the first examination concluded her breast lump was just a benign fibroid:

By that time I watched many programs on television warning about breast cancer and asking women to check their breasts regularly. So every day I did my own exam, then one day I found a lump. Right after that I visited a private clinic where they told me it was benign but then I talked to an acquaintance working at the Medical College Hospital. She told me to get there and have another check-up. There they found out it was cancerous. (Duờng, aged 47, Hue City)

The role of one’s social network in encouraging women to seek care did not only come in the form of advice or information, but also in the provision of practical support during their visit to a hospital for examination. For patients who lived in remote locations, having an acquaintance or a relative living close to major public hospitals notably facilitated their access to specialised oncology services. It was also critical for those with limited prior experiences with the health sector like the majority of my informants. Having someone

familiar with the hospital assisted women in navigating throughout the medical system, for instance, regarding the administration process, or by recommending services or providers, or providing temporary shelter. Mong, who lived in a rural district in the province of Quang Binh which is approximately 5-hour bus ride from Hue, first ignored the node (“*hạt*”) in her left armpit. In our interview, she stressed that if it would not have been for her sister who lived close to the hospital, she would not have been able to obtain her breast cancer diagnosis:

I was so foolish that time. I thought that it was just a benign symptom and did not need to be examined. Until I talked to my youngest sister. She said: “My dear, you must do it [go for an examination]. (...) Then we came here [the Central Hospital] for the first time in my life. She took me to have an examination, then a biopsy. (Mong, aged 53, Quang Binh)

### **An absence of routine breast screening**

During my fieldwork, I met some women who reported that their breast care practices were conducted with reference to television programs calling for women to attend to early breast cancer symptoms. However, most of my participants could not mention any set of guidelines for performing breast self-examination in our interviews and tended to describe their practices as more instinctive (“*theo phàn xạ*”) than methodical. For instance, the women often described their breast examination as part of their everyday routine such as while taking a bath, getting dressed, or lying down at bedtime. In reviving their accounts with respect to their first detection of a breast symptom, the women strikingly emphasised the sudden, self-detected nature of their discovery rather than the role of any structured screening program. While clinical breast-exam and mammogram is recommended in Western countries as a component of annual routine care, such a practice was non-existent in my informants’ accounts.

This situation was common for women who were employed in the formal sector who were covered by the UHI, as well as those in the informal sector. As set out in *Article 152* of the existing Labour Code issued in 2012, employers shall provide an annual health check-up for all staff. For female staff, this must include gynaecological exams. My informants who worked in the formal sector often reported their participation in regular

health check-ups, usually on an annual basis, which was provided to them as part of their employment benefits and in many cases, entirely covered by their employers. However, the examination package seemed homogenous for women of all age groups and did not include a component of breast screening. Like many other patients, 47-year-old Hay (from Quang Tri), accidentally found a lump in her left breast when she was resting in bed. She recalled that at first she was not sceptical about its malignancy partly because the results from a health screening early that year did not detect any suspected signs. Looking back to the period before her cancer diagnosis, Hay critically questioned the reliability of the examinations organised by the child-care centre she had been working for when interviewed during my fieldwork:

Every year we were sent to have a medical check-up. However, during such examination, it was done perfunctorily, mainly focused on ear-nose-throat. They did not check your breasts, no test, nor ultrasound, not even a breast physical examination even though most of the staff at the childcare are female. (Hay, aged 47, Quang Tri)

The case of Hay was common. Many other informants reported their presentation for their routine health examinations, but rarely or never had their breast screened for cancer. While a small handful of women recalled receiving a clinical breast examination, including an ultrasound as part of their care, none of the informants I interviewed had ever had a mammogram prior to their cancer diagnosis. The story of Khiêm below was a deviant case among my patient participants whose cancer was the only one detected during an annual screening. While her account contrasts to that of most of my informants due to her background as a health professional, as well as her access to medical screening provided by her employing hospital, Khiêm's story typifies the situation suggesting the absence of breast screening in routine examination programs.

### ***Khiêm's case***

Working as a senior nurse at a cardiac department since 2004 after she had finished her nursing degree at Hue Medical College, Khiêm (aged 45, Hue City) had presented to all health examinations that the regional hospital she worked for held every year. However, as Khiêm recalled, it was not until 2016 that she started receiving a breast ultrasound as part of the check-up. Previously, she had experienced some thyroid-related illness and so

she tended to focus her attention upon that area of her body rather than the breasts even though she still performed breast self-examination regularly at home. More than ten years ago after Khiêm stopped breastfeeding her youngest daughter, occasionally she found a breast node but she had not sought any examination. An ultrasound at her hospital in 2016 further confirmed that there was no problem with her breast.

In late 2016 after her mother passed away, Khiêm experienced prolonged menstrual bleeding for two months and a follow-up examination suggested that she had a benign fibroid in her cervix. Her colleague from the gynecological department then recommended her to either have surgery to remove it or take hormonal medication. Khiêm was hesitant about the surgery and decided to take hormones to treat her fibroid. Three months later came the medical check-up for 2017 at her hospital for which she again enrolled. One of her colleagues told her she should also register for a comprehensive breast screening and she agreed. It was the first time Khiêm had ever presented for mammography. Further tests followed and when the results came, she was overwhelmed because it showed that she had breast cancer which was already at an advanced stage (stage IIIB).

I visited Khiêm during her hospitalisation for chemotherapy to treat her lung metastasis after several encounters at peer group events when she took part as an organising member. In our conversation, she shared with me that despite a woman's careful attention to any bodily change, given the unpredictable nature of cancer, she would not be able to have an early detection without being screened by professional team as in her own case:

You know, it was the first time I was sent out for a real test that the hospital paid for. Previously, there was nothing like that (..) When I had the surgery [mastectomy], the lump was still small, only 1 cm [in diameter]. It was right on the top of the breast, exactly at the same location as the node I discovered some time ago. It was not big, that's why I could not identify it myself.

Khiêm felt pity for herself because her employing hospital did not offer its employees a screening package with necessary examination and tests which would have enabled the discovery of her illness earlier: "We are right at the centre [of the hospital] but did not have the conditions for an early detection. So what about others in remote areas? That's

why since I was diagnosed, I am really keen on doing community events to raise the awareness of the women.”

While women like Khiêm or Hay had access to annual health check-ups as part of their employment benefits, those who made up more than half of my sample worked in the informal sector and therefore were not entitled to such coverage. For those women, a routine check-up provided by employers remained inaccessible, not to mention that related to the breast screening. In the section below, I consider community initiatives attempting to increase women’s access to breast cancer health promotion programs.

### *Community initiatives*

My visit to the rural commune of Bộ Đội where I interviewed commune clinic and local officers overseeing health-related issues, as well as during my focus groups with the women villagers, revealed the limited presence of local health initiatives on breast care. Most of those programs primarily focused on gynecological health and screening for cervical cancer. Meanwhile, programs on breast cancer awareness raising or early detection were largely missing. This situation is noted in recent research on the use of breast cancer services in Hanoi and Ho Chi Minh City (Jenkins et al. 2020). Their study finds that concern and awareness among women around breast health prior to their diagnosis is lacking, which starkly contrasts with the wider knowledge concerning the role of screening in detecting and preventing cervical cancer.

In the same vein, during my interview with Bình, a representative of the Women’s Union, she shared with me that most community health initiatives were built around issues related to reproductive health, notably family planning and screening for cervical cancer. For such reasons, these programs mainly targeted women of reproductive ages (aged 25-40) while excluding middle-aged and elder women – the groups recognised for carrying higher incidence and risk of breast cancer (Tao et al. 2015). Bình remarked on the limitations of their outreach programs: “We widely announce our programs which often take place twice a year, but there are only around 200 to 300 participants [attending medical examination] a year [while the total number of the Union’s members was 610 at the time of my fieldwork]. The rest still prefer visiting a clinic at the city. Only women farmers chose to visit the commune health station for examination.”

During my observation at the commune, I noticed that there were only three to five visitors on a typical working morning and most of the time, the two-storey building housing the CHS remained quiet, which stood in stark contrast to the constantly overcrowding at the Central Hospital and the provincial hospital I attended. Unlike the long process required for approving my interviews at the national hospitals, my requests for interviews were promptly accepted at the health station where the head doctor agreed to meet with me for as long as I wished. During our interview, the doctor provided me with detailed statistics on their most recent cervical cancer screening organised for the villagers in collaboration with the province's Centre for Disease Control more than six months prior to my fieldwork. For that particular screening, the health station gathered 66 samples which were sent out for testing. Speaking of the clinic's capacity in detecting breast cancer, the doctor admitted that their main jobs dealt with delivering child immunisation, rolling out family planning policies, monitoring pregnancy, and attending normal births. In terms of breast screening, they could only perform manual breast examination due to the fact that their only ultrasound machine had been out of order for the past three years.



**Plate 6. 2.** A consulting room at a commune health station

Given the sporadic nature of local health promotion programs combined with the lack of medical facilities and expertise at the local clinic, it was not surprising that most villagers participating in my FGDs affirmed their trust in higher-level hospitals in screening for and treating serious diseases such as cancer:

Trang: In case you suspect that you might have cancer, what will you do?

Woman 1: Go to the clinic

Woman 2: Immediately to the clinic

Trang: Where will you go? To the commune clinic?

Woman 1: No, go straight to the national hospital.

Woman 2: Only at higher level

Woman 3: Maybe the general hospital [at district] screen and identify something, they will transfer you to higher level for a confirmation.

Woman 4: If the low level finds something, maybe you are already at very late stage [of cancer]

Woman 5: Yeah, they can only find out [that you have cancer] when you feel very painful, then they will transfer you to the hospital in Hue city.

Trang: So it means you have greater trust in national hospitals?

Woman 1: That's right. There they have different specialisations [not like the district general hospital], so they must be better.

(FGD 02)

Hue Central Hospital itself was involved in rolling out community screening at the headquarter in Hue and the satellite unit in the district of Phong Điền (around 20 km from the main site) on certain occasions, for instance, during the Pink October month. These events could attract the participation of a wide audience because all components of the screening (consultation and examination including mammography) were delivered free of charge and were attended by the medical staff working at the Central Hospital. As reported by one of the directors of the Oncology Centre who was among my informants, the October 2018 event attracted approximately 1,200 attendants at one site. While the Central Hospital did not charge any participation cost nor restrict those from locations other than Hue and the district where the Hospital's satellite unit was situated, those screening events were only advertised on the hospital's website, on posters hung around the Hospital's premises, or on local communication channels. This meant women residing in remote locations or other provinces would experience significant hurdles in accessing

such information or traveling to the sites where the screening took place. My interviews with several Hospital's staff suggested that such events were not held regularly and subject to the availability of external funding from non-governmental organisations or pharmaceutical companies.

The constrained resources facing the local health system, the limited availability of breast care programs delivered at community level, coupled with the lack of breast coverage in regular health check-ups to certain population groups explains the absence of routine breast screening among the women of this study. Given this situation, as revealed in the accounts of my informants, most of the women only sought medical care when some symptom arose. Their encounter with the formal health sector, even when it was done immediately after their discovery of a breast lump, was not, however, synonymous with prompt detection of cancer, as I later demonstrate.

### **Seeking medical attention: encounters with the health sector**

At the discovery of a potentially serious breast symptom, prompted by other people in their network, or when the symptom that was deemed benign in the first place persisted or worsened, women would present for medical examination. Their subsequent care-seeking trajectory from the initial medical contact until the confirmation of breast cancer often involved visits to different healthcare providers at different levels and sectors of the health system. The case of the 48-year-old woman I met at a consulting room below exemplifies typical patterns of care-seeking behaviours.

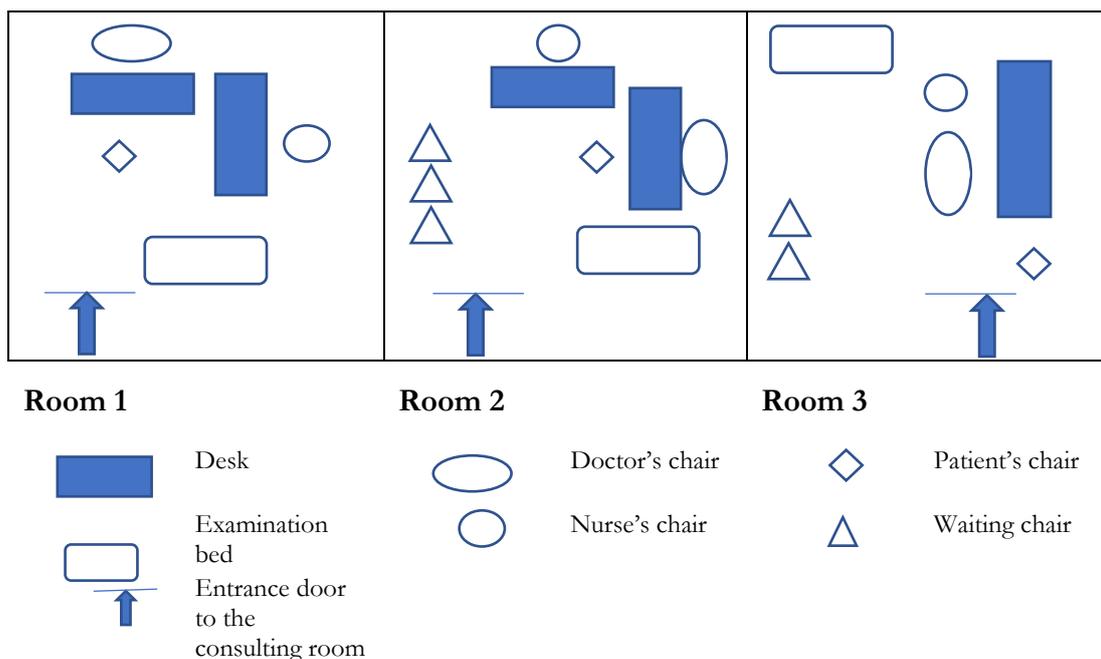
At a quarter to nine a woman came in to have her breast examined. Dr. Nguyễn asked her to take the seat closest to him and to unbutton her shirt. In the room there were four other women waiting for their turns (see Figure 6. 1 illustrating the physical set-up of consulting rooms) and a man who had just finished his consultation and was now waiting for the nurse to print out his prescription and follow-up appointment.

The woman did not unbutton her shirt but only lifted it up to render both of her breasts visible. Dr. Nguyễn started to look at the breasts, and manually examined them; simultaneously, he asked the woman a couple of questions about the

symptoms she had noticed. Then he directed her to the examination bed at a corner of the room and requested her to close the curtain surrounding it. He reminded her to keep her chest uncovered for further examination.

As Dr. Nguyễn was walking towards to bed where the woman was lying, another patient entered the consulting room and questioned him about the tests he had been requested to take. The doctor turned to him and explained for about three minutes. After that, he went towards the bed. He used his left hand to press around each of the woman’s breasts while looking at the ultrasound film that he carried on his right hand and reading about the tumour description that a physician had previously provided.

After two minutes, Dr. Nguyễn told the woman that it was just a cyst (“u nang”) and no mammogram nor surgery was needed because the tumour size was not big. He advised the woman to keep an eye on it, but for now she could leave and should return in three months. She looked confused and remained in her seat, opened her handbag, and took out several sheets of test results she had done previously elsewhere. She told Dr. Nguyễn that she had many other tests, not only the one of her breasts. The doctor refused to have a single look and reiterated that she did not need to worry because it was a cyst: “there was no fluid, no stone.” (Fieldnote, 2019)



**Figure 6. 1.** Set-up of the consulting rooms

The case presented above resonates with many other patients I encountered whose pathway to cancer diagnosis often involved numerous visits to different hospitals stretching over an extended period of time and across space. As I talked to that woman at the end of her visit, she told me that in 2018 whenever she took a bath or her menstruation was approaching, she found nodes in both of her breasts. Having a sister-in-law and colleagues previously diagnosed with breast cancer made her worried and triggered her to visit a provincial hospital in her home city of Dong Ha (Quang Tri province) and to have a breast examination, only the second breast check-up in her life. After receiving the benign results from her first encounter, her fear was not settled, which prompted her to take sick leave to visit Hue Central Hospital for another examination. At the confirmation the woman received from Dr. Nguyễn, she still had some doubts, but she told me she was feeling better for she knew about the expertise and reputation of Dr. Nguyễn and the Central Hospital.

In many patients' accounts, upon the discovery of a breast lump, their care-seeking trajectory often started with a visit to a private clinic. The preference for private care has been similarly noted in studies on health service utilisation in Vietnam. For instance, anthropologist Martha Lincoln (2014), when researching medical stratification in Vietnam, illustrates an ambient paranoia about Vietnamese public facilities among her respondents in Hanoi who often perceive the socialist medical system as frightening. Many of these low-income families in Lincoln's ethnography show a preference to use private clinics and use them when they can afford to. Such preference for private medical services was apparent among my participants despite the incurred higher costs. There my participants reported having paid from 70,000 VND to 150,000 VND (~US\$3.08 to US\$6.58) as compared to 39,000 VND per consultation charged at a public hospital like the Central Hospital where my research took place (see Appendix 6 for the Central Hospital's charge of main diagnostic services). On average, when visiting a private clinic, a patient would expect to pay a minimum of 40%-50% extra cost. In some cases, the gap fee might be double, or even triple. For instance, a breast ultrasound costs 45,000 VND (~US\$1.97) at the Central Hospital, but approximately 120,000 VND to 150,000 VND (~US\$5.26 to US\$6.58) at a private clinic according to some participants' record. While medical services are charged at lower rates at public hospitals, my informants often explained their decisions of choosing a private clinic visit as the first point to seek medical

attention for multiple reasons, such as closer proximity to their home, shorter waiting time, and easier registration procedure.

The private-public segregation is not always clear because many doctors at public hospitals are also employed by private clinics on a part-time basis or themselves own one where they work after official working hours. Given such characteristics, in seeking care for a health condition like a breast symptom, patients often moved back and forth between the two sectors. For example, at several consultations throughout my ethnography, I watched doctors give their private mobile numbers to incoming patients and advise them that they could undertake a minor lumpectomy for the patients at their after-hours clinic. Some explicitly offered services at reduced costs as compared to the same operations performed at the public hospital where they were working. In other instances, patients shared stories of their first breast examination and ultrasound conducted at a home-based clinic of a senior doctor. This provider then arranged for her mammogram at another private clinic and later helped her with the admission to the public hospital where he worked after the arrival of her cancer diagnosis.

### *Misdiagnoses*

Inaccurate diagnoses are recognised among the most important factors that contribute to late detection of breast cancer, hindering patients from obtaining timely treatment and thereby, incurring significant financial burden to patients and their families as the cost for treating breast cancer is substantially higher when it is diagnosed at later stages (Khakbazan et al. 2014; Moodley et al. 2016; Unger-Saldaña and Infante-Castañeda 2009). While my informants' accounts highlighted the common practice of visiting a private clinic to have their first examination of a suspected breast symptom, it was also at this level that patients were more likely to report the incidence of medical errors. For example, 39-year-old Xinh, an office worker from Nghe An province perceived herself as a very health-conscious person who always paid attention to any abnormal bodily changes. In 2012 in her five-month gestation, she found two nodes in both of her armpits which she believed to be associated with cancer. As Xinh recalled, the nodes "had the same size of a corn. They kept growing as my belly expanded." As the nearest central-level oncology hospitals in Hue and Hanoi are both approximately 8 hours away by bus, Xinh decided to visit a clinic in her hometown to have an examination which subsequently indicated the nodes were not cancerous. However, later in 2017, she again discovered a lump in her

left breast which was later diagnosed as cancer at the National Cancer Hospital in Hanoi. Xinh was convinced that she should have been diagnosed earlier:

Back then when I went visit the private clinic, there they took out a specimen from the nodes and tested. But later they said they were benign. They should have performed an ultrasound for me. That suggested how poor their capacity was. I told the doctors there my sister and mother both had fibroids in their breasts (“*u xơ tuyến vú?*”) and they said because of that it, was also likely for me to have the same condition. But they never sent me for additional tests.

In most cases when patients reported experiencing diagnostic errors, their accounts mainly pointed to a healthcare provider’s misinterpretation of clinical or ultrasound results. A few mentioned that a misdiagnosis came after a biopsy; meanwhile, I met no patient with an account of a diagnostic error that involved the use of a mammogram. This might be suggestive of the limited capacity of healthcare providers, as well as the shortage of breast screening facilities at lower-level clinics. This was not solely reported among patients who initially sought care at a private clinic, but also at local public hospitals, as exemplified in the following story of HỒNG, 51-year-old farmer from a rural village in the province of Ha Tinh.

HỒNG had been diagnosed with stage II breast cancer and undergone a mastectomy and three cycles of chemotherapy by the time we first met. A couple of years back, she found several nodes in her armpit and visited a district public hospital where she was physically examined by a doctor who later told her that those nodes were benign and prescribed some medicines. Hong finished the medication, but her symptoms did not disappear. Feeling worried, she travelled to a provincial public hospital where the doctors re-examined her condition and sent her out for an ultrasound. Again, they concluded that the nodes did not reveal any malignancy. This time, she left without any medication. Hong no longer paid attention to such symptoms until in 2018, after attending a funeral, the nodes she had discovered before started to hurt, which she thought would be an indication of cancer. She returned to the provincial hospital and that time, they sent her out for a biopsy and told her she had breast cancer, and later referred her to Hue Central Hospital.

While oncology services have been improved across the country in response to the rising cancer burden, related diagnostic and treatment services remain highly centralised

in Vietnam where the most well-equipped oncology facilities are concentrated in a few major cities (Stalford 2019). As mentioned in Chapter 3, it is estimated that the existing oncology system can only accommodate 30%-40% of the people's needs and fewer than 10% of oncology centres offer all essential cancer treatment, including surgery, radiotherapy, chemotherapy, and palliative care (Ministry of Health and Health Partnership Group 2015, p. 226). The women's narratives as I present in this section provide further evidence on the constraints regarding laboratory and imaging capacity at lower-level hospitals. These accounts illustrate that a patient's immediate care-seeking behaviour upon her discovery of a breast symptom does not always secure her a prompt cancer diagnosis due to the limitations at the healthcare providers' end. This explains the strong preferences for "level-skipping" ("*vượt tuyến*" or "*trái tuyến*") that is to bypass lower-level facilities without referral (for further details see Stalford 2019 regarding the diagnosis and treatment of serious diseases like cancer).

Among my study participants, traveling to an urban hospital for care was inevitable for those who had doubts about the local hospitals or could not obtain accurate diagnostic services. It was also the trajectory for those who initially sought care at a public hospital in their place of residence but received referral due to constrained local health services. For instance, 46-year-old Phan claimed that by the time she had mastectomy, her breast tumour had already been as "as big as a chicken egg." The woman recalled that upon the discovery of some painless lumps in her breast, she first went to a provincial public hospital in the municipal town of Quang Binh province where she resided with her husband and two daughters. After one examination, the doctor there concluded she had cancer, but had to refer her to a national hospital. This was because despite being the largest general hospital in the province of nearly a million people, that hospital did not house an oncology department, and thus, lacked the capacity and facilities to confirm and treat a life-threatening disease such as cancer:

I went for an examination in Dong Hoi. There the doctor came to the conclusion that it was breast cancer. Only by [physical] examination he told me, without sending me out for any tests. And he said because it was malignant, I had to be treated at another hospital. He asked me whether I would like to go to Hanoi or Hue.

***Level-skipping and under-utilisation of health insurance***

When travel is inevitable, patients are subject to logistical frustration, as well as financial hardships throughout their care-seeking trajectories. In a rich ethnographic account examining travel for cancer care in rural Vietnam, Stalford (2019) explores the embodiment of disadvantage over time, but also in the course of movement between places. Her study reinforces the concept of structural vulnerability (Quesada et al. 2011) by further considering spatial practice's impact on health inequalities. In the specific case of most women in my study who lived far from a hospital with oncology services, throughout their search for a cancer diagnosis, level-skipping practices were common. While some women completely bypassed the lower-level facilities to obtain screening and diagnosis at the highest-level public hospital, a significant number did so only after their negative experiences (mainly medical errors), or at the recommendation of doctors at a lower level due to their shortage of oncology expertise and/or resources. Against this backdrop, such decisions are more of an involuntary rather than "active" nature (Leonard 2014). However, from the perspectives of the formal health system, they are all classified into the "level-skipping" category, which impedes patients' ability to utilise their UHI for the purpose of cancer detection.

According to current regulations (*Law 46/2014/QH13* amending the Law on Health Insurance), a holder of a UHI card is only entitled to being fully covered for examination or treatment fees at the point of registration, usually at a commune- or district-level health centre (see also Dao 2020), due to the authorities' attempts to decentralise the delivery of care and curb the overcrowding facing urban public hospitals. When a person seeks care in the highest-level tertiary hospitals without a referral, as in the case of most women in my study, they are only reimbursed up to 40% of inpatient treatment fees. This means that costs related to examination are non-reimbursable. In order to have a referral to a higher-level hospital, a person needs to provide a confirmation of a serious disease that cannot be treated at the healthcare centre they have registered as the primary point of receiving care. This, at the stage of seeking cancer detection, brings to the fore the "chicken or egg" dilemma: a person needs a referral to benefit from their insurance entitlements when seeking examination necessary for a diagnosis; meanwhile, such a diagnosis is a prerequisite for getting a referral.

Within my study context, the majority of my informants reported having to pay for screening and diagnostic services entirely out-of-pocket at provincial or national hospitals irrespective of their public insurance status. The additional tests required to confirm a diagnosis may, in many cases, included the same tests a patient had previously undertaken because of the unconnected characteristics of health facilities (Ministry of Health and Health Partnership Group 2015). Trà (56-year-old from Quang Tri), for instance, recalled her first days at Hue Central Hospital to seek a diagnosis after her initial breast examination suggested suspected malignancy. She was admitted as an inpatient for more than 20 days and went through various diagnostic tests, including another ultrasound which a district public hospital had previously performed on her earlier that month: “I paid the hospital fees, so they admitted me. I was staying in the inpatient room waiting for the test results. I did the tests again and again.”

Apart from medical costs, people who seek screening in a specialised hospital far from their place of residence must bear additional non-reimbursable costs, notably related to transportation, which considerably add to the total expenditures. For instance, in the case of Giang and her husband, whose account was provided earlier, Giang’s breast examination cost them 655,000 VND (~US\$28.73) and they had to pay an additional expense for transportation (880,000 VND or ~US\$36.60 for the two return bus tickets to/from Hue back to their hometown in Gia Lai). This excludes the opportunity cost of the visit as a woman might lose her full-day wage which ranges from 200,000 VND (~US\$8.77) in the rural area to 400,000 VND (~US\$17.54) in a city setting should she take a day off to travel to other province in order to seek care.

In view of this, contrary to much existing research (for summary see Khakbazan et al. 2014), I would argue that being covered by the UHI did not improve accessibility nor prompt a person’s cancer-diagnosis seeking, because in most cases it had limited use when most women practiced “level bypassing.” While having no insurance was not explicitly mentioned by any women I met during my ethnography as a barrier to seeking medical help for a breast symptom, some medical staff flagged the issue regarding the exclusion of screening and diagnostic tests in the universal insurance scheme: “Screening mammography is not yet covered by the insurance now. It creates a big barrier to early detection of breast cancer.” This provider believed that screening services should be widely available at district-level hospitals where people could access it with their public insurance card:

We need screening units at district hospitals so that people don't have to travel far to get screened. Second, we need to accelerate awareness raising at that level. District [hospitals] need to educate people about the availability of screening services and latest innovations in detecting cancer. That is most important; otherwise, people will not have "correct" knowledge of breast cancer and not present for screening." (Dr. Điền, male, Managerial Role)

### **Receiving the diagnosis: "the sky is falling down"**

Frustration and anxiety while seeking a diagnosis of cancer was not settled at the arrival of a confirmation. Rather, those feelings intensified and seeped into the moment a patient was confirmed she had breast cancer. Narrating the first time they discovered their cancer, most of the women I met in my ethnography provided retrospective accounts filled with shock, panic, and despair, a feeling like "the sky is falling down" due to their belief that the disease would be terminal, incurable, and "100 percent cause [them] to die" (Thi, aged 54, Hue City). The common notion that equated breast cancer with death was drawn from their own witnessing of the fates of cancer sufferers in their community or family, but also from the lack of explanation from the medical professionals who had released their results. Such reactions are similar to those of women elsewhere described in the current body of literature (see for instance, Hunt 2016; Manderson et al. 2005).

As I noticed throughout my observation at the consulting rooms, when most diagnostic tests had been done and suggested a cancerous status, doctors were more likely to speak to a patient's family member rather than the patient herself. Cancer concealment was deployed by many family members and doctors and experienced by many patients I interviewed. This made their cancerous status unknown to them and caused notable anxiety and confusion, even by the time some form of treatment had commenced, as described in the account of My, one of the youngest informants in my ethnography:

After the first surgery to remove a lump, the doctors got my biopsy test, but they only told my husband then. He did not say anything about its malignancy to me. Two days later I had to be readmitted. That time they said they would remove my left breast. I had not known anything about my status though I could sense that it was not benign as the doctor had previously told me. Only after the mastectomy

I learned that my husband had known about my cancer and he had already told everyone in my birth family. (My, aged 29, Thua Thien Hue)

On several occasions when the doctor had to deliver a cancer confirmation, I observed that this consultation mainly consisted of advice on aspects related to insurance arrangements and was very brief given the fact that the consulting room was rarely private and often attended by several patients at once. Questions related to prognosis and treatment procedure were rarely addressed at this stage, which obscured understanding of breast cancer curability among both patients and their family members, reinforcing death-associated beliefs. Xinh (aged 39, Nghe An) acknowledged the doctors who had overseen her treatment for their competence. However, she got frustrated with the poor communication during the days she first learned about the cancerous tumour in her left breast:

I could not ask the doctors anything (...) I had no idea about how my cancer was, what the treatment would be, which medicine I would take, and used for what. I tried to ask once but they didn't answer me. They didn't even allow questions (...) One male doctor, his face was always cold. He never said a word. I found the environment was too tense, it made me feel unhappy. Imagine yourself being a patient there, how could you get any better?

Xinh's recollection resonates with the experiences of underserved women in other study settings. For instance, as noted in research in Malawi (Kohler et al. 2017), the absence of communication with physicians following a cancer diagnosis results in women's misconceptions about the need to pursue further treatment as they assume that the biopsy procedure has already comprised a form of cure for breast cancer. For that reason, they do not return to hospital after the diagnostic tests until their conditions become severe. The poor doctor-patient communication experienced by the women in my study led to their confusion about the specificity of their cancer and their desire for explanations was palpable during my fieldwork, which was similarly noted by researchers conducting ethnography at oncology wards in other developing countries (cf. Livingston 2012). Very often was I approached by women who insisted on my help in interpreting a test result and informing them of the cancer stage they were at or in ascertaining them as to whether their cancer was "acute" or not, like my encounter with HỒng (aged 51, Ha Tinh) at an inpatient room:

On knowing that I was doing a study of breast cancer patients and was not a doctor at the Central Hospital, Hõng handed me her test results and asked me to help her explain the meanings of medical abbreviated terms written in the several sheets (i.e. histologic grading II and hormonal status involving ER, PR, HER-2, and Ki67) she had received. She wanted to know if there was any information in those papers indicative of the seriousness of her cancer. She was not reluctant in admitting that she had limited knowledge and education because she was a farmer and had only completed primary school. Hõng complained that there were too many abbreviations in the results, along with percentage figures (related to the hormone-receptor status), which confused her greatly. She wanted me to tell her whether she could live longer or shorter as compared to other patients who had lower figures in their papers. Some of the peers sharing her inpatient room took these tests to ask their acquaintance who worked at the hospital. However, as Hõng did not know anyone there, she could not find out since her admission for mastectomy and now her first round of chemotherapy. I asked her if she had ever consulted a doctor about this, but Hõng explained to me she didn't dare to because she was afraid of being scolded. (Fieldnote, 2019)

Under the circumstances where patient-doctor interaction and communication was often limited due to a large patient flow and poor spatial arrangement at the consulting rooms, patients like Hõng and many other women I met during my fieldwork had no choice but to rely on non-medical persons, most notably their peers, in order to obtain an explanation of their diagnosis. While participating with the Pink-shirt team, I observed that the group often received requests for explanation of diagnostic tests from the patients and helped them make sense of the technical terms in the simplest, comprehensible ways. For instance, during a visit to patients who were receiving treatment at the Central Hospital, members of the Pink-shirt team advised a woman who was awaiting her biopsy result: “if you receive five sheets of paper, it means good news. If 10 [sheets] come, it means cancer. 10 sheets is the life sentence (*án chung thân*).” In another instance, when asked by a patient about her cancer stage based on the TNM staging system a doctor had written in her medical book, a team leader told her to memorise that T always indicated the tumour, and N stood for “*Nách*” (armpit), meaning how many nodes (“*hạt*”) in the armpits she had. Even though the latter explanation was insufficient as N refers to the number of nearby

lymph nodes that have cancer (Chavez-MacGregor et al. 2017), in most cases the patients seemed satisfied with the response because they eventually got one explanation.

## Conclusion

This chapter has illustrated the nuances of the process from the first detection of a breast symptom until the arrival of a cancer diagnosis. When a woman discovered a lump in her breast, she faced the decision to either leave the symptom unattended or turn to traditional healing methods if she appraised the symptom to be a benign condition, or to seek biomedical advice and examination. The interpretation of breast symptoms as abnormal or acute, the persistence of breast symptoms after attempts to treat a lump assumed to be benign, and the encouragement of people in her social network, prompted a woman to seek biomedical healthcare services. This chapter highlights the importance of women's interaction with people in their informal networks, notably, with cancer patients and those with a medical background, as motivators to their help-seeking practice at the discovery of symptomatic breasts. Such findings invite health promotion programs to engage with those facilitating forces, such as cancer patient peer network, as well as grass-root mass organisations at local levels to raise early symptom awareness and encourage women's practice of seeking help in response to possible signs of cancer.

In their search for a breast cancer diagnosis, women spent large sums of money and travelled extraordinary distances. Their trajectory to diagnosis was not a linear but a painfully circuitous path that involved multiple visits across time and space, and experiences of various forms of diagnosis delay produced by the health system, which led women to perceive their clinical tracks with anxiety, frustration, and distrust. The women's narratives shown in this chapter negate the assumption that the urgency to seek help when a symptom or bodily change arises would lead to prompt detection as conveyed in health promotion messaging. Tracing women's trajectories from their first discovery of a suspicious lump through to the detection of a cancer is contingent upon many factors and the quality of care women receive during their medical encounters is often limited and compromised by systemic constraints: the absence of a national screening program; limited oncology capacity and resources; and the lack of patient-centred care at urban hospitals within a health system in a lower middle-income setting. The arrival of a cancer diagnosis, for a few, marks the end of their search, while for many, it leads women to

experience greater levels of confusion and apprehension. Seeking and securing a diagnosis, regardless of how devastating and dreadful it appears, is in most cases just the beginning of a prolonged, rigorous cancer care continuum.

# Chapter 7.

## The Burdens of Seeking Treatment

### Introduction

Moving from the diagnosis of cancer, patients enter what Julie Livingston refers to as the “rigours of oncology” which involves numerous forms of radical treatment (Livingston 2012, p. 70) and throughout their care-seeking trajectories, a hospital offers a site for patients to access biomedical technology and expertise where their cancer is detected and hopefully, put under control. In this regard, the hospital is an avenue of hope and healing. On the other hand, hospitalisation for breast cancer treatment tends to disrupt the everyday life of the patients and their families. It lays bare the multiple layers of vulnerability within a context where there is an imbalance of oncology services between urban and rural areas and formal support remains scarce or precarious to sufferers of a health shock like cancer. To increase their chance of survival following a diagnosis of breast cancer, breast cancer patients in my research context, as elsewhere in the global south (see Manderson and Wahlberg 2020), must travel extraordinary miles to reach a tertiary hospital to obtain oncology care and acquire medicine stock because such services and products were either non-existent or of substandard quality in their immediate vicinity. Hospital-based cancer treatment, given its lengthy duration and tremendous costs, exhausts all of the physical, emotional, and economic resources they have at their disposal and threatens the welfare of the patient herself, as well as her family at large, rendering them in a more fragile and vulnerable state of living. Accessing hospital to obtain cancer care in this way exposes patients to disruptions, suffering, and despair. This chapter illustrates the emotional toll, trauma, and social and economic constraints facing breast cancer patients in their therapeutic process through which they seek to manage a life-threatening condition.

In the section that follows I present two case studies of H<sup>o</sup>ng and Long, whose treatment-seeking journeys represent the patients I met, to exemplify the long periods of

time that breast cancer treatment involves, as well as the burdens falling on them during and beyond their hospital-based treatment. Their stories reflect that entering the hospital after one's cancer diagnosis does not always admit a patient to immediate bodily interventions which lead to a cure scenario. But it also requires extraordinary stays, sometimes only spent in dealing with multiple non-medical demands associated with hospitalisation logistics, scheduling, and bureaucratic navigations (see Appendix 7 for a more detailed description of various stages of breast cancer treatment). As can be seen later in this chapter, the burden of managing breast cancer does not end with the accomplishment of primary treatment. Instead, it produces what Mattingly, Grøn and Meinert (2011) have termed the "chronic homework" when referring to the immense efforts and dilemmas imposed upon the patients and their families when living with a chronic medical condition. Against this backdrop, I argue that pursuing breast cancer treatment is not merely an event of biological nature but has become a "long-term career" for the sufferers of this illness.

I select these two cases because of the bonding we formed in the early weeks of my ethnography. When I first met Hõng, a 51-year-old farmer from a rural district of Ha Tinh province who insisted on my help in interpreting her examination results mentioned in the previous chapter, she was an inpatient receiving the third cycle of chemotherapy as part of her primary treatment. Meanwhile, my first conversation with Long, an urban resident from the Central Highlands, occurred when she was waiting for her hormone therapy as an outpatient at the Central Hospital. Our first encounters with these two women then evolved into many follow-up appointments both inside and outside the Central Hospital until my very final days in Hue, allowing me to gather the details of their experiences throughout our honest and intimate discussions. Hõng and Long's stories reflect the varying situations facing them at the time of their diagnosis which determined the different ways they approach breast cancer. However, their narratives both suggest the crippling and far-reaching consequences of their treatment which are produced and intensified by the operation of the social structures of cancer care. Following the presentation of these two cases, I discuss the consistencies of their trajectories to breast cancer treatment with perspectives from other patients to illustrate how the women are socialised into their cancer patienthood after the diagnosis of a pathological condition. Finally, I examine the presence of formal safety net programs available to support families

in coping with a health shock and how the patients navigated the state's social protection policies to manage the burdens of breast cancer.

### **The case of Hõng**

When she was diagnosed with breast cancer at Hue Central Hospital in late 2018, Hõng immediately went back to her hometown to sort out an administrative application for her insurance policy (which she had previously purchased for the whole family via the state's voluntary scheme) to be transferred to Hue so that she would be eligible for a full coverage. At the first attempt, her application was rejected at the provincial division of health insurance who insisted that Hõng should be treated at the local oncology ward in their province. Having mistrust with the expertise at the provincial hospital, Hõng refused to take their recommendation. But without a referral, she would not be able to receive any treatment at Hue Central Hospital - her preferred point of care because she could not afford to pay 70% of medical costs out-of-pocket as a bypassing patient. Feeling desperate, she returned the second time to the insurance office after being told by an acquaintance to pay a bribe of 4,000,000 VND (~US\$175.44) and it went through.

By the time we met during her hospitalisation, Hõng was always accompanied by a caregiver who is a member in her immediate or extended family. Throughout the period Hõng was undergoing chemotherapy, one of her sisters would arrive on the third day of each cycle. For the duration of their stay, the caregiver was responsible for alerting the in-charge nurse as soon as a tube of drugs drained or walked her around if she felt exhausted from chemotherapy's after-effects. The caregiver would also help the patient with administration work or other day-to-day activities, such as setting up the bed, cleaning, bathing, or going outside the hospital to buy meals for both of them because there they could select from a wider range of dishes at relatively cheaper prices than those catered by the hospital kitchens.

I met Hõng's younger sister – one of her caregivers – at one of our encounters early in my fieldwork at a wet market close to the hospital where they purchased some food before heading back to their hometown that night. Her sister told me that to visit and care for Hõng, she must reschedule her own family chores to accommodate the caregiving responsibilities. This caused considerable interruptions and a burden for the

sister's family because she had to leave all her farm work behind or hire someone else to take care of her rice field while she was away. However, the sister told me she could not leave HỒNG alone because HỒNG's husband was then very sick with pneumonia and could not accompany her to the hospital. Later, I met HỒNG again while she was receiving her 7<sup>th</sup> cycle of chemotherapy. This time, her elder son who was at Grade 11 joined her. HỒNG told me that since her husband remained very sick and that her eldest daughter had recently given birth while all of her sisters were busy with their families, she had to take her son with her during the final days of his summer break. HỒNG pointed to her son who was watching a video on his phone on the adjacent bed and talked to me: "At night if that bed was spare, he would sleep there; otherwise, I've already bought a foldable bed for him to sleep next to my bed."

As soon as her cancer was confirmed, HỒNG's husband sought the village head and commune authorities to inquire about the possibility of their family being nominated as a poor household which would ensure they received the social cash transfer from the government after her illness. However, her request was rejected. Her commune in the district of Huong Khe was recently awarded with the title "New Rural Commune" – awarded by the government to acknowledge communes who have succeeded in improving the local infrastructure and standards of living (see Government of Vietnam 2010 on Decision No. 800/QĐ-TTg dated 04/06/2010 approving the National Program of New Rural Village Development between 2010 and 2020). To this end, further incidence of poverty recorded in the commune might threaten their recent massively celebrated achievement, which is unsurprising given that poverty statistics are often regarded as manipulative tools for local political expediency (World Bank 2019). They instead directed her to apply for social assistance as a person with a disability. Her application was approved and with that HỒNG was granted a government-funded insurance with a 100% coverage.

In every appointment during my fieldwork, HỒNG frantically shared with me about the possibility that she would need to go through radiotherapy because it would require another month-long stay. Even with the 100% insurance coverage she was entitled to, she claimed: "I still have to pay the hospital in advance, so they will admit me to the ward." HỒNG recounted the various expenses she had incurred during each hospital visit:

Going to hospital is really costly. The one-way train ticket costs 200,000 VND (~US\$8.77) each person. Every time I need someone to go with me, so the transportation costs alone are 1,000,000 VND (~US\$43.86) because we also have to transfer to/from the two train stations. And there are a lot of other expenses during your stay. With the insurance, they place a cap on hospitalisation of 20,000,000 VND (~US\$877.19), which meant that if I am required to stay longer, I have to pay out-of-pocket. And for each stay, sometimes the doctors prescribed me some medication that was not available here [at the hospital], and I had to purchase them from the private pharmacies, or some milk they said would benefit my health during chemotherapy. For all those things, I had to pay.

For Hõng, the transportation and other non-medical expenses for herself and the caregivers during their previous hospitalisation had depleted her savings and loans she sought from “any possible channels.” She confided to me that she turned to her siblings and relatives for zero-interest loans, along with that from a local post office’s credit at an annual rate of 15%. Simultaneously, Hõng took another loan worth 50,000,000 VND (~US\$2,192.98) at a lower rate from a commercial bank using her family’s land use right certificate. This means that her family would not be able to borrow more money from formal financial institutions if they wanted to expand their agricultural activities. All these loans went towards paying for Hõng’s medications that were ineligible for reimbursement, as well as other non-medical expenses incurred during her hospitalisation.

### **The case of Long**

The story of Long, a younger patient from the Central Highlands, varies from Hõng’s trajectory. Long obtained oncology care at different sectors and tertiary hospitals partly due to her initial mistrust with biomedicine, but also her better access to financial resources and wider social network. Despite her more advantaged status, her narrative manifests other aspects of hardship faced by a waged worker in an urban labour market when repetitive hospital visits are required to manage a chronic condition like breast cancer.

Long was diagnosed with stage II breast cancer in 2011 when she was only 27 years old at a public oncology hospital in Ho Chi Minh City. At that time, she was working

as an accountant at a firm in Buon Ma Thuot, the capital of Dak Lak province where she lived with her husband and only daughter who was then only two years old. Advised by the oncologists in Ho Chi Minh City about the mastectomy and chemotherapy, Long was hesitant to follow the regimen for fear of the mastectomised body and treatment side effects. She explained:

There they told me my condition was “ác tính” (malignant). I thought I was still too young, just twenty-six, twenty-seven. Why should I go to have my chest cut off? Why should I lose my hair like those undergoing chemotherapy I saw at the oncology hospital? I dreaded just thinking about it. At that time the hospital conditions were terrible. Whenever I saw a patient with a bald head, I did not want to be one like them. So when the doctors told me to have a surgery [mastectomy], I decided to leave and seek “thuốc Nam” (Southern or herbal medicines) instead.

Long went back to her hometown and found a traditional healer who sold her various doses of herbal medicines promised to cure cancer without any type of painful surgery at an extremely expensive charge. Long reported to having paid 200,000,000 VND (~US\$8,771.93) to this healer for two years, which was more than three times her annual income back then. In the first months after taking the medicines, Long’s lump seemed to shrink, and she did not feel any sign of fatigue like people undergoing chemotherapy typically experience. However, in the second year, the site where her cancer was detected became inflamed and the lump kept growing in size. Her health condition declined precipitously.

It was only then Long stopped visiting the healer and went back to the oncology hospital in Ho Chi Minh City where she enrolled for mastectomy and treatment. There she kept on waiting in an inpatient room for weeks without being informed when her mastectomy would take place. “You need to bribe a lot of money if you wanted a faster surgery,” Long recalled. Feeling desperate, Long received a call from her cousin who told her that his acquaintance in a hospital in Hue agreed to put her on the priority list for receiving treatment. Therefore, Long left Ho Chi Minh City and travelled 20 hours northward up to Hue. There Long was requested to redo all the laboratory tests at her expense because the previous hospital refused to release her medical records and her insurance card, explaining that they only received a short notice prior to her departure.

Therefore, despite having insurance as part of her employment benefit, she still had to pay for 70% of the surgical and hospitalisation costs in Hue. In addition, Long reported having paid a bribe to expedite radiotherapy:

I was kept for two weeks waiting my turn for radiotherapy. No one called me in to have a radiotherapy mask while all the remaining patients in my room had already had one and get prepared for the therapy. And one day one of them came to ask me whether I had “done my task” (“*làm thủ tục*”). I thought they asked me about the tests and responded yes. Then I told them about all the examinations and administrative procedures, etc. I asked them what else I should do and they explained to me the task they referred to was an under-the-table sum of money I should give to the physician in charge. The next day, I went to do “my task” and they let me proceed with the radiotherapy right away.

During the primary treatment which consisted of a mastectomy followed by eight cycles of chemotherapy and radiotherapy in 2013, Long and her husband who was a building contractor, had to temporarily relocate to Hue. There they rented a room for over six months in a guesthouse close to the hospital because they could not return to their home in the Central Highlands, which is around 700 kilometres or 14-hour bus ride away. During the day, Long’s husband would look after her in the inpatient room and when he was not allowed in, he came back to their rented room and prepared meals for both. In the first two weeks after her mastectomy, at night Long’s husband slept on the foldable bed in the post-op room that Long was sharing with ten other patients, usually more, along with their caregivers. They could stay together during the weekend at their rented room, and on some Fridays, Long’s husband would take her home on his motorbike (to avoid paying the bus fares) so that on Saturday they could see their daughter who was staying with Long’s parents and came back late Sunday in time for the next round of treatment.

During her prolonged hospitalisation, her husband’s business was completely disrupted, and they had to finance Long’s treatment and their lengthy stays by using up their savings. As she recounted in one of our appointments, after the primary treatment ended, Long still continued to travel back and forth every month between Buon Ma Thuot and Hue in order to obtain hormone therapy, including an ovarian suppression injection and a 28-day dose of tamoxifen. For each visit, Long left home in the afternoon and

reached Hue early the next morning and then spent a whole day to complete the administrative procedures and receive her treatment. Once the injection was done, she called a motorbike-taxi driver who took her directly to the bus station where she caught the 4 PM ride back home. She would arrive in her hometown at around 5 AM the next day. Due to her extended and frequent absenteeism, Long had to quit her accounting job and shifted to work several part-time roles so that she could continue her recommended treatment regimen. At the time of my study, Long told me she had recently worked for a family-run beauty salon from which she earned an unstable income but could cover her transportation to the hospital and partially shoulder her medical bills with her husband.

The status of Hõng and Long cases differed as they entered an existential struggle over a life-threatening disease. They were diagnosed at different stages and each had a different pathway and varying experiences in pursuing treatment to manage their ill health. By the time of their first detection, the patients' financial circumstances, employment statuses, and social experiences were dissimilar, which determined the extent to which they accessed breast cancer care. In the case of Hõng, a woman from a low-income farming family, even with a state-funded health insurance coverage, she had to consider the very likelihood of whether or not she should comply with the recommended regimen for fear that she would exhaust her family's scarce resources. Compared to Hõng, Long was more financially capable due to the employment status of herself and her husband prior to her diagnosis. This enabled her to try different healing methods before the start of her biomedical treatment (though unfortunately her first attempt with the traditional healer did not yield the desired outcomes). However, as they embarked on their therapeutic journeys, they were made increasingly vulnerable as they entered the continuum of adversities underpinning the process of treating a chronic acute disease and the tremendous financial and emotional burdens that it involved. In many ways, stories of Hõng and Long typify the patients I encountered during my ethnography whose lack of control over the disease's malignancy and the aggressiveness of cancer treatment in physical, emotional, and financial terms was devastating. Their accounts also demonstrate how patients were forced by the health system to juggle the multiple risks that cancer treatment involved and their pursuit of cancer care was indeed informed by risk management that was individualised and stratified.

## The vulnerability of hospitalisation

The experiences of undergoing breast cancer treatment as illustrated in the two case studies differed markedly as Hõng and Long entered the hospital where they were first diagnosed. What the two women had in common was the determination to pursue radical forms of surgery and treatment in a fervent hope that the invasiveness of a cancerous tumour would be brought under control. To realise their fierce will to live, patients like Hõng and Long had to travel long distances via multiple modes of transport at significant expenses in order to seek care in a tertiary hospital distant from their homes. Medical services, particularly specialist care such as oncology, mostly concentrates in urban national-level hospitals in Vietnam. A survey based in Ho Chi Minh City Oncology Hospital, one of the same level as Hue Central Hospital where my ethnography was situated, estimates that as many as 70% of the hospital's patients receiving care at that hospital were from other localities (Hoang 2017). They are those whom Stalford (2019) refers to as patients “from the provinces” in her ethnography in Southern Vietnam when she describes cancer patients irrespective of whether their residence is rural or urban who must travel to major cities for cancer treatment. Stalford recounts a story of a woman who has endured dozens of agonising bus trips from her hometown to a hospital in Ho Chi Minh City while suffering chemotherapy's crippling after-effects, and as a consequence, that patient strongly resists the prospects of ever returning for follow-up care. Likewise, in Livingston's ethnographic accounts of a cancer ward in Botswana, lengthy bus trips entailing expensive fares and bumpy distressing rides are a source of constant anxiety for patients who spend countless hours waiting for a turn to obtain a therapy or see an oncologist (Livingston 2012).

Livingston's research (2012) further unfolds the exhausting reality of day-to-day life in the oncology ward where patients must surrender themselves totally during their inpatient experiences. In the case of Vietnamese public hospitals as described in the cases above, lengthy periods of hospitalisation do not only involve patients who require cancer care but also their caregivers who do not have cancer. Due to the overcrowding and systemic shortage of professional nurses at public urban hospitals (see Santin et al. 2020), as in many other settings around the world (cf. Mulemi 2010; Macdonald 2016), patients rely on domestic kin work rather than nurses when it comes to the provision of routine inpatient care. Such arrangements place conflicting burdens on the caregivers since they

have to fulfil critical caring roles, but also make important decisions on treatment and end-of-life care decisions for the patients, while simultaneously providing income to finance enormous medical and non-medical expenditures (Ho, Jenkins, Nghiem, et al. 2021; Stalford 2019).

Within my research context, as it is clear from the accounts described earlier, for patients “from the provinces,” a trajectory to treat cancer involves prolonged, arduous stays at the hospital during which serious hardships fall not only on the patients diagnosed with cancer but their caregivers as well. Arranging for a caregiver to stay at the hospital for long periods of time was not a simple task, as exemplified in the following account by a 64-year-old woman from Quang Tri who was awaiting her next cycle of chemotherapy when I met her at an inpatient room:

During my stay at the hospital, my daughters who live in Saigon had to take turns to fly to Hue and take care of me. They might arrive a bit later than I did, but always by the day when the chemo started. Hospitalisation disrupted everything, not only in my family but in theirs too. On a normal day, they stayed with me here at the inpatient room. But if it became too warm, they rented a room in a guesthouse so that they could sleep a bit and returned the next day to watch over me. Even for me, when it was hot, I found it really hard to fall asleep [in the inpatient room].

Meanwhile, some other patients had no accompanying caregiver during their hospitalisation due to their single status, the coincidence of sickness among other family members, or the urgent financial needs that required their family members to continue with their income-generating work. In such cases, their time in hospital rendered such patients more physically and emotionally depleted. For instance, Trà (aged 56, Quang Tri) reflected on how she struggled with her limited mobility due to the pain of chemotherapy and feelings of self-pity when her husband and son were both sick at home:

Other patients had caregivers to help them rise up when they wanted to drink water, they only need to let their husband or child know. But I had nobody to help me (...) The nurse told me to drink plenty of water. You would die if you don't drink water during chemotherapy. But I did not dare to drink much water because I was afraid to pee. There was no one to walk me to the restroom, no one helped me put away the [urine] bucket.

Tho, who lived a four-hour-bus ride away from Hue, could manage day-to-day practical matters on her own; however, she was adversely affected by the public judgement towards her solitude during hospitalisation:

At first during the time of my surgery [mastectomy], I was in Saigon and my younger brother who lived there came to take care of me. Later, my husband or either of my sons would be there with me. But when I received chemotherapy, I was on my own because everyone else had to be home to continue working to earn money... I remember in one hospitalisation, Dr. Quang sent me out for a bone scan and asked me if I had company. When he found out I was on my own, he did not let me take that test... When I was staying at the hospital, other patients all had their caregivers while I was all alone. Many were curious about my situation, they asked me if I was abandoned by my family who refused to take care of me.

Lengthy periods of hospitalisation also exposed patients to moral jeopardy linked with the inability to observe religious practices, which adds to the stress of treatment as they are at a time when religious observance is acutely needed to influence one's karma. For instance, 46-year-old Xuân who lived a 12-hour bus drive from Hue in a rural district in Khanh Hoa province, recounted her struggle to maintain her vegetarian diet as a Buddhist due to a narrow choice of food at the hospital:

At home I pray every night but when I stayed at a hospital, it was difficult for me to find a quiet place. So, sometimes I tried to say some prayers while lying down on the waiting bench for a quick rest. But maintaining a vegetarian diet was far more difficult. Oftentimes, I had no option but to “ăn măn” [eat non-vegetarian dishes]. My son often went out and bought us two lunch boxes. He could not find a place that sold vegetarian meals. So he bought rice with pork or fish which I had to eat. At home I always cook different dishes for me and my children. We share the same rice cooker, but I use different pots and pans. I have my own set of cutlery too because my children's cutlery they use for eating meat.

To mitigate the disruptions, many patients attempted to normalise the period of hospitalisation by transforming their in-patient rooms into a place with parallel functions to a home. During my ethnography when the patients began to trust me as a researcher not affiliated with the hospital, I was sometimes invited to join them for lunch or dinner

that they cooked together right inside their hospital rooms. There they shared electric cooking utensils and took turns to shop for fresh groceries and cook two meals a day. By doing so, they could ensure they had sufficient nutrients and tasty meals during the days when they often felt nauseous because of treatment side-effects. Simultaneously, they could avoid the risks associated with consuming unsafe street food outside the hospital (see Chapter 5 for mounting concerns on food safety in Vietnam) or the unsavoury food catered by hospital kitchens while saving on their budgets. Meal preparation and cooking had to be hidden from any hospital staff because it was not allowed on the hospital's premises due to concerns over fire risks. I heard many stories from patients that their cooking tools had been confiscated when the hospital staff suddenly inspected inpatient rooms. In such circumstances, they had to suspend their "secret mission" and only resumed after a couple of days.

It is obvious from the patients' narratives that hospitalisation for breast cancer care precipitates a cycle of interruptions to the everyday life of patients and their caregivers and throughout this particular period, they are exposed to multiple forms of suffering and vulnerability. Because major oncology hospitals are situated in big cities in Vietnam, hospital-based treatment for an acute condition like breast cancer requires frequent, persistent stays and arduous travel for patients who reside in rural or smaller towns like many of my informants. This troublesome period of hospitalisation causes psychological distress to patients during their stay and leaves agonising memories which potentially deter them from returning and seeking additional care in the future (as we see later in Chapter 8 on women's decisions regarding breast reconstruction). The prolonged hospitalisation also generates compounding burdens on their accompanying caregivers as they have to take charge for multiple caring roles with minimal support and limited health literacy (Ho, Jenkins, Nghiem, et al. 2021). Such arduous periods force patients to be more than sufferers of their fate, but managers of risk or reflexive with health threats. As the hospital setting has transformed, so has the role of the patients and their caregivers. While the ruptures of everyday life caused by hospitalisation might be temporary, treatment for breast cancer which demands huge financial and time commitments leaves longer-term setbacks far beyond the hospital setting and forces changes in various aspects of life for the affected patients and their families.

## Financial burden of treatment

Treating a life-threatening condition like breast cancer involved enormous out-of-pocket medical costs even for insured patients, let alone other costs associated with transportation and prolonged stays for themselves and their caregivers during periods of hospitalisation. The issue of under-coverage among insured patients arose from the widespread practice of bypassing local-level hospitals to obtain better quality of care and treatment that I mentioned in the previous chapter. For instance, Minh, the commune officer who believed in the link between her cancer and Agent Orange in a preceding chapter, like most patients I met during my research, still had to finance a significant proportion of the treatment expenses out-of-pocket even though she had been covered in the mandatory scheme for working as a civil servant at her commune. By the time of her diagnosis, Minh wanted to be treated in a national-tier hospital in Hue. “Because the capacity at provincial hospitals is very low with many cases of failed treatment and accidents, so we cannot trust them,” Minh explained. However, Minh could not wait for the insurance transfer to be cleared at both district and provincial levels because her tumour progressed rapidly and thus, she had to pay for roughly 70% of the mastectomy’s cost and all other hospital expenses as a bypassing patient. It was only after her mastectomy that Minh sorted out the transfer approval which allowed her to receive her insurance entitlements because a cousin helped her with the bureaucratic procedure at “a small charge” owing to a contact he had at the province’s office dealing with health insurance. Minh’s case exemplifies how patients have become very “active” along the continuum of seeking treatment and that cancer care is largely about managing the health system.

While most forms of primary treatment, including surgery, chemotherapy, and radiation therapy are included within the public insurance scheme, the coverage rates for certain medications to treat breast cancer are remarkably lower, which aggravates the burden on patients’ budgets should they wish to comply with the regimens recommended by their oncologists. The co-payment rate for certain types of medications, such as Herceptin (chemical name: trastuzumab), a targeted drug therapy prescribed to curb HER2 - a growth-promoting protein which is detected among approximately 15% to 20% of all breast cancers (Loibl and Gianni 2017), is set at 40% at the time of writing. This means that insured patients, regardless of the coverage status of their insurance policy,

must bear a significant cost which ranges from 250,000,000 VND to over 400,000,000 VND (~US\$10,964.91 to US\$17,543.86) in total depending on the drug manufacturer and this will increase with a patient's weight.<sup>10</sup> Throughout my ethnography in Hue, I met many women who had decided to opt-out upon being informed about the cost of this targeted treatment. Only a few patients enrolled but even in such cases, they could not complete the recommended course of treatment. 55-year-old Bông from the city of Hue, for instance, only opted for half of her prescribed dosage as she lacked the money to get herself enrolled for the whole course of treatment. Some advanced-stage breast cancer patients like postmenopausal women taking Aromasin (chemical name: exemestane) in combination Afinitor (chemical name: everolimus) can only receive a maximum ten-day dose of their medication according to current insurance regulations, and hence need three visits to the hospital every month if they want to fully adhere to their prescription. Afinitor is prescribed to be taken once a day and each tablet costs 1,400,000 VND (~US\$61.40). Considering its extremely high cost, when a patient cannot travel to get it from the hospital, in most cases, she would miss the whole dose as she would not be able to afford it from any pharmacy.

Meanwhile, women diagnosed with positive hormone receptor status which is found in roughly 80% of breast cancer patients (WebMD 2020) such as Long and many other patients interviewed in my research, additionally bear significant non-medical costs during repetitive visits to/from the hospital on a monthly basis. This creates a major deterrence to their compliance and ability to access quality treatment. Hông, one of the two case studies, for example, told me about her strategy of navigating her troublesome hospital visits after her oncologist recommended her to have hormone therapy for the next five years. Similarly to many other peers, Hông decided to buy her medications (anastrozole) from a local pharmacy at her own expense without visiting the Central Hospital to get the insured dose, “because the train tickets cost me more.” She planned to go back for her quarterly follow-up appointment only if she received the money from a relative who promised to lend her some. In Hông's case, she took an individualised responsibility to maintain her treatment compliance rather than depending on the health system to provide the insured medications, and simultaneously control the financial risks associated with a long trip to the hospital. Her story exemplifies how fate is turned into

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<sup>10</sup> A recent study estimates that the cost of targeted therapy may soar to over 649,000,000 VND (~US\$28,464.91) because it is not covered by the current public insurance scheme (Iran et al. 2021).

self-management of calculable risks (Beck, Lash, and Wynne 1992) in a sense that HỒNG had to take her own actions to reduce the uncertainty of her illness because she was inadequately insured against the health and financial risks when breast cancer occurred to her.

There were also reports from my informants that on certain occasions, even when they visited the hospital at the right time as designated in their appointment letter, they could not obtain their medications because the hospital ran out of stock, which was widely covered in the press (see, for instance, Nguyen, H. 2019). This shortage compelled insured patients to privately fund their drugs from elsewhere or they lost the dose completely because they could not afford to pay out-of-pocket. The situation of cancer medications is similar to that related to antiretroviral drugs in many LMICs which often face challenges concerning supply uncertainty and stockouts of crucial HIV commodities (for a summary see Stulens, De Boeck and Vandaele 2021). Although research into the supply of cancer drugs is scarce in Vietnam, a recent scoping review on cancer burden and control notes that during 2011-2015 period, only one of the new 42 cancer drugs was available in Vietnam's pharmaceutical market (Pham et al. 2019). It is reported that the country's manufacturing capacity remains limited to standard and radical therapy drugs for treating early-stage cancers but only 30% of patients in Vietnam are diagnosed at this stage (Tran et al. 2016), signifying Vietnam's heavy reliance on external suppliers when it comes to cancer medications.

Vietnam's Social Security – the state agency in charge of social and health insurance -has recently introduced reforms to protect its financial sustainability. Specifically on policies related to cancer medications, changes have been made either to increase the co-payment rate for certain medications (many of which are used for patients diagnosed at an advanced stage of cancer) or replace the existing lists of insured medications with cheaper ones. The reforming agenda inevitably exacerbates the already-tremendous financial hardship on cancer sufferers and widens health disparities. It has also met with harsh resistance<sup>11</sup> from healthcare providers who are gravely concerned over the deteriorated quality of treatment as Dr. Thi remarked:

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<sup>11</sup> This provider's stance over the superior quality of brand drugs also suggests her mistrust with inexpensive generic drugs which are mostly manufactured in developing countries. Such widespread perception is found in other settings, such as China (World Bank 2010), and requires further research on the role of the government in enacting Essential Medicine Policy, overseeing and assuring drug quality, as well as the significance of communications in relation to the values of off-patent drugs.

We previously prescribed some medications for lung cancer patients which were very effective and the insured patients received 100% reimbursement but now the policy has changed and they have to pay half the price. Or some medications can keep patients with brain cancer alive for another 1.5 years. Now it is no longer insured. Lots of insured drugs now are not brand-name ones, and they cause many side effects for the patients. And for cancer patients, especially those whose cancers are at late stages, they have to pay 10,000,000 VND (~US\$438.60) a month which is a huge cost even for urban middle-income residents. So they tend to accept using the insured drugs (rather than purchasing better ones at their own expense). But those insured medications, which sometimes cost one-tenth of the bioequivalent brand-name drugs, will never yield optimal outcomes.

***Financing breast cancer treatment: borrowing from “any possible channels”***

Since the vast majority of patients I encountered were rural-dwelling residents and/or from a low-income background and worked to make ends meet, they had to finance their expensive cancer treatment via support from their kin, either in-kind or cash. In Vietnam, treatment of a serious illness like cancer is a collective endeavour, rather than a mere individual affair, whereby many family members co-shoulder its costs (Stalford 2019). Members in the same family are bound by moral and legal obligations when it comes to caring for each other (Nguyen, M. T. N. 2015). In the context of my research, patients often narrated their treatment trajectory with an important role of assistance from people in their extended families, for instance, providing care during hospitalisation as presented earlier, offering in-cash gifts, or low-to-zero-interest loans which helped patients cover parts of their treatment’s costs.

Nevertheless, for limited-income households who had already spent a significant proportion of their resources on financing burdensome treatment costs, support from their social network did not suffice given that those people were likely to have similar levels of wealth to that of the patients. It is, therefore, inevitable that cancer patients’ families resorted to loans from credit institutions or the underground market. For instance, 46-year-old Xuân, a street vendor from Khanh Hoa, sought an underground loan (“*vay nóng*”) which charged her a usurious interest rate of 10%/month to pay for an immediate mastectomy and ensuing hospitalisation because she had no insurance by the

time of her diagnosis. H $\ddot{O}$ ng, one of the case studies, on the other hand, despite having a full-coverage insurance, still had to borrow money from “any possible channels” due to the enormous costs associated with under-insured medications and non-medical expenses during her hospitalisation. Incurring crippling debts became a primary strategy to cope with spikes in medical spending at the persistence of health shocks even for households like H $\ddot{O}$ ng’s with health insurance. This situation is usually noted in previous research analysing the consequences of managing ill-health in Vietnam, suggesting tremendous out-of-pocket expenses associated with hospital-based treatment and the limited protective role of health insurance against the detrimental impacts of high health expenditures (Wagstaff 2007; Nguyen, C. V. 2012; Hoang et al. 2017). The lack of proper insurance coverage constitutes a significant source of “structural violence” (Farmer 2004) as it impedes patients’ capacity in maintaining the continuity of care, thereby negatively affecting health outcomes and survival.

My study provides additional insights on how burdensome healthcare costs results in households’ heavy and persistent indebtedness which has been established as a major factor explaining households’ descent into poverty across multiple countries (see Krishna 2011 for a summary of literature in this respect). While borrowing may serve to meet the urgent health needs of the debtors, these strategies expose them to exploitation, enhance their future vulnerability, and leave long-term consequences for household welfare (Mitra et al. 2016; Wagstaff and Lindelow 2010). Being burdened with debts increases the risk of impoverishment because managing severe and chronic diseases like breast cancer involves persistent spending associated with repeated hospitalisations and prolonged use of medications, which possibly demands additional debts over the course of treatment while the initial ones remain unsettled. Indebtedness is also related to households’ vulnerability to poverty due to the patients’ loss of earning capacity or immediate measures taken by their loved ones to repay their outstanding debts which have deleterious for households’ welfare over the long-run which I analyse in the next section.

Considering the enormous financial burden placed onto cancer patients during hospitalisation, monetary assistance has become a central pillar in charities’ and peer group’s activities, which has been explored in ethnographies elsewhere in Vietnam (see, for instance, Swenson 2020). During my fieldwork observation, I noticed the occasional provision of free meals provided by a Buddhist temple situated next to Hue Central Hospital. The Pink-shirt team itself also delivered in-cash support to poor inpatients

undergoing treatment at the Central Hospital, which was funded from its members' contributions and sometimes from private non-member donors. Via their larger platform of the Courageous Women Club, the peer group often mobilised support from the wider public on their social media channels, for instance, by posting a certain case of a patient who needed immediate financial assistance or organising fund-raising events (such as a marathon) when all monetary donations went to sponsor insurance cards for poor patients. Some of the patients I interviewed also retold stories of doctors and nurses who offered their monetary assistance to the patients they cared for. On one occasion, during a consultation I observed, a doctor gave 50,000 VND (~US\$2.20) to an incoming ethnic minority patient. He explained to me that he had done so every time the patient (who had been diagnosed with stage IV breast cancer) came to his practice so that she had money to buy her lunch while visiting the hospital.



**Plate 7. 1.** Patients and caregivers queuing up to receive free lunch catered by a Buddhist Temple

## **Beyond the hospital: risk, precarity, and the hidden costs of seeking breast cancer care**

The treatment of breast cancer, given its chronicity and time commitments, causes remarkable disruptions to patients' employment and earning capacity, leaving long-lasting and in many cases, insurmountable, impacts on the welfare of the patients and their families. Documenting the therapeutic itineraries of immigrant cancer patients in France, Sargent and Benson (2019) drew on the concept of "precarity" (Kalleberg 2009) to underscore the uncertainty experienced by this group. Their ethnography details that while navigating complicated residency and national healthcare programs for cancer treatment, those immigrants confront social marginality, economic instability, risks, and a sense of existential precarity due to their loss of income, employment, permanent housing, as well as dependency on a complex system of state assistance. Among my informants, I argue the concept of precarity can serve to mirror the various forms of social and economic instability placed upon women with breast cancer and their families when their life circumstances have deteriorated because of this life-threatening condition. Pursuing tremendously expensive treatment aggravates the precarity for the affected people as it places patients at greater risks of unemployment or underemployment and further consumes their households' already-scarce resources. These families must make hard calculations as to whose needs should be prioritised, and in many circumstances, are forced to choose between pressing health need of a member diagnosed with cancer and the educational opportunities of their young children. The priority on cancer treatment in this way has been made to the detriment of families' future income and welfare, producing hidden costs for the affected people which cannot be always captured in quantitative terms. While in Vietnam a UHI scheme is present, enrolled patients still bear significant out-of-pocket expenses, due to an inadequate coverage of certain treatment and medications, as well as the enormous non-medical costs incurred throughout their therapeutic but onerous trajectories.

Long, one of the two case studies introduced at the beginning of this chapter, submitted herself to the chronicity of repetitive hormone therapy by presenting at the hospital as an outpatient every month since the primary treatment had finished. As oncology services were not available in her home province, she had to pursue a year-long period of hospitalisation followed by repetitive outpatient treatment in a faraway city. This

saw the rupture of Long's past employment in a stable job as an accountant and later she had to accept the precarity of a new part-time role which allowed her to take two days off to travel to Hue in order to get her monthly injection and medications to suppress the growth of her hormone-sensitive tumour.

Job disturbance to patients who had previously been employed in the formal sector were notable among my informants and appeared more pronounced for older women because they were left with limited ability to seek new opportunities given their age and health status. 47-year-old Hay, for example, a former childcare educator whose husband suddenly passed away due to a stroke at the same time of her mastectomy, shifted to work a manual job in a factory far from her home after accepting a reduced pension from her previous role:

My working time [at the childcare prior to her diagnosis] was not flexible. Now that I still have follow-up care, for some appointments I have to take leave for 2 or 3 days. I decided then that I would quit because I did not want to affect my school. Many kids would not be taken care of. And I wanted to have some rest. But because I retired earlier, my pension was reduced a lot. Each month I could only receive 2,000,000 VND (...) I've been working in a new job in a factory, assembling bottles and cleaning. They pay me 4,000,000 VND (~US\$175.44) a month. With that I have more money to raise my younger son who is now at high school.

40-year-old Thu, a teacher in a rural commune in Thua Thien Hue province who was diagnosed with stage I breast cancer, was able to retain her job post-treatment. However, due to limited sickness allowance, she had to take a long period of unpaid leave to recover from chemotherapy and subsequent hospitalisation to treat a recurrence two years after her breast-conserving surgery:

For employed people, breast cancer treatment causes a lot of difficulties. Unlike farmers or freelancers, we cannot take leave whenever we want. After my hospitalisation [for surgery and chemotherapy], I had to stay home for a year. I could only receive paid leave for 6 months, the rest I did not have any salary... I have been taking the medicines [hormonal treatment] and experienced a lot of side effects, like pain on every finger tips, fatigue, migraine, so I could not teach everyday. Not all colleagues understand my condition. Not many could help.

When I'm sick, I cannot take sick leave because finding a relief teacher is not always possible.

Meanwhile, for other patients who were self-employed in the agricultural sector (like the case of HỒNG) or working under an informal, casual contract with little or no income protection or safety nets, pursuing a prolonged treatment incurred a complete loss of income. The prolonged hospitalisation, in many cases, simultaneously disrupted their family members' working arrangements such as in the case of Long whose husband had to stop working and relocated to Hue to provide care to her during her hospitalisation. In view of this, since the start of their treatment trajectory, patients bore the brunt of multiple losses throughout periods which involved extensive spending but no source of earnings. The situation, as I have explored in the previous section, left them with little choice but to become indebted. Many patients expressed uncertainty as to how and when they would be able to repay all debts given that they themselves had lost the capacity to resume work to the pre-cancer period. These compounding burdens struck patients' families in every sense, forcing them to take on a precarious future and leaving devastating and long-lasting effects on their family members, particularly young children. For example, Ninh, a 51-year-old single mother from Quang Binh province, had always wanted her only son to go to college – a dream she had had to abandon to take care of her siblings because her parents were too poor. However, the advent of her diagnosis and expensive treatment shattered her son's educational prospects:

My son only finished high school. At that time I fell sick [with breast cancer], so he did not go to university. He just wanted to go for a shorter vocational training so that he could go on to earn money soon (...) My life has already been tough. If I had had more money back then, I would have sent him to college. But I did not. I feel so much pity for him. I always wanted him to have a good education, so he can find a good job, and get married. But I still had to leave him go [start working instead of going to higher education].

Being deprived of the opportunities to pursue higher education equates to a limited pathway to overcome poverty and find a well-paid and high-status job in a society like Vietnam that has a long history of desiring university degrees (see, for instance, Tran 2014). The burdens brought about by oncology care, in such ways, further aggravate the

already vulnerable situations of those families, throwing them into a cycle of indebtedness and poverty.



**Plate 7. 2.** The house of a patient in a rural village

For affected young women, dropping out of school is likely to lead them to marriage at a young age given job scarcity in rural areas and their limited mobility to migrate to urban cities in search of employment. For instance, Khanh (a single mother from Bộ Đội commune, Thua Thien Hue), had to be accompanied by her then 17-year-old daughter during her year-long treatment journey in Hue and also in Danang City (which is more than 3 hours by bus from her hometown) for radiotherapy when the machines in the Central Hospital broke down. This was during the period when her daughter was preparing for university entrance exams. Khanh believed her advanced cancer diagnosis and the uncertainty of the ensuing treatment caused her daughter to abandon hopes of a university entrance, take on a casual job, and undertake a decision to get married:

When she was working at the clothes store after getting the high school certificate, she met a man 5 years her senior who was a timber trader. They saw each other for about a year and then she came back home one day and told me she wanted

to marry him. She was only 19 years old then. That time I was still exhausted. My hair just started to grow a bit. I did not recover much and could not make any important decision on my own. So my two younger brothers called for a big family meeting on my behalf to discuss her marriage. In the end everyone agreed that she should [get married] because they were all afraid that I would die soon.

The early marriage of Khanh's daughter was considered by her whole family as a decision of fulfilling the daughter's filial duties due to the societal pressure on children to get married (Williams 2009), especially in a context of a parent's frail health. In Vietnam, there is social recognition attaching marriage's values with not only an individual's achievements, but also their family's symbolic capital (Nguyen and Hoang 2019). Such a decision was also a strategy of securing the daughter's future and easing the financial burden on her family when the breadwinner fell seriously ill. Although the marrying decision reduced certain risks to their life, it foreclosed future opportunities of higher education and a secure job for Khanh's daughter.

### **Seeking formal support: navigating the politics of social protection**

Both of the case studies presented at the beginning of this chapter tell us much about the vital importance of the UHI that ensures a patient's access to at least some form of treatment for breast cancer. In its absence, a patient is more likely to drop out or only complete part of the recommended regimen. However, in most instances, being covered by health insurance does not entitle patients to a full reimbursement rate. As current regulations suggest, holders of public health insurance card, including those who are enrolled in the voluntary or compulsory scheme (see description of the Healthcare system in Vietnam in Chapter 3) shall be covered 80% of treatment and hospital costs at a designated hospital (or a higher-level one with an approval of transfer). This rate of coverage is not uniformly applicable to medications (described earlier in this chapter). Higher coverage shall be applied to patients with state-funded insurance cards, including those from poor-households (100% coverage), near-poor households (95%), and people with certain disability levels (see Government of Vietnam (2018)'s Decree 146/2018/NĐ-CP). In addition to insurance-related benefits, social protection beneficiaries also receive a monthly cash transfer starting from 405,000 VND (~US\$17.76) and school tuition fee

exemption. While formal public assistance is available, as I discuss later, access to such support is erratic and subject to numerous constraints and factors largely beyond a patient's control.

***“Running for Insurance” and cancer disclosure as a strategy***

To mitigate the impacts of an inadequate insurance coverage and circumvent the financial burden of cancer care, many patients sought an alternative to their current insurance policy via “chạy bảo hiểm” (“running for insurance”) which refers to the practice of immediately registering an insurance for the uninsured or obtaining a formal entitlement granting them higher rate of coverage by applying for a poor household or disability status. For instance, the aforementioned Hay, a former childcare teacher from Quang Tri province who had to retire earlier after her illness, had already enrolled in the compulsory insurance scheme by the time of her primary diagnosis due to her previous employment status. With this, she was covered 80% of her treatment costs. However, when she met fellow patients at the hospital, she was told that “paying only 20% of the remaining costs was already a burden.” Hay attempted to seek a “poor household” certificate by paying a bribe to a commune officer and village head. With that she was granted an insurance card with 100% coverage along with a monthly cash transfer.

Meanwhile, Trà - a farmer from Quang Tri quoted above who had no insurance by the time of her diagnosis, could not afford to pay for such a bribe. Alternatively, Trà deployed the same tactic as many other patients who sought additional support through making their cancerous status known to people in their social network. She explained:

I did not try to hide my illness from others in the neighbourhood, because you know, when I told them I had cancer, they came visit me. They also helped give me some money. I could use the money to pay back the interest rate (...) A neighbour in my village, he said that he sold rice for 500,000 VND (~US\$21.93), so he lent me that money. Many others living nearby heard my story, and they came to give me 50,000 VND (~US\$2.20) or 100,000 VND (~US\$4.39). (Trà, aged 56, Quang Tri)

More importantly, disclosure carried further benefits for Trà because it could influence the process of gaining social protection benefits as an economically disadvantaged

household: “Other villagers also cared about me because in my family, the mom was sick, the son was also sick. They nominated me to get the poor household status.”

According to the current regulations, a household might apply for social protection entitlements themselves by filling out a form and presenting it to local authorities with sufficient evidence of their financial status or the suffering of a shock (such as a serious illness, an accident, or a sudden death of a breadwinner) that leaves them with a significant loss of income. A panel designated for certifying poverty will gather and score applications and determine their status of poor, near-poor, or unsuccessful will be determined (MOLISA 2016). This process will be accelerated when a household is nominated by other villagers or the village head. This community-based targeting approach also applies for screening disability status. In this regard, a recent assessment of the social protection system for persons with disabilities in Vietnam notes that few people apply for disability assessment on their own and highlights the determining role of village-level leaders in identifying potential beneficiaries based on their observation and local knowledge, as well as in assisting with the application process (Groce et al. 2017). Against this backdrop, a policy officer at Bội Đội commune where part of my ethnography took place similarly mentioned the facilitating role of villagers in this process:

[For a household that wishes to be certified as a poor household] It is subject to their neighbours. If the neighbours can witness their poverty, that household does not need any further evidence. For example, if Mr. A’s family has a member who falls sick with a life-threatening condition, neighbours can make a rapid judgement, they might report to the commune authorities so that we can work with the village members and assess that household.

Considering the importance of referrals, my research reveals that disclosing one’s cancer status was common among my informants who reported having no hesitation in speaking about their illness with people in their kinship networks, as well as those living in the same village or commune. This finding contrasts with previous studies in other countries which often point to the widespread stigma towards cancer patients and their families, which prompts them to adopt concealment among their social contacts as a means of coping (cf. Mulemi 2010; Cho et al. 2013; Suwankhong and Liamputtong 2016; Nyblade et al. 2017; Banerjee 2020). Patients in my research context had few options but disclosure to open the possibilities for them to mobilise financial support from people who learned

about it because those were obliged to offer help to needy families due to the social norms of Vietnamese kin and sociality. Speaking with others about cancer also helped patients deal with the intricacies of the bureaucratic procedure, speeding up the process of being recognised as a beneficiary of social protection and obtaining its associated entitlements, including insurance with greater coverage. Through this practice, patients therefore exercised a strategy whereby their financial motivation outweighed any fears of social and cultural stigmatisation but in doing so, forewent any possibility of medical confidentiality.

### *The uncertainty of formal support*

My interviews with patients revealed the regional differences regarding the implementation and availability of social protection benefits applied to breast cancer patients. 36-year-old Hôm (from Thanh Hoa), for example, described to me that her application for disability status was swiftly processed and approved with the submission of only a single copy of her medical records; whereas it was not considered for other patients she befriended while participating in the peer network. Hôm explained to me:

It is totally dependent on the commune authorities. If they are flexible, they will consider [breast cancer] and approve it [disability status]. Like my friends in Nghe An province, some live in a commune where they receive it, while others in another town cannot. Even within the same district they have different policies.

The implementation of inconsistent criteria for assessing disability level was also present in my interview with 56-year-old Lan (Quang Binh province) who believed that her household was eligible for both a poor household status and disability benefits due to her single status and cancer. By the time of her diagnosis, Lan was not covered by any health insurance because she only worked a casual job at a timber-processing plantation and could not afford to enroll her family of four people (Lan's parents, her then school-age son, and herself) in the voluntary insurance scheme. After having to pay for the mastectomy and other medical costs entirely on her own, Lan came back to her hometown and was advised by her neighbours that she could apply for the state-funded benefits at the commune's Office of Social Policies. However, her application returned unsuccessful:

In 2018, I completed all the procedure, submitted everything required. I sent them my medical certificates from the hospital which took me a long time and lots of money to prepare. My family was already very poor. But later they told me I was not qualified because I could still walk on my own and they thought I was able to continue earning money.

The authorities then determined that Lan could only receive a health insurance card for a near-poor household with 95% coverage. It came without the social cash transfer. At the same time, Lan also tried to seek the disability allowance because she knew someone in her commune who also had breast cancer had already received it, but her attempt failed again. Lan lodged a complaint to the policy officer in her commune who subsequently provided an unconvincing response:

They told me that woman's condition was more serious because she had both breasts removed while in my case, it was only my left one. But I know the main reason was because my family could not afford, you know, the condition [to pay a bribe]. That woman's family, they are better-off, they invited the commune officers to dine in at a restaurant I'm sure.

Lan's remarks bring to the fore the issues of evaluating disability type and the inequities that arise from the inclusion of a chronic disease like cancer in categories of people with disabilities who can receive social protection from the government. According to my interviews with the authorities in Bội Đới commune where some cancer patients were certified as beneficiaries under the disability scheme, the commune's evaluating council classified the condition under the "Others" category in the official list of disability types (National Assembly of Vietnam 2010).<sup>12</sup> Reflecting on their understanding and implementation of this category, interviewed officers in my research responded with ambiguity as to which criteria they referred to when determining the disability status of an applicant who was a patient living with a chronic condition. As a policy officer explained to me: "If a person has cancer, and her condition has not improved even after undergoing treatment, we will bring her case to the [commune's] panel to assess her disability level." In view of this, it would be challenging for village and commune officials to screen for eligible applicants who are chronically ill because many patients living with

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<sup>12</sup> Categories of disability as stated in the Law include: Physical; Sensory; Visual; Mental and Psychiatric; Intellectual; and Other disability (Article 3).

breast cancer or other types of cancer may show no visible impairment or disfigurement even though their illness might be terminal and significantly affect their daily functioning and income-generating capacity.

The timing of disability assessment that happened after the completion of one's cancer treatment as mentioned in the quote above overlaps with many accounts such as one provided by Lan but contradicts with that retold by H $\ddot{O}$ ng whose application was processed right after her diagnosis. These disparities again suggest the inconsistent implementation of disability policies from region to region, which, as revealed in the women's stories, might be largely subject to the interpretations, personality or "the enthusiasm of the official" (Groce et al. 2017, p. 18), sometimes augmented by gratuities, thereby amplifying the precarity for the applicants.

It is clear from the women's narratives in this section that while social protection for cancer patients exists, the accessibility depends on numerous factors over which they have little or no control. Due to a community-based approach to identifying eligible recipients that has been in place, an application will be given more favourable consideration when submission is done with the referral of an influential person in the community. Knowing the "right person" also enables one's access to information regarding her eligibility, application procedure, and entitlements. This means that people with limited social capital or living in remote areas encounter greater barriers in accessing the right contact point.

Being covered in the social protection scheme theoretically offers obvious benefits, especially because it provides recipients with the highest insurance coverage and a regular cash transfer, along with other benefits such as travel discount for people with disabilities. Nevertheless, in practice, the extent to which institutional support contributes to warding off the burdens resulting from expensive oncology care remains under question. For instance, people with a disability card are eligible for a discount when purchasing tickets they can use on the state-owned train network. However, as most patients seeking care in urban hospitals live in rural areas (accounting for 70% of the total population in Vietnam) with limited train connectivity, they either prefer or have no other choice but to use inter-regional buses mostly run by private operators through which no discount is applicable. Additionally, in most cases when an application for social protection is successful, the associated benefits will take effect only after the whole or a significant part of the primary

treatment process has completed, leaving the struggle to access cancer care private to the sufferers and their families. The timeliness of formal protection is also affected by the feature of the certifying process whereby applications for being considered as a poor or near-poor household can only be assessed for designated time periods (usually once at year-end) and subject to termination once a household is deemed “out of poverty.” The change in status from “poor” to “no longer poor,” as well as the distinction between different poverty levels, as previously noted, is heavily influenced by the power dynamics at the local level (World Bank 2019). In such circumstances, a cancer patient of an eligible household might not be able to receive their benefits if their diagnosis arrives early that year and urgent treatment is needed to manage their cancer.

As for the disability scheme, which is separate from the former income-based system, applications are processed more regularly and the benefits are usually valid for longer or permanently. However, owing to the functioning-based nature of the scheme and the lack of consensus regarding the inclusion of patients suffering chronic diseases, beneficiaries can only receive their entitlements upon satisfactory provision of proof showing their declining health and the inability to recover. This, in most cases, is only possible when patients have exhausted all treatment options that are available to them. Because of that, the health insurance that beneficiaries obtain as part of their social protection entitlements can only be used for follow-up care and treatment of recurrence or metastasis but yield a meagre effect in relieving the financial burden incurred to patients during their primary treatment which are often more expensive and longer in duration.

The limited buffering role of social protection benefits also comes from the current restriction on the number of schemes for which the person is eligible. Specifically, persons with disabilities who are receiving other monetary benefits are not entitled to a monthly disability allowance. In case where the person is eligible for multiple schemes, they will only receive allowance of the highest amount (see Article 51, Law 51/2010/QH12 in National Assembly of Vietnam 2010), instead of a cumulative sum of all eligible benefits. For the case of HỒNG, the farmer from Ha Tinh in one of the two case studies, her application for poor household status was rejected and she only received the benefits under the disability scheme even though she was eligible for both. It means that she could only receive the health insurance and monetary allowance for her own case while no protection was provided to her sick husband and school-age son against their income loss and the outstanding debts they had incurred to finance HỒNG’s treatment. As we have

seen in the patients' accounts throughout this chapter, a family with a cancer patient must bear not only tremendous costs related to the treatment of their illness. They also suffer from caregivers' loss of income during hospitalisation and long-term economic consequences of the patient's reduced level of functioning. In that sense, the imposition of such restrictions fails to acknowledge the compounding burdens inflicted on patients and their whole family.

## **Conclusion**

In this chapter, I have demonstrated that women seeking breast cancer care undergo enormous disruptions during the course of prolonged and frequent hospital-based treatment. Like the experience at a cancer ward in other less resourced contexts, hospitalisation for cancer treatment exposes patients and their accompanying caregivers to multiple forms of physical and psychological suffering, and increases their anxiety and uncertainty (cf. Mulemi 2010). The long-lasting effects of prolonged, repeated hospitalisations, especially the financial burden that these entail, creep into every life aspect of cancer sufferers and their families. As recent literature notes, families with cancer patients across Vietnam face financial catastrophe and/or impoverishment for having to pay for treatment costs (Hoang et al. 2017). Defined as a situation when out-of-pocket payment for medical bills exceeds 30% of household income, financial catastrophe is estimated to hit 64% of cancer patients in Vietnam within one year since their primary diagnosis (Bhoo-Pathy et al. 2017). In the context of breast cancer, many families have to sell their properties, including their houses, to finance oncology treatment (Jenkins et al. 2020). For most patients in my study, as formal assistance is limited and uncertain, they must rely on informal arrangements, partly on support from their social network but heavily via "detrimental coping strategies" (Nguyen, K. T. et al. 2012, p. 724), such as borrowing high-interest loans, to settle the enormous medical and non-medical expenses associated with breast cancer care. Consequently, households and individuals, many of whom are already resource poor prior to cancer diagnosis, are financially crippled by burdensome treatment costs, facing the risks of impoverishment. In this way, the precarity of living with breast cancer extends beyond individual patients to their families and communities and carry economically harmful ramifications for the society at large.

Considering risk-mitigation strategies, some women speak of themselves and others resorting to paying a bribe while others find that they need to disclose their ill health to others in an attempt to make themselves qualified for some types of assistance. These can be regarded as pragmatic actions attempting to resume control over their disrupted life and mitigate the burdens of cancer care that they cannot afford. When these strategies are successful, however, they can only obviate a modest fraction of cancer care problems or decelerate their life from falling deeply into rupture and destitution. They cannot help them avoid nor overcome the crisis.

This chapter provides further on-the-ground evidence of the striking impacts of managing a serious health condition like breast cancer on the well-being and resilience of an individual patient and their family. Breast cancer patients' ability to seek treatment and the quality of options available to them are seriously constrained by their precarious financial status, and at the structural level, by geographical imbalance of oncology services, an under-resourced healthcare system, and the limited institutional protection in case of a health shock. The advent and treatment of their illness, on the other hand, dramatically alter and weaken the economic stability and social standings of the sufferers and those close to them. Seeking care for breast cancer impoverishes families over time since it causes immediate and long-term loss of income, depletes household's savings and assets, destabilises social relationships, and deprives young children of future educational and employment prospects. Therefore, as they attempt to treat their illness, the patients' life has been simultaneously traded for precarity in a sense that breast cancer management reduces their capacity to deal with other life challenges. For already poor and low-income families, the life conditions following breast cancer, like in the circumstances of other life-threatening chronic conditions, are rendered more vulnerable and abject as their illness reinforces the vicious cycles of poverty and disadvantage that continue across generations (Manderson and Warren 2016).

My findings in this chapter emphasise the need to attend to how living with ill health for people in under-resourced settings is shaped by and amplifies social and economic inequalities. To this end, the definition of chronicity in the context of breast cancer is not limited to medical aspects but one that is construed by political and economic facts (Smith-Morris 2010). Having to shoulder tremendous financial burdens beyond their affordability over lengthy periods of time, patients have already found themselves with

little or no means to rebuild their life in the aftermath of cancer even when treatment is still on-going and the chance of survival remains equivocal.

## Chapter 8.

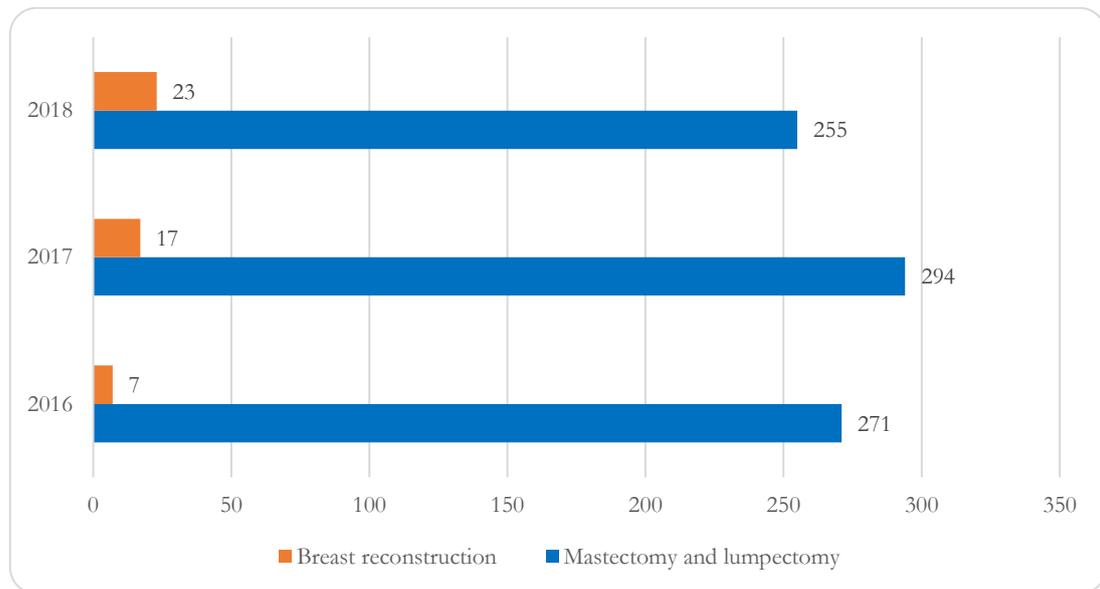
# Reconfiguring Breast Reconstruction in the Post-cancer Life

### Introduction

Prior to my fieldwork I had started to follow the Facebook fan-page of the Courageous Women Club and was intrigued by its posts about women's experiences of breast reconstruction ("*tái tạo*" in Vietnamese, many people also called the surgery "*làm lại vú*" or remaking the breast) which they often referred to a "journey to find myself again" ("*hành trình tìm lại chính mình*"). Their operations were not performed in Hanoi where the major, largest, and the most modern hospitals of the whole country are most concentrated. Even though most of them lived in Hanoi or neighbouring provinces, they had travelled by various means, via bus, plane, or dozen-hour-train journeys down south to Hue Central Hospital. In my first month of ethnography in Hue, I came across Hải-Anh and her three other Northern peers who had just completed their first reconstructive surgery. They all knew one another via Facebook, connected, booked appointments, and underwent their operations around the same time (April, 2019) by the same surgical team. I also met several patients who came to the Central Hospital for follow-up examination years after their reconstruction. Most of these women were either from Southern (mainly Ho Chi Minh City), or Northern areas such as Hải-Anh in the case I select for analysis at the beginning of this chapter.

Later in my fieldwork, I learned that Hue Central Hospital was among the first hospitals in Vietnam that have successfully performed reconstruction for patients after radical or partial mastectomy since the early 2000s, and frequently hosted national and international workshops on these techniques, as well as receiving groups of surgeons from foreign institutions to visit and perform breast reconstruction for local patients along with the staff of the Central Hospital. The hospital has conducted both basic forms of

reconstruction, including implants and flap methods, at the Oncology Centre (see Figure 8. 1 for their latest report on the number of surgeries performed at the Centre), and the International Unit where patients pay surcharges in order to obtain faster or high-tech services and stay in serviced apartment-like inpatient suites. In implant reconstruction, a saline or silicone implant is inserted beneath the chest muscle to recreate the shape of the breast. Meanwhile, in the latter method, tissue is taken from other parts of the body (for instance, back, abdomen, inner thigh, or buttock) and transferred to the chest wall to make the new breast.



**Figure 8. 1.** The number of breast cancer surgeries at the Oncology Centre 2016-2018

*Source:* Oncology Centre (2019)

Reconstruction became a topic I regularly recorded among my informants. I often listened to patients chatting about a woman with a “pretty, round, firm breast but without a nipple” sharing a bed in their inpatient room. As I joined the Pink-shirt team in their monthly gatherings, I was amazed by how frequently they retold the story of someone they knew who had come from elsewhere and would start the surgery such as the case of Hải-Anh that I present later in this chapter.

### ***The complexity of breast reconstruction decision-making***

Statistics across the world suggest that the percentages of women undergoing the procedure have been on the rise in Western countries. In Australia, for instance, it is

estimated that 18.3% of women with breast cancer opt for reconstruction (Flitcroft et al. 2016). In the United Kingdom, it is estimated that among women undergoing mastectomy, 21% opt for immediate reconstruction while the corresponding figure in France is 16.1%. In the United States, the overall rate of reconstruction (immediate plus delayed reconstruction) is approximately 63%, which varies from 33.4% among American women aged over 60 to 75.7% among the group younger than 40 years (for summaries see Holland, Archer, & Montague 2016; Nègre et al. 2020). Many Western and Asian countries such as the United States, Australia, China, Japan, and South Korea have already made the surgery free to access via public insurance schemes (AIR 2013; Alderman, Wei, and Birkmeyer 2006; Cancer Council Australia 2017; Kim et al. 2018; Yang et al. 2015).

From medical practice viewpoints, reconstruction is viewed as vital to remedying postsurgical asymmetry and enhancing a woman's psychological well-being and quality of life. For those reasons, the medical literature gives an impression that all women would desire reconstruction post-mastectomy, claiming that it is the ultimate goal for women with a mastectomised body (for instance, see Cromptvoets 2006a; Fang, Shu, & Chang 2013). Those studies often portray non-reconstructed bodies as incomplete and physically deformed (Coll-Planas, Cruells, and Alfama 2017) and women who refuse reconstruction as those from socio-economically underprivileged backgrounds or with limited control over their treatment (Cromptvoets 2006a; Fang, Shu, & Chang 2013). They are also faced with negative responses from their medical teams (Holland et al. 2016) or the risk of being categorised as desexualised women (Rubin and Tanenbaum 2011).

Feminist analyses, on the other hand, consider the surgery as a form of social control over women that reinforces their conformity to beauty ideals (Ferguson 2000). For instance, feminist Audre Lorde (1997) is particularly concerned with such assumptions made by medical professionals of reconstruction as surgically optimal and that some form of replacement breast comprises an indispensable element of cancer survivorship (Rubin and Tanenbaum 2011). Feminist scholars often argue that such perceptions towards a woman's breast loss are configured through the objectified male gaze (Young 2005) and reconstruction is more about "expectations" than "choice" and used to pressure women to realign themselves with the ideal female body (Gibson et al. 2014, p. 537). Recent research increasingly questions reconstruction as a panacea to restoring the body-self alignment with accounts revealing it as an illusion that is unable to recreate the feeling of the pre-cancer body wholeness (Manderson 2016). After the surgery

women are left with an unnatural breast with little or no sensitivity, possibly ending up “more damaged” (Crompvoets 2006, p. 89) while many suffer post-operative scar symptoms with impacts on their emotional, social, and cognitive functioning (Everaars et al. 2021).

Despite these growing critiques and compared to the literature reflecting the experiences of women choosing reconstruction, there remains limited scholarship on non-reconstructive decision-making. This under-representation reinforces the argument that women who forgo the procedure are those without agency over their bodily experiences and further marginalises them from the mainstream assumption that the surgery is desirable as it provides the means to conform with societal constructions of beauty and femininity. Challenging the assumption that non-reconstruction is a non-choice, recent studies have demonstrated that for most women, choosing not to restore their lost breast is made with respect to their assessments of the prospective pain and complications resulting from the length and invasiveness of reconstruction (Porroche-Escudero 2012; Rubin et al. 2013). It is a decision based on the women’s research on different surgical options, peer consultations, and in consideration of pro-reconstruction information delivered to them by their healthcare providers (Holland et al. 2016). To these women, not pursuing reconstruction is the resulting choice of a process of navigating and accepting their changed bodies (Archer, Holland, and Montague 2018). It is also a proactive, viable decision against the perceived norms of reconstruction within a paternalistic care model (Holland et al. 2016). For instance, the women’s resistance to medical authority and normative femininity via their decisions against reconstruction is pronounced in La, Jackson, & Shaw’s research (2019) whereby breast cancer survivors emphasise the “active” element in their discourses, claiming their feminine identity and sexuality is not located in the breasts, and repositioning their non-reconstructed bodies as strong, healthy, and independent rather than weak or malfunctional subjects.

Below I describe the case of Hải-Anh who represents a woman who had a burning dream to have her breast reconstructed ever since the mastectomy but later faced sheer disappointment as the reality of the surgical procedure did not match her expectations. Her story typifies the situation of other women who have travelled across regions to Hue with a hope to restore the breast they had lost to cancer.

### **The case of Hải-Anh: “When I become a ghost, I still need to be with both breasts”**

Hải-Anh (aged 37, Hai Duong) was diagnosed with stage I breast cancer in 2016 and received primary treatment at the National Cancer Hospital in Hanoi. She was among the inpatients from Northern region I encountered at the post-op division in April 2019 when I first commenced my ethnography at the Central Hospital. Hải-Anh sat up in her hospital bed talking to me a couple of days since her six-hour-long reconstructive flap surgery. She told me that she was extremely happy and contrasted her optimism with her feelings after mastectomy: “They were both two long sleeps. After the first one, I woke up feeling a tremendous loss. This second sleep, I woke up finding myself again. No matter what happens, I still need to make myself pretty.” Hải-Anh shared with me that she had held the dream to rebuild her breast every moment since her mastectomy because for Hải-Anh her breasts signified her womanhood. She had tried many ways to conceal her absent breast and sickness, for instance, sewing different cushions onto her bras, or wearing bras specially made for the mastectomised breast. However, she had still faced many inconveniences and especially felt distress about her body:

Whenever we had sex, I did not take off my bra, never. I took off the pant under there, but never went topless. I tell you this honestly that I never dared to undress my clothes in front of my husband ever since [the mastectomy]. He is kind, so he doesn’t complain a word. But I think he got fed up. Now there are so many women out there with both breasts. Meanwhile, I only have one. I feel so insecure, so inferior (“*mặc cảm*”).

Hải-Anh was married with three children. Her husband was an immigrant worker in an industrial plant in South Africa and only home for a couple of weeks every year. Hải-Anh worked as a chef at a factory’s canteen close to her home. She described her family’s income status as being able to make ends meet. After her cancer diagnosis, Hải-Anh had to pay a bribe to obtain a near-poor household certificate which granted her a subsidised insurance card. Early 2019, after reading a Facebook post written by a woman in her mid-50s who retold her successful reconstruction with a famous surgeon at Hue Central Hospital, Hải-Anh contacted the surgeon and decided to fly to Hue to realise her dream.

Hải-Anh bought the return airfare for 2,500,000 VND (~US\$109.65) and also had to pay for airport transit from her hometown to Noi Bai airport in Hanoi, as well as from/to Hue airport to the Hospital. She was admitted for a 20-day period during which she spent an average of 100,000 to 150,000 VND/day (~US\$4.39 to \$6.58) on meals and drinks. The surgery, medications, and hospitalisation cost her 27,600,000 VND (~US\$1,210.52). Her first reconstruction cost was therefore approximately 35,000,000 VND (~US\$1,535.09). As Hải-Anh joined other fellow patients to Hue, she could rely on them or their carers for buying her meals during the first days after the surgery when she could barely walk out of her inpatient room. Otherwise, she would have needed a family member and incurred notably higher expenses.

We parted one day before she returned home. She also asked me to add her as a friend on Facebook and keep in touch. Hải-Anh said she looked forward to seeing me when I was back to Hanoi. She was eager to experience her new body.

At the end of my ethnography, I could eventually talk to her again, a couple of weeks before I returned to Australia. Contrary to our conversations back in Hue, Hải-Anh's latest account was filled with uncertainty, pain, and regrets. Her surgical wounds were more serious than she had anticipated, disabling her from getting back to work for more than two months because her abdomen hurt whenever she stood up. She reported that the reconstruction was the worst surgical experience she had been through, far more painful than all of her previous operations (including her two caesarean births, mastectomy and oophorectomy to treat her hormone receptor-positive status). She underscored she was not recommending the reconstruction to anyone, especially older patients with frail health, because of the intense pain she had endured, as well as the large amount of medications she had to take that she believed had already taken a toll on her immunity. Hải-Anh described her "new" breast, repeatedly sharing her feelings of sadness:

I'm very sad because mine is not as pretty as others'. My body has formed keloids around the navel and along the abdomen. The scars are so big. And I don't know why I haven't felt any sensation on my [new breast]. (...) There if I press down with my fingers, I cannot always feel my fingers at all. I'm very sad because I went for the surgery but I could not become whole ("*tròn vẹn*"). Now I can only say that the new one is only 6 out of 10 compared with the remaining one.

As our conversation went on, Hải-Anh recounted that her sex life remained unchanged as she still could not comfortably undress her bra. She wanted to return to Hue for the nipple and correcting surgery. For that operation she might need to borrow money from her relatives; however, she was sure she always desired to regain her breasted experience: “I told my husband that let me go for it, I’m willing to exchange some years of my life expectancy. When I become a ghost, I still need to be with both breasts.” Hải-Anh told me she was planning for her next operation, but she was unsure if it would be the final one.

During my fieldwork, I often also found myself immersed in conversations with the patient informants about reconstruction that were similar to Hải-Anh’s narrative, and discussions as to whether or not someone should restore her breast. Despite this, I rarely encountered a patient from Hue City and the Central region in general coming to the Hospital for reconstruction. Only two of 33 patients from the Central region participating in my ethnography had an immediate reconstruction, three had breast-conserving surgery, while the rest had radical mastectomies without any form of reconstruction.

As noted earlier in Chapter 5, in Vietnamese local knowledge, women’s breasts primarily signify women’s maternal role rather than a sexual object as often captured in Western literature. During my interviews and focus groups, only a few women perceived a woman’s breasts in a context of an intimate relationship by associating them with sexuality, for example, “[Breasts] are for the husband to admire” (FGD 01). This is resonant with a handful of research in Eastern settings. An early study by Yap (1998), for instance, reveals that breast cancer patients in the Philippines are less likely to associate their breasts with sexuality or femininity and feel a sense of relief because breast loss is thought of as a way to remove their cancer. More recent studies similarly find the dissociation of the absent breast with the loss of sexuality, femininity, and romanticism among women in Asian settings like Japan or Hong Kong (Sun et al. 2018). Given the utmost importance of breastfeeding, many patients interviewed in my fieldwork dismissed the necessity to have their breast restored post-mastectomy since they had already finished their nurturing roles and “done with their breasts.” This belief could further explain a widely-held perception that breast reconstruction was more relevant for younger patients in their 20s or 30s to support their courtship and marriage purposes, but not for elder women as I discuss later in my chapter.

## Fears of additional surgery

Since most of the women participating in my research had undergone mastectomy without an option of an immediate reconstruction, having their breast restored would require them to be re-hospitalised and undergo additional procedures. Such additional surgery was fearful for my informants due to the complex technicalities of the reconstructive process which led to their scepticism about the surgery's success and concerns for its post-op repercussions. Women often pointed to cases of other patients they knew who had experienced surgical failures and been left with serious wounds or infections. For instance, Hay (aged 47, Quang Tri) was worried about the flap surgical methods and the risk that the newly constructed breast would become incompatible with her body. When her oncologist presented to her the option of reconstruction, Hay refused to expose her body to what she viewed as a highly risky situation:

Any wound would be painful. It hurts even when you accidentally cut your finger. When you do it [reconstruction], they cut your stomach and take out the flesh and sew it onto your upper part. Will the flesh stay alive, or become rotten? Some people have done it beautifully. Only a few failed... But how can I avoid being in the minority? Failures might not be due to the surgeons. It may depend on one's skin, flesh, and blood... I don't know how my body ("*cơ địa*") will respond. I don't know if it turns out good or bad. So I decided not to, never.

For others, the idea of an additional surgery revived their illness accounts which entailed physical pain and distress associated with their mastectomy, as well as a traumatic period of hospitalisation throughout their treatment journey. Long (aged 35, Dak Lak), whose accounts of hospitalisation was provided in the previous chapter, asserted that she rejected reconstructing her breast because for her, any operation was a reminder of her past hospital experiences:

He [the surgeon] told me that the operation would use my own fat. He would take out the fat from my shoulders or my stomach. Heaven! Just listening to him scared me badly. After my mastectomy I felt almost dead. If I had another one [surgery], I would never be able to endure it.

Long dreaded another surgery as she knew it would again cause her severe physical pain, and because it would simultaneously disrupt her husband's business because he would

have to accompany her during that period (see one of the cases described in Chapter 7). Moreover, the hospital stay would affect other family members whom she would need to take care of her only daughter while she was away.

### **Survival prioritising**

Many women opposed reconstruction because the surgery contradicted their long-held belief of breast cancer curability. In their opinions, irrespective of the cancer stage, the best and only way to treat breast cancer was to have their breast completely removed by radical mastectomy. Retaining a breast, either by conservation (“*bảo tồn*”) or reconstruction, therefore, interfered with their concept of treatment effectiveness since it provided a breeding ground for “cancer roots,” thereby accelerating the growth of cancerous cells to other parts of their bodies and prompting the relapse or metastasis:

You should remember that there [where the cancerous lump is found] nodes (“*hạch*”) keep multiplying. Cancer is like a rambutan (“*chôm chôm*”), with many prickles springing outwards. If we remove only the lump, its legs are still there, like the roots, we can’t get rid of the roots (...) So we have to cut [the breast] out totally. (FGD 02)

This belief was prevalent among my informants, leading to their decisions for a radical mastectomy even when they were eligible for breast conservation at their first diagnosis, like the example of Hay who was previously mentioned. Hay insisted on having a mastectomy right at the beginning although at that time, her tumour size was not large and lumpectomy was still possible:

At first the doctor told me about three options, one of them was to conserve, that was to cut out the lump, then having radiation at the same time of the operation, so I would still keep my breast. But I thought it was unsafe, what if the lump had already spread (“*lan tỏa*”) and stayed in the surrounding skin and flesh? (...) If they only took out the lump, radiated, and sewed it [the breast], the breast would stay

there. I did not know if the cancer was there in the lump, or it was metastatic (“*di cấn*”), if he<sup>13</sup> [the cancerous lump] had legs which made him cling onto other parts.

The fear of “awakening cancer” linked to the intervention of surgical equipment was also prevalent among my interviewees, which some healthcare providers confirmed when reflecting on the reasons why most of their patients expressed their attitudes against reconstruction. For example, Dr. Uyên reported: “Central woman are more complacent. They usually avoid doing something with the tumour because they are scared the tumour will develop or create a new one. That’s why I think not many people want to do reconstructive surgery.” (Female, aged 33, medical oncologist).

Recurrence/metastasis-prompting concerns were also linked to women’s self-perceived frail health since primary treatment had ended, as Hay maintained: “it will negatively affect my health, requiring more antibiotics.<sup>14</sup> I will become weaker, so metastasis will occur faster.” Long, too, perceived herself as physically disqualified for the surgery though many people, including her oncologists, believed that she was now cancer-free. While always appearing youthful and energetic, she never felt she had recovered from her sickness and reported chronic anxiety due to her fear of cancer relapse and severe side effects of hormone therapy: “I have so many side effects. Since taking the oral medicine [tamoxifen] and [monthly ovarian suppression] injection, I often suffer from back pain, and my vision is decreased. Sometimes I cannot see things clearly. I think it is because of the medication, but am also afraid of brain metastasis.” Despite her young age and insecurity about her mastectomised body, Long remained unshaken by her husband’s expectations for reconstruction because of her concerns that the invasiveness of the surgery would jeopardise her current precarious healthy status. She emphasised that forgoing reconstruction was one way to protect her survival – her greatest priority, and that “staying healthy, not pretty, was a bigger blessing than winning gold.”

In these patients’ beliefs, reconstructive surgery’s future risks outweighed its benefits which they assumed to solely focus on aesthetic, not medical, aspects. Their non-reconstructive practice was therefore a rationalised decision to protect their survival and

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<sup>13</sup> This woman, like many other participants I met during my ethnography, used the pronoun “*hắn*” when referring to cancer. “*Hắn*” is often used in spoken informal Vietnamese to mention a man with unpleasant characters, quite similar to the word “bastard” in English.

<sup>14</sup> As noted in Chapter 3, in Vietnamese popular knowledge, antibiotics as Western medicine is widely perceived as of “hot” and harmful quality and therefore, people should restrict their use or take small doses, which contrasts with traditional Vietnamese medicine which is believed to be benign and nutritious (Craig 2002).

avoid placing their health in precarity, but also not to expose themselves to others' disapproval of a surgery that was deemed only for appearance purposes.

### **Like “elevating one’s nose”: breast reconstruction as a cosmetic practice**

Breast reconstruction was widely viewed among my research participants as a procedure that could merely improve the aesthetic aspects of a patient’s appearance, rather than a necessary treatment providing medical, psychological, and other practical benefits. This view was partly attributable to the fact that for most women reconstruction was rarely considered at the same time as their mastectomy. Believing that reconstruction had no, or even adverse effects on a breast cancer patient’s health and survival, most women referred to the surgery as a cosmetic practice like one to enhance the face: “[I]t’s using the knife to cut, like people going for a cosmetic [surgery], like you know, elevating one’s nose, I read about this in the Internet, it is terrifying” (38-year-old Lien, Hue City).

Very often my participants described those who restored their breast as someone who was vain and their decision was a health trade-off, as 47-year-old *Dương* remarked: “Those women were unknowledgeable. They only cared about their physical appearance but were irresponsible for their own health.” This perception was also evident among those with a medical background. *Khiêm*, a 45-year-old patient with stage III breast cancer, who herself was a nurse at a hospital, shared her viewpoint: “From the beginning I did not want to do it [reconstruction] (...) After the surgery the quality of life will stay the same, there will be no changes. The only difference is that you look a bit prettier. But that I no longer need. When I fall ill, life (*tính mạng*) is the only thing that matters.”

When reviewing media coverage on breast reconstruction released by large medical institutions in Vietnam, I also found that aesthetic benefits were promoted as a selling point for this surgery, one that remedied poor self-image post-mastectomy. Consider, for instance, an article published in an online newspaper managed by the Provincial government - reporting the successful DIEP (Deep Inferior Epigastric Perforator) flap operations performed by the surgeons at Hue Central Hospital. This advanced technique is described as bringing “dual-joy” for breast cancer patients: “The use of lower abdominal also helps aesthetically for those with stretched skin because of

belly fat (*'béo bụng'*). Patients will not only have a full breast (*'ngực đầy đặn'*) as originally, but also a flat stomach (*'eo thon'*)" (Minh 2019).

The first of the two sub-headings of this article reads "Regaining confidence for a woman aged 35," which presents a case study of a 35-year-old woman working in a public-relation job who has recently been operated on to restore a natural-looking breast post-mastectomy. The news goes on to the second section explaining the current trend of breast cancer incidence, demonstrating that it has been growing among women in their 20s and 30s. With that, the article emphasises the justification for targeting of this aesthetically innovative surgery: young women who are below 40 years of age.

Such belief also affected the formulation of surgical eligibility in relation to a patient's age. Findings from Western countries often note that cosmetic surgery is mostly sought out among middle-aged and older women with a common hope to dispel aging anxiety or cope with ageist stereotypes of old people (see, for instance, Dean et al. 2018; Kinnunen 2010; Slevic & Tiggemann 2010). In contrast, during my ethnography I found a pervasive perception holding that cosmetic practices, such as breast reconstruction, only suit young women. Many women over 60 years of age, or as young as those in their 40s cited their old age as among the important reasons discouraging them from seeking restoration. Minh (aged 53, Quang Tri) who worked as an officer at her commune's mass organisation, for instance, laughed with her fellow patient Hồng during our conversation in their inpatient room when Hồng brought up the topic of reconstruction. She denied the salience of reconstruction because she had passed her youth: "If I was still young and continuing working for many more years, I would consider it. But now I am close to retirement age [55 years for a female public servant as per existing Labour Code], I have already had grandchildren from my daughter and son. I only need to stay healthy. I do not see any point of staying pretty."

In my focus groups, I used a vignette of a 53-year-old woman who was considering reconstruction after her health status was stable five years since the completion of her treatment. I requested participants to give their advice to her and additionally asked about who should do the operation. Most of the women believed that the surgery was more relevant for young women: by "young" they referred to the 30 to 35 year-old age range. They were reserved in supporting a person in her 50s to opt for the

surgery because her physical appearance was no longer under public scrutiny, according to the FGD participants:

Because at age 60 it [the breast] has already shrunk, there is nothing left. Even if you have it restored, nobody will see it. Should not. Give that money to your children. I saw my mother-in-law taking a bath the other day. She took off all her clothes, I did not see anything on her “*bư*” [breasts], hers were as flat as a man’s.

Because when you are old, even when you do it [reconstruction], there is none who cares. At that age the body is flat. Only those who dread looking ugly will do. (FGD 01)

### **Judgement against cosmetic surgery**

Notably, in viewing reconstruction as a purely aesthetic practice, my participants widely expressed their judgements against those who seek this surgery. For instance, during my FGDs, the women villagers showed their disapproval of a woman’s decision to “do aesthetics” (“*làm thẩm mỹ*”) by restoring her breast, due to their views that it was a morally unacceptable behaviour of a virtuous woman, even within the context of recovery from cancer. While expressing pity for patients living with breast cancer who lost a breast to mastectomy and their willingness to offer help to those people, participants strongly opposed reconstructive surgery, believing it was not related to health, “just beauty.”

She should not do it, rather put that money aside for her children and grandchildren. (FGD 01)

If you do aesthetic surgery and something bad happens to you, they hate you more. They will tell you “it [the failure] serves you right.” They would accuse you, saying that you are already old [but still prefer doing aesthetic]. (FGD 02)

Cosmetic surgery is gaining popularity in contemporary society. However, negative attitudes towards the surgery and women undergoing the procedure still prevail worldwide. Studying a group of women in Southern California (the U.S), Saxena (2013) found that women who undergo breast implant surgery feel judged by others as having a “fake” character and are susceptible to negative stereotyping as “airheads and bimbos.” Labelling recipients of cosmetic surgery as those with negative characteristics (e.g, lazy,

materialistic, and perfectionistic), considering the procedure as unacceptable, or being hesitant to socialise with those recipients are commonplace among the public in both Western and non-Western countries (e.g. Bonell et al. 2021; Tam et al. 2012). Some research even demonstrates that moral condemnation of cosmetic surgery is present among the recipients themselves (Davis 2009). A significant body of feminist scholarship notes that naturalistic fallacy which upholds the naturalness standard of female beauty often forges hostile attitudes towards those who seek surgical beautification (Bonell et al. 2021; Fraser 2001; Hurd Clarke and Griffin 2007). Regardless of any settings whether the prevalence of cosmetic surgery is high or not, in most societies, it is undoubtedly expensive and unaffordable to the low-income working class. Cosmetic surgery is regarded as a special commodity (Luo 2013), signifying the owner's economic success (Taylor 2012). In research with Chinese women, Luo (2013) posits that the consumption of cosmetic surgery marks the growth of consumerism and showcases the class status of the people who purchase it, similar to consuming upscale brands.

These tenets related to the naturalistic fallacy and cost can be drawn out to understand the judgements against those seeking reconstruction which is viewed as a cosmetically surgical procedure among my research participants. As a means to artificially alter one's appearance, cosmetic surgery violates the culturally ingrained values that uphold the importance of maintaining the body intact to be filial to parents in countries like China (Tam et al. 2012), which shares many cultural values and demographic context with Vietnam. Secondly, the prevalence of cosmetic surgery and particularly breast reconstruction is still low in Vietnam. While there are not official statistics showing the trend nationwide, a recent study conducted on a sample of 202 women with breast cancer using an online and face-to-face survey reveals that only 10% underwent breast reconstruction surgery (Tran et al. 2021). As this remains an uncommon procedure, people are less likely to encounter those undergoing the surgery, which might render them less tolerant towards its recipients. This is reflected in the many accounts' where my informants often emphasised that women opting for breast reconstruction were deviations from the majority. For example, when Mong (aged 53, Quang Binh) recalled a patient who came to have her breast restored at the same time as Mong's hospitalisation, She deployed various terms to refer to the "otherness" of the patient. According to her observation, those women usually came from big cities within regions with higher status of economic development and could afford special commodity and services:

Trang: You told me that you heard from others that it cost 20 million?

Mong: 20 million per breast.

Trang: How about you? Will you consider doing it later?

Mong: No. Many patients are much younger than I am, but they have not done it. So why do I? I know that woman coming from Hanoi. She had been treated overseas, in Singapore. And then she came here [Hue Hospital] to do reconstruction. She had bought two [silicone] breasts from overseas, or maybe in Hanoi, I'm not very sure. But she had the surgery here for a week or so. And then she left by plane back home.

The description of *Dương* (whose account and that of her mother I described in Chapter 5) clearly show the perceived class differentiation between those who do not have their breast reconstructed and those who do because: “people who are extremely rich will do aesthetics (*“làm thẩm mỹ”*), not [as poor] as I am who cannot get such an amount of money” (aged 47, Hue City). Her statement evokes the socialist public morality of Vietnam which condemns excessive economic inequality among the population and points to the third element that can be used to explain the moral judgement against this surgery. Given the high cost associated with the reconstructive procedure, consuming this luxury seems to deviate from the norms of frugality that was long upheld during socialism. In this respect, I also argue that the exclusion of breast reconstruction from public health insurance reinforces the belief of the surgery as merely related to enhancing one's appearance, as well as its associated moral judgements.

### **Cultural constructions of dutiful women: A decision to conform**

Considering this widespread condemnation of pursuing breast reconstruction - a perceived cosmetic procedure, as morally unacceptable, an opt-out can be, therefore, seen as a decision to conform. By forgoing breast reconstruction, the women are able to maintain the status of a good cancer citizen who does not indulge themselves with costly luxury. In addition, this decision is also a manifestation of their adherence to gendered roles and situated within the cultural constructions of a dutiful woman and femininity.

Specifically, it is an act in conformity with the state-promoted moral virtues of endurance and self-sacrifice that have traditionally disciplined Vietnamese women (Gammeltoft 2021) because in this case, they carefully apportion the limited resources for survival and family economy, not for their own sake.

In the local gender norms, women hold a more vulnerable social position vis-à-vis men and their bodies manifest the honour, morality and reputation of not her own case but her whole family (Rydstrøm 2002). As described in Chapter 3, while Confucian-informed masculine qualities have diminished their influence, discourses that emphasise a woman's Four Virtues (*Tứ đức*) which consist of *Công* (Labour) - *Dung* (Appearance) – *Ngôn* (Speech) - *Hành* (Behaviour) still dominate public discussion of a modern female figure in the post-socialist state (Khuat et al. 2010). Vietnamese women continue their subjugation to core feminine ideals that centre around Confucian-informed domestic femininity, whereby they are expected to show their devotion, selflessness, endurance, and hardship-bearing ability in everyday life (Gammeltoft 2018; Pettus 2004). These tenets are also tied to Confucianism-Buddhism that undergird Vietnam's moral codes in which individual desires are subordinated and sacrifice for the sake of intimate others is an integral part of familial relationships (Shohet 2013). Against this backdrop, a practitioner explained why a restorative operation was not popular among her breast cancer patients:

My patients mostly belong to the 40 and above age group. Women in their forties you know, Central women, their biggest concern is their children and how they can provide the best care to their children during the rest of their life. Aesthetics and beauty are not their priority (...) What they often asked me the most was their chance of survival because they wanted to know how much time they would still have to look after their children. (Female, aged 33, medical oncologist)

Similarly, the women patients often drew on their social gender roles to rationalise their non-constructive decision. They knew that undergoing the surgery would expose them to the uncertainty, risks, and complexity threatening their physical well-being. Its resulting impacts could also be detrimental to the women's moral standing within their local social worlds, as well as disrupt their domestic caregiving responsibilities. As the existing literature notes, women in Vietnam bear much if not most housework and childcaring responsibilities (Teerawichitchainan et al. 2010). Most of the patients in my research, regardless of their spouse's or own employment status, were the main caregivers in their

families, performing the carework for their young children, parents or parents-in-law, or grandchildren. The occurrence of breast cancer could only cause temporary disruptions to their domestic domains since most of them reported returning to their day-to-day caring responsibilities as early as the primary treatment had ended. With that in mind, forgoing the reconstruction enabled them to avoid the limited mobility caused by the surgery's invasiveness and its associated hospitalisation which would inevitably interrupt their duties and the well-being of the people they care for, as 36 year-old Tuyen (from Quang Binh) affirmed: "I never desired to have it [breast] back. I only wished that my treatment went well and I could live longer to take care of my children."

Meanwhile, aware of the fact that the act of seeking reconstruction often faced moral judgement from the people in her community, women who had undergone reconstruction tended to conceal their status, or adopt a blame-averting strategy as the case of 60-year-old Mai:

I had met Mai at two monthly events of Pink-shirt team prior to a visit to her home in a newly developed residence zone northeast of Hue. Contrary to her usual silence at the group gathering, Mai was chatty since the beginning of my visit. She spoke to me about her previous teaching career in Dong Ha (Quang Tri province) and her decision to retire in Hue where she was born and grew up. In 2011 when she was diagnosed with stage II breast cancer, her doctor advised her about immediate reconstruction following mastectomy. "I myself had no idea what it meant but he told me it was possible, so I just went with it. Because at that time I was still working as teacher in Vietnamese Literature and had to wear 'Áo dài' (traditional long dress) to class very often, I did not want to look asymmetric ('*mất cân đối*')." Mai was content with her post-surgical body and without any hesitation offered me to look at her new breast. She commented that even without a nipple, it still looked "authentic, full." She joked with me that when she was home with her husband, sons and daughter-in-law, she did not need to wear a bra and everyone hardly noticed her reconstructed breast. However, she often concealed her situation from other peers by responding: "I only did what the doctor told me to do" whenever she was asked, and only a few Pink-shirt team members knew that Mai "still had two breasts." (Fieldnote, 2019)

In the case of the **Duong**, she often told me that she felt “lucky” for retaining her breast since she had quite large breasts and without one, she would certainly experience a lot of dressing-related inconvenience. However, at the peer network’s gatherings, interestingly, **Duong** was strongly vocal about her attitudes against reconstruction, claiming the practice was too costly and harmful to one’s health. She repeatedly asserted that she “had no idea” about the procedure:

When I came to see him before the operation, he told me that he would do a conserving surgery. I had no idea what it was like. I asked him whether I should have a mastectomy because I knew other breast cancer patients all had that. They all had their [cancerous] breast removed completely. I told him to remove it so that I don’t mind about it later. Then he told me to leave it to him, let him do [conservation]. Only after the surgery, I learned that conservation meant they only removed 3 out of 10 of my breast.

This account exhibits shifting the decision-making responsibility onto the doctor, thereby helping her to avoid the judgement from other people. In addition, **Duong** often referred to herself and other peers who had undergone any form of breast reconstruction as “a doctor’s lab rat” (“*chuột bạch*”). The use of a metaphor that their surgery was just a medical experimentation also demonstrates the patients’ scepticism over the procedure’s success in an uncertain context and may signify their mistrust with healthcare providers and the health system at large as often captured in past research of underserved populations (cf. Ferrera et al. 2016).

## **Health-system issues**

The women’s decision-making in relation to reconstructive surgery can be further examined by taking into account health-system factors, including provider-related issues, for instance, patient-provider communication, the availability of surgical expertise, as well the procedure’s cost and related insurance regulations, which I analyse below.

***Patient-provider communication: absence and ambivalence***

Previous research suggests that Asian women are more likely to view their doctors as authoritative figures and rely on their doctor's advice for making cancer treatment decisions, including breast reconstruction (Kwok and Koo 2017; Soon et al. 2019). For instance, a recent study conducted by Soon et al. (2019) comparing the reconstruction experiences of Vietnamese- versus English-speaking women in Australia identifies the salient facilitating role of doctors among the former group. My ethnographic data, nevertheless, suggests that within my research context there is limited provision of consultation on reconstruction and medical providers generally take a hesitant stance towards the surgery.

Earlier anthropological accounts often note that medical practitioners overlook socio-economic factors in their interactions with patients which are seen as secondary to the biological body (for instance, Martínez 2018). The focal point for physicians remains at the bodily level as Kleinman (1988, p. 5) points out: "Disease is the problem from the practitioner's perspective. In the narrow biological terms of the biomedical, this means that disease is reconfigured only as an alteration in biological structure or functioning." This resonates with my observation of routine follow-up appointments at the Central Hospital during which a patient first met with the doctor who started their consultation by asking "How is your health?" In response, the incoming patient spoke briefly about their health status and any physical symptoms they had experienced in the previous months since their last appointment. Based on such information, the doctor might perform a physical examination on the patients, or send them for necessary tests. During these encounters, topics of conversation primarily focused on biological functioning of the body; meanwhile, women were reticent to discuss topics which they considered falling out of the physician's body-focus.

My research informants only spoke to their doctors when asked to, and rarely took the initiative to open the communication during their consultation. The main reasons they explained for not being outspoken were "being hesitant to bother doctors because they are already busy," fear of "being judged" or "being scolded," the thought of their concerns perceived by doctors as "nonsense" ("*tào lao*"), too sensitive, or the embarrassment of being classified as "ignorant." For most women patients, remaining silent or only talking in response to doctor's inquiries manifested their compliance in a

“patient role,” that was not to challenge the doctor’s authority during a medical encounter (Do and Nguyen 2020). Therefore, personal topics such as financial constraints, psychological experiences, post-surgical body image, or sexuality were largely absent during routine consultations because they were deemed to be unrelated to the biomedical treatment of cancer. This left patients’ grief, anxiety, and distress post-mastectomy unknown to their providers, rendering the latter to undervalue the psychological and pragmatic problems facing patients in their post-cancer life.

As I recorded during my observations at the public hospital, the consultation that occurred during their routine follow-up appointments usually lasted up to ten minutes when examination was performed, and on average from five to seven minutes otherwise. During the course of the consultation, doctors did not spend time entirely on communicating with the patient. Rather, they might conduct other tasks, such as finishing the patient’s medical record book, discussing issues with the nurse, or attending to requests from other patients. In general, the longest consultation patients received was prior to their first round of chemotherapy. Dr. Thi, a medical oncologist, confirmed this to me in one of our interviews, claiming that she always tried to provide as much information as possible at the consultation at the beginning of the chemotherapy cycle, which covered topics related to side effects, the types of food the patient should increase in their diet, or activities that they should refrain from. Another detailed consultation would follow prior to the hormone therapy. She admitted that as the patient went into their treatment process or during their outpatient period, such a long consultation was not available due to the immense workload at several roles she undertook, both at the Oncology Centre, and the Central Hospital’s satellite units.

The physical setup (see Chapter 6) and staff allocation of the consulting units created additional drawbacks for the interaction between patients and their doctors. As doctors of different sections were rotated to attend the three consulting rooms throughout the month, outpatients were unlikely to meet with the same doctor in their routine follow-up visit. From my interviews with the women, I identified that each woman often had one or two preferred doctors with whom they felt most comfortable to talk. However, the arrangement of the consulting department, as well as the insurance regulations that stipulated a fixed ten-day period for follow-up visits restrained the patients from making the appointment of their choice.

A statement by Dr. Tuấn exemplified a male doctor's view towards the loss of a breast for a woman patient: "I think losing a breast is for them a normal issue (*'binh thuong'*), similarly to a situation when you have another disease which requires an operation. It is not something too serious that gets on their nerves." This perception was not unusual among the healthcare providers I interviewed, most of whom assumed that patients often had low interest in having reconstruction. The importance of a reconstructive operation for some women often remained unrecognised: only three out of eleven interviewed medical staff reported that they had explicitly endorsed and recommended reconstruction to the patients they had cared for. Meanwhile, only a low number of patients (13 out of 33 patient informants) had received consultation from a healthcare professional on reconstruction either at the hospital or via peer group events by the time of my fieldwork.

In most provider interviews, I found reservations as to whether or not a patient should go for reconstruction. Its potential interference with other methods of treatment was among the major reasons explaining the medical staff's concerns. For instance, amid ongoing discussion regarding immediate reconstruction being covered by the UHI scheme, Dr. Hồng, a female oncologist, critically talked about the possible harms for radiotherapy of immediate reconstruction: "The advantage is that the patient has to suffer once, but the disadvantage is the operation will be much longer, so more complications. Further, it affects the treatment that follows, for example, if she needs radiation, the reconstructed breast will be subject to radiation effects. Many side effects can occur. It will be no longer beautiful." (Female, aged 33, medical oncologist)

Speaking of barriers that prevented patients from accessing reconstruction-related services, one surgeon believed that medical staff's disapproving attitudes played a significant role. He asserted that this "gap" should be among the first to be addressed in order to shift the existing judgment against reconstruction, specifically to falsify the patients' perception that associated reconstruction with increased risk of recurrence, and by doing so, promote the surgery among breast cancer patients:

All oncologists have the responsibility to inform patients about reconstructive options. However, now their awareness [of reconstruction] was not homogenous, some wanted to direct patients to different decisions. I can say that because most doctors have received education only on treatment, they do not gain a proper,

comprehensive view of this (...) For instance, a patient receiving chemotherapy was often confined to only her medical oncologist, even after the therapy was over. Doctors were not willing to refer them [to points of contact where reconstruction information was available]. (Male, aged 58, surgeon)

The lack of expertise in plastic surgery posed another concern regarding patients' accessibility, as well as the operation's outcomes. By the time of my research, only two surgeons at the Oncology Centre were capable of advising patients on and performing reconstructive surgery. One of these two surgeons was not assigned to attend consulting rooms, which meant that outpatients virtually had no opportunity to see them in the first instance when they had requests for information related to reconstruction; instead, they had to meet with a doctor at the consulting room who would later refer them to those surgeons.

It is also worth mentioning that both of those two surgeons had been originally trained and practised as surgical oncologists whose number of reconstructive surgeries was limited throughout their professional life. Patients would therefore carry the risk of enduring surgical failures or requiring several operations to match the reconstructed breast to the natural one, such as the experience of Hải-Anh presented at the beginning of this chapter.

In addition, all surgeons and most doctors (22 out of 25) at the Oncology ward are male. Because of this underrepresentation of female staff, women patients were likely to be attended by a male provider in their routine consultation. The gender discordance between patient and doctor might jeopardize certain aspects of the treatment, especially regarding communication on intimate issues such as women's body image or sexuality. There has been abundant evidence in earlier research showing that compared to female physicians, male doctors seem less capable of building rapport with patients, less sensitive to gender-related issues, and more controlling while interacting with women (for example, Allen et al. 2001; Weisman & Teitelbaum 1985). Both male and female oncologists I interviewed acknowledged the gender asymmetry evident at the Oncology ward and the consequence it had on establishing doctor-patient relationship. Consider the response below from Dr. Truong about the barriers he faced in understanding the patients' needs when women patients were unwilling to discuss how they would like to be treated. Dr. Truong thought his practice was threatened because of the gender difference and

insecurity facing women when they presented themselves in a mastectomized body to a male person:

Breast cancer patients are mostly female, sometimes we received 1 or 2 male patients. Because they are women, what they care about is practical issues in their life, such as outward appearance (...) If they had undergone radical mastectomy without reconstruction, they feel insecure, much more than towards hair loss. They feel a big loss in their body. They would no longer feel like a normal person, no longer women. These [feelings] influence a lot their mentality (“*tâm lý*”). They also affect the interaction between the patient and healthcare workers. When they do not feel alright with their body, they will not feel comfortable conveying their symptoms, their needs. This influences the quality of treatment (...) A patient’s satisfaction is important and to achieve it, we need to treat them effectively. But patients need to be honest, sincere to workers. Otherwise, it is impossible (...) It is a very big barrier. (Male, aged 38, radio-oncologist)

### ***Surgical costs and insurance coverage***

The cost of the procedure was another reason usually mentioned by healthcare staff that limited the provision of information to their patients regarding reconstructive options. According to existing regulations set out in the MOH’s *Decree 39/2018/TT-BYT* dated November 30<sup>th</sup>, 2018 (amended with *Decree 13/2019/TT-BYT* dated July 5<sup>th</sup> 2019 and *Decree 13/2020/TT-BYT* dated June 22<sup>nd</sup> 2020), breast reconstruction when performed as a delayed procedure is not recognised as an item covered by the UHI. Therefore, patients who have their breast restored post-mastectomy must pay for the surgery out-of-pocket, which ranges from 30,000,000 VND to 45,000,000 VND (~US\$1,315.79 to US\$1,973.68).

Many doctors explicitly raised their attitude against reconstruction by arguing it would place additional financial burdens onto the patients due to the exclusion of delayed reconstruction from the public health insurance scheme. Knowing that patients had to bear the surgical costs entirely out-of-pocket, some doctors chose to selectively provide information on reconstruction to certain groups of patients they thought would afford the operation:

The problem now is if we provide them with the information [about reconstruction], they want to do it, but cannot afford to because the insurance does not allow it. Then they will feel disadvantaged (“*bị thiệt thòi*”). This will decrease their quality of life (...) Now that the insurance regulations about the coverage are not stable, we will not provide advice frequently. I only see who has the demand and advise them on this. When they have such a desire, they will be willing to pay. (Female, aged 35, medical oncologist)

Additionally, I learned from the peer group gatherings that patients often made honorary payments ranging from 5,000,000 VND to 15,000,000 VND (~US\$219.30 to US\$657.89) in order to select the surgeons they preferred, or with a hope that the surgeons would perform a better operation. Such payment is not rare in Vietnam’s medical context and abundantly mentioned in the existing literature (see for instance, Tran et al. 2011; Witter et al. 2011). People usually consider that informal payments made to doctors with an aim to establish intimacy with them (Dao 2020) are acceptable since they are culturally expected and symbolise an act of social reciprocity (Vian et al. 2012). Taking it altogether, the total cost of the reconstruction ranged from 30,000,000 VND to 60,000,000 VND (~US\$1,315.79 to US\$2,631.58). It should be noted that this sum is not a one-off payment since it excludes the cost of reconstructing the nipple (which is usually half the cost of the breast, both in terms of surgical cost and hospitalisation length), or additional revisional operations to achieve the optimal outcome. At Hue Central Hospital where my ethnography took place, at times there were exchange programs in collaboration with a foreign hospital when visiting surgeons operated free-of-charge. In other cases, the Hospital received donated-silicone implants, which allowed several patients to have reconstruction at a reduced cost. However, these programs were temporary and information on eligibility and access was not widely announced,<sup>15</sup> resulting in only a minor number of beneficiaries.

For the vast majority of women, the reconstructive option is considered after the primary treatment is finished, usually a couple of years since the initial diagnosis of breast cancer. By then, the illness has already depleted the financial resources of many patients’ families and a significant number of them are still living with outstanding debts incurred throughout their treatment trajectory, which is noted in the previous chapter. Considering

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<sup>15</sup> I interviewed a woman who had her breast restored via such a program who reported that she had known about the promotional surgery because of a relative working in the International Unit of Hospital.

that an operation's cost is equivalent to the national income per capita which was 58,500,000 VND (~US\$2,565.79) in 2018 (GSO 2018), it is not surprising that many women have made an opt-out decision.

### **A sense of control**

While constrained by inadequate insurance coverage, limited accessibility to information and services, and social prejudices, the women patients participating in my research were not passive in making decisions about reconstruction. Dissimilar to an operation to treat cancer following the primary diagnosis which they had no or limited ability to act upon, my participants emphasised themselves as active agents of their choice, as 38-year-old Liên remarked, “even with insurance [coverage], I would not do it.” Reconstructive decision-making is hardly a simple process because in considering reconstruction, women confront debates about agency and complicity with sexist social values (Manderson 2016). In this section, I demonstrate that by deciding not to have their breast restored, women both conform to existing gendered norms and expectations as analysed in the previous section while simultaneously challenging and defying them. The “act of doing nothing” or opting to forgo reconstruction is not an inaction but a practice made with intention and an element of choice. In view of this, I argue that prior assumptions that label non-reconstruction as a non-choice overlook the contextual dynamics surrounding a woman's decision-making, but also the nuances of her agency.

A woman's decision for or against reconstruction is invariably considered within a patriarchal society that emphasises the importance of symmetrical breastedness to a woman's beauty, femininity, and sexuality (Cromptvoets 2006b). My male FGD reaffirmed these normative beauty standards by articulating the necessity for a woman to retain both of her breasts. They provided gendered configurations of a bodily disability by describing a woman without a breast as a physically handicapped person and contrasting their situation with that of men whom they believed could live well in deformed bodies:

Men, they can have some health defect, or lose some part of their bodies. They can accept it, unlike women. Women won't accept that loss. A man can lose an arm, but not a woman. Put it simply, do you see that a man with an arm disability, he still feels confident. But you will see a woman with such disability differently, right? Or

an one-eyed man can comfortably go out drinking with others, but a woman will not dare to go anywhere. (FGD 03)

Interestingly, unlike the women participants mentioned earlier, the men in my FGD tended to disregard the economic aspect of the surgery and maintained that its cost would not pose a barrier to their support of reconstruction, as the following participant suggested:

If the family situation is too difficult [financially], and they can only make ends meet, two or three hundred million [VND] should be considered carefully. But some dozen millions can be manageable because now the living standard for a farmer is increased. So I think that she should do [reconstruction]. (FGD 03)

These aesthetic values placing expectations for women to retain symmetrical breasts were similarly apparent in the patients' narratives describing the husband's role in their surgical decision-making. However, speaking of their spousal preferences was a means through which my patient informants implicitly challenged and resisted the normative ideals of a female body, thereby asserting their sense of control. Specifically, many women spoke about the role of their spouse in looking for a famous reconstructive surgeon or information related to the surgery, but came to contrast this with their final decision to defy a husband's endorsement for a wholly-breasted state. Such accounts exhibit how they made the decision to forgo reconstruction as autonomous rational individuals, without having to rely on their partner. The women were unwilling to subject their bodies to pleasing their husband's expectations for wholeness and acted to protect themselves from enduring further surgical interventions or accepting a foreign object (a new breast) implanted onto their bodies. For instance, Tuyến (aged 36, Quang Binh), whose husband was supportive of and financially prepared for the surgery, resisted his suggestion though she was very young (34 years old) when she had her right breast removed following her cancer diagnosis. Tuyến explained her decision: "If it was my breast loss that made my husband no longer love me, he deserved my abandonment."

Likewise, Khiêm (45-year-old, Hue City) described her opposition to her husband's preference as a rational decision to protect the economic well-being of her whole family, which also helped sustain her financially independent status: "My husband wanted me to do the reconstruction because you know men all like beauty (...) But I do not want to endure another surgery (...) In my family I am the main income earner. He gives me his

salary, but it is only symbolic, cannot even cover the kids' tuition. So I told him I need to survive to keep managing everything.”

In not realigning with the ideal female body, the women patients also sought to build the new configurations by rejecting the dichotomy between being feminine, beautiful and having a one-breasted body. Throughout my fieldwork, I participated in various events where the peer network encouraged its one-breasted members to confidently perform or present themselves to the public in curve-accentuating outfits that are deemed only appropriate for women with symmetrical bodies such as swimsuits or “áo dài” (see Plate 8. 1). “Áo dài” is the traditional costume usually worn at formal occasions, such as Lunar New Year or wedding, as a uniform at certain schools and political organisations, and a compulsory garment at every beauty pageant. Although in the past it was worn by both sexes, now *Áo dài*'s meanings are associated with the Vietnamese traditional concept of beauty and femininity. Because it is often made with transparent fabrics and requires custom tailoring to make it a form-fitting dress, it accentuates the shape of the wearer's body (Lieu 2000) and all natural curves despite its being a long flowing dress, covering almost every part of the whole body. News and pictures of those events were later posted in the group's public site and its members' personal social media, thereby being used to alter the norms of the ideal female beauty and society's labelling of a breast loss as a “physical handicap.”



**Plate 8. 1.** The peer group posing for a picture in “*Áo dài*” and “*nón lả*” – a traditional conical hat - during the Pink October by Sông Hương – the iconic river of Hue

## Conclusion

This chapter has unfolded the multiplicity of forces which influence women’s reconstructive decisions post-mastectomy, thereby revealing the social and cultural embeddedness of reconstruction-seeking behaviours. Limited reconstructive services and expertise, and doctors’ hesitant attitudes towards reconstructive surgery are major impediments to patients’ accessibility to information on available surgical options. Another critical issue that creates a major barrier both to a patient’s reconstructive decisions and doctor’s delivery of information is related to insurance payment regulations. Because it is not covered by the UHI when conducted as a delayed procedure, patients must pay for the operation at their expense, which poses a significant financial burden upon them and their family.

While financial cost greatly influences the decision-making in the context of breast cancer care (for summary, see Greenup et al. 2019), this chapter has illustrated the various

logics applied to women's reconstructive decision as they navigate throughout the post-cancer life and grapple with their mastectomised body, and revealed that the economic aspect is not a sole factor accounting for women's decisions to forgo reconstructive surgery. Their behaviour is influenced by an interplay between various individual, interpersonal, and broader contextual drivers. Fears of additional surgery are a prominent trigger to women's decision-making against reconstruction, which resonates with previous studies emphasising concerns for extensive pain and recovery time, as well as its post-operative results as deterrence to the women's pursuit of the surgery (Holland, Archer, and Montague 2016; Rubin et al. 2013; Soon et al. 2019). In my research, these fears are grounded in patients' negative hospital experiences that they have previously endured in a context where public distrust with the quality of healthcare services and professionals is commonplace (see, for instance, Vu 2014). Potential health risks associated with the complex surgical procedure pose further anxiety for the women. Believing that reconstruction expedites cancer's recurrence or metastasis or perceiving themselves not to be physically qualified for the surgery discourages patients from seeking reconstruction.

Reconstructive surgery in Vietnam is widely perceived as having aesthetic, not therapeutic significance, and entails moral judgements against it. By associating reconstruction with cosmetic surgery, my informants' accounts illustrate the various ways people view the act of restoring an absent breast within local gendered moralities. People widely perceive that seeking reconstruction contradicts the socially acceptable behaviours of selfless women who, according to established values, are expected to fulfil their nurturing and caregiving responsibilities before paying attention to their own needs (Fang, Balneaves, and Shu 2010). Therefore, a woman who does not choose the procedure protects her moral standing since she has put others' well-being ahead of hers, behaved selflessly and sacrificed her personal needs. It is also a proactive decision to uphold social values assigned to women's gender roles as primary caregivers and by doing so, they lose an opportunity to resume a whole body, but maintain their life in order and under control. Their to "do nothing" decision is, therefore, a deliberate act, a form of social action meaningful to the women who make that decision (Scott 2018).

Throughout the life course, a woman's body, including her breasts, invariably confronts pressures to conform. As Yalom (1997, p. 3-4) notes, a woman does not necessarily own her breast because it might belong to child who suckles it, to a man who fondles it, to religious and moral judges maintaining coverage of the breasts, or to the

biomedical sector who recommends mammography and decides when to remove it when a tumour is identified. In Vietnam, women's bodies have been constantly placed under suppression by Confucian-dominated virtues that expect them to be physically attractive only to their husband (Marr 1981), but also by state discourses targeting their bodies as dangerous objects that needed to be concealed during wartime, or controlled by the national population-planning interventions in contemporary times (Khuat et al. 2010). Post-mastectomy women face the social obligation to alter their one-breasted body because it is deemed "physically handicapped," alien to the culturally and socially acceptable version of an ideal female body. Against this backdrop, women who decide against reconstructive surgery affirm their ability to return to normalcy in their post-cancer life and simultaneously perform an autonomous act of detaching their selves from being possessed by others. For them, in refusing to realign with the social attitudes that objectify women and their bodies, the asymmetric single-breasted body has become a site to exercise their agency and reinstate ownership over their own bodies and sense of self.

It is also worth considering the peer network's influences in reconstruction-avoiding behaviours. In the Facebook fan-page of the Courageous Women Club, its administrators often host Q&A information sessions with medical experts and widely share latest biomedical news related to breast cancer, including reconstruction, to its extensive network of members which reached over 7,500 at the time of writing. Nevertheless, the page no longer allows personal posts featuring any case who has undergone reconstruction. According to the executive boards in my personal communication, they were concerned that such messaging might conceal the harms the patients had actually experienced, and that some might use the platform to promote certain surgeons or clinics.

In summary, my findings demonstrated in this chapter expand the scholarship revealing the contextual influences and inter-relational dynamics surrounding women's health-seeking decisions when living with the uncertainty of breast cancer (Lewis et al. 2021; Steinberg 2015) with perspectives from a non-Western research setting. In most Western consumerism-driven societies where the pursuit of treatment attracts greater value than opting out (Greener 2009; Lewis et al. 2021; Sinding et al. 2010), breast reconstruction is particularly framed as essential to cancer survivorship due to its widely-perceived remedial role in enhancing a woman's psychological well-being and quality-of-life, and those who refuse the promise of reconstruction are often faced with negative

labelling as having limited control (see Cromptvoets 2006a; Fang, Shu, & Chang 2013). Questioning the simple classification of reconstruction opt-out as a lack of choice, my findings highlight the complex social process of that decision: women must continuously consider their preferences vis-à-vis knowledge of the surgery's harms and benefits, the cultural ideas of womanhood and femininity, and familial roles and expectations. They must act to exercise responsibility and control in a situation where related services and expertise are limited and unpredictable. In addition, my research also raises doubts towards the assumption based on normative concepts of femininity maintaining that post-mastectomy, all women would desire reconstruction (Naugler 2009). In this regard, my findings have practical implications for the patient-centred approach (Rubin et al. 2013) that respects women's values and preferences, highlighting the necessity to have a balanced view towards non-reconstruction as a social action, not a lack of choice. I share this viewpoint with feminist Audre Lorde (1997) and believe that no woman should be pushed into pursuing such surgery in order to cope with the paternalistic pressures to regain a feminine appearance. At the same time, I do not negate the crucial importance of supporting those who desire the surgery and emphasise that every breast cancer patient should have access to the information and counselling that prepares them for the surgical reality, something Vietnam presently does not provide, as well as appropriate reimbursement of different options whether they choose an immediate or delayed reconstructive procedure.

# Chapter 9.

## Conclusion

As the first ethnographic study exploring women's experiences with breast cancer in Vietnam, my thesis has provided detailed accounts into the striking impacts of this serious illness on the physical, emotional, social, and economic well-being of patients and their families in a low-resourced setting. By situating breast cancer within social context, my research has attended to the formation of breast cancer knowledge and the varying ways people respond to their illness. In doing so, my research contributes a transcultural perspective to the proposition that health and illness are not merely biological entities; rather, they are social facts that are inextricably tied to cultural values, social practices and relationships (Kleinman et al. 1997; Wislkinson and Kleinman 2016); the unequal distribution of economic and social resources (Farmer 2004); and power relations within political economy (Baer et al. 2013; Singer 1990). This concluding chapter reflects upon the major themes throughout my thesis in relation to the three research questions I aimed to answer: (1) How is breast cancer understood among patients and their families? (2) How do patients and their families respond to their illness? and (3) What are the structural social, cultural, and economic factors that shape the understanding and experience of breast cancer? In this chapter, I also describe my contributions to the literature, as well as the broader practical implications for cancer care in Vietnam and other LMIC settings.

Firstly, the construction of breast cancer understanding is predicated upon biomedical knowledge transmitted via public health education, the health sector, peer support network, cultural specificities, and women's situated experiences. In Central Vietnam, people widely perceive that breast cancer is caused by food contamination and exposure to the toxic environment which overlaps with dominant biomedical discourses of cancer risk factors. The understanding related to *karma* or fate that is often mentioned in existing literature on illness causation is less prevalent in this setting. However, laypeople cannot identify themselves in dominant discourses in biomedicine that focus upon individual responsibility for breast cancer but insufficiently speak to people's lived

experiences (Crompvoets 2006a). While adopting biomedical knowledge in their aetiological models, laypeople in my research build their own frameworks to make sense of breast cancer. They relate the development of breast cancer to the collective vulnerabilities caused by structural forces, such as the market economy, modernisation, economic hardships, toxic warfare, or the sufferings of womanhood that resonate with the historical and contemporary circumstances shaping their life experiences.

Breast cancer is understood as a life-threatening condition that requires biomedical interventions to detect and confirm its malignancy status. Unlike a benign breast lump that can be treated with traditional healing methods or left unattended, women widely perceive the critical need to seek medical attention to have the cancerous lump removed immediately with radical surgery because they believe it has many legs and roots which are abruptly and constantly multiplying. In such a belief, people also understand that any procedure that does not result in complete removal of the cancerous breast, for instance, breast-conserving or reconstruction, is not of therapeutic significance, and therefore, should be avoided.

While the ways women make sense of their bodily experiences, such as the discovery of abnormal breast symptoms, are informed by public health messaging calling for early symptom awareness, the interpretations of symptomatic breasts are intrinsically linked to their life situatedness. For instance, women appraise the acuteness of sudden changes in their breasts based on the co-occurrence of other bodily changes or the advent of other important life events, which determines the perceived level of urgency to seek medical advice and examination. Likewise, the perceived curability of breast cancer, despite being influenced by medical discourses which highlight the positive prognosis brought about by early diagnosis, is heavily dependent on their social situations and subject to change according to their observation of the fate of many cancer patients in their kinship or community. Such understanding, therefore, leads to imminent anxiety and shock when women receive a diagnosis of breast cancer as they dread the “death sentence” it may similarly bring to them. Findings on the construction of breast cancer knowledge as explored in my research speak to the concept of “local biologies” (Lock and Kaufert 2001) in a sense that how people make sense of their biological bodies is socially conditioned. In view of this, my thesis invites health interventions to work beyond an image of a standardised body (Merrild, Vedsted, and Andersen 2017) to recognise the inseparability of the physical and social bodies, and meaningfully engage with local

explanatory models in order to influence cancer prevention awareness and early symptom recognition.

The second theme is concerned with the ways women patients and their families manage breast cancer. In perceiving breast cancer as a life-threatening condition that was not common in the past, my participants emphasise the vital need to manage it with radical biomedical interventions rather than traditional methods using herbal medicines or practices. In that sense, women act promptly when experiencing suspicious signs of cancer in their breasts. They navigate through different public and private health facilities to seek medical advice and access diagnostic examination in distant locations when laboratory and imaging services are not available or of sub-standard quality in their nearest vicinity.

When a breast cancer is detected, women and their families devote enormous resources and efforts in accessing urban public hospitals with renowned biomedical technology and expertise so that they can immediately pursue radical forms of surgery and treatment. To put cancer under control and realise their fierce will to live, women and their accompanying caregivers travel extraordinary distances and spend arduous stays in tertiary hospitals throughout their prolonged treatment. Given the tremendous costs and time commitments required to manage breast cancer, but also the physical and emotional treatment after-effects, many women patients have to take long unpaid leave, quit permanent jobs, or withdraw themselves from their everyday waged activities. In this way, following the diagnosis of breast cancer, women are socialised into their patienthood and managing this pathological condition becomes a long-term career.

Throughout the accounts in my thesis describing how people respond to the illness, I have demonstrated the importance of family in the management of breast cancer, thereby highlighting the inter-subjectivity of this illness experience (Kleinman 1988; Wilkinson and Kleinman 2016; Broom et al. 2018). Managing cancer, as consonant with findings from other studies on cancer lived experience in other developing countries (cf. Mulemi 2010; Lora-Wainwright 2013) or in other regions of Vietnam (Stalford 2019), is a family endeavour rather than an individual affair. The family has a central role in encouraging women to seek medical attention at the discovery of symptomatic breasts, making important treatment decisions, providing care and support, and co-shouldering enormous treatment costs, in terms of providing in-cash gifts or preferential loans. Family members also have to deal with the uncertainties and complexities following the diagnosis

and treatment of breast cancer. A patient relies on her extended family who accompany her during hospital visits and provide inpatient care during repeated hospitalisations due to the persistent shortage of professional nurses at most public hospitals. Because of that, the caregivers, likewise, are faced with disruptions in their jobs and patterns of daily living throughout the cancer treatment and care. Their welfare and future well-being are also impacted by the depletion of family resources or the burden of debts to cover costly cancer treatment, which leads them to abandon educational opportunities to take on precarious paths to early marriage or low-prospect employment.

The third theme of my research highlights the importance of context - the wider cultural, social, economic, and political contexts of Vietnam within which breast cancer is lived. Cultural constructions of womanhood and gender roles pervade people's perceptions of cancer aetiologies and care-seeking practices. In Vietnamese society, normative gender ideals emphasise the expectations for women to realise their "heavenly mandate" of childbearing and breastfeeding (Rydström 2006) and protect the nation's population (Gammeltoft 2014). Against this backdrop, it is unsurprising that aetiologies related to a woman's failure to fulfil her womanly destiny as a mother are often narrated among my research participants - a means to reflect moral commentaries on established and modern values. Gender norms regarding women's duties also impact upon community perceptions towards certain forms of medical procedure and influence women's decision-making of seeking care. This is the most resonant when women consider breast reconstruction post-mastectomy. Deemed as a practice only serving cosmetic, but not therapeutic, purposes, women opting for breast reconstruction confront moral condemnation for violating the moral virtues of endurance and self-sacrifice that are expected of a good woman (Gammeltoft 2021). Aware of this widespread judgement, many women forgo the procedure to maintain the status of a good cancer citizen and adhere to traditionally gendered roles.

My research reveals the health system constraints that significantly limit women's access to breast screening services and quality treatment options. Consistent with previous studies (for instance, see Jenkins et al. 2020), my thesis corroborates the absence of a national breast screening program and women's limited access to routine breast care. For the majority of women participating in my research, seeking medical advice for symptomatic breasts is conducted on an ad hoc basis. Most women present for screening after self-detection of a breast symptom rather than participating in any routine program.

Even though some have access to annual health screening as part of their employment benefits, such practice does not involve breast examination with the use of mammography and is often performed in a perfunctory manner. This situation, as we have already known from large-scaled studies across the world, leaves asymptomatic breast cancer or painless cancerous lumps undetected, leading to late presentation and subsequently increasing mortality and the burden of treatment not only for the families but also the health system. My research further points out the limited diagnostic capacity and inadequate laboratory and imaging facilities at lower-level hospitals which causes misdiagnoses or diagnosis delay, and forces women to take a circuitous path often circumventing standard referral procedures in their search for a cancer diagnosis. Considering these, my thesis highlights the urgent need for a mammographic screening program nationwide. The widespread perception towards to importance of biomedicine in detecting and treating cancer as I have identified throughout my ethnography holds the promise for women's high uptake of screening mammography when it is made widely available and accessible.

The social and health inequalities resulting from economic and political forces are nowhere else more pronounced than those produced by the concentration of oncology services and expertise that is skewed in favour of large metropolitan cities in Vietnam. This unequal distribution of resources has disproportionate impacts on patients residing in rural or smaller urban areas because they are inevitably prompted to travel long distances, bear substantial costs associated with their medical travel, and get exposed to multiple forms of disruptions and suffering during the prolonged periods away from home and their social support network. In this way, geography has become a form of structural vulnerability (Stalford 2019) as it constricts the agency of people with this health problem, tightens their choice of diagnostic and treatment options, and significantly interferes with health outcomes, especially for women who need to return to the hospital to treat cancer recurrence or obtain monthly hormone therapy over a long period of time.

In recounting women's experiences with breast cancer, my study has shed light on the various ways that health insurance determines their treatment trajectories. Women speak at length about the importance of securing an insurance card upon the confirmation of cancer diagnosis and how concerns over insurance referrals and coverage regulations permeate everyday practices of managing their illness. While universal health coverage is present in Vietnam, as shown in my current research, out-of-pocket payments are still catastrophic regarding breast cancer-related services. Women with public insurance are

not reimbursed for certain services, partly owing to the widespread practice of bypassing the primary point of care in the patients' attempts to seek timely diagnosis and quality treatment. Even for those who are entitled to the highest rate of insurance coverage, they are still required to pay for high-technology procedures and patented medications, such as ones prescribed to treat HER-2 positive breast cancer or breast reconstruction. Despite Vietnam's highly acclaimed success in rolling out UHI, my thesis has revealed how current coverage regulations complicate treatment decision-making and insurance utilisation regarding oncology care and exacerbate the already-tremendous financial hardship of living with breast cancer. Health insurance-related policies do not only affect patients' cancer management, but also care delivery as exemplified in the cases when medical staff have to consider what to prescribe for advanced-stage cancers because of the costs or selectively provide consultations on reconstructive procedure. In such regards, my findings contribute on-the-ground evidence into the intricacies of the UHI implementation and call for improving primary healthcare and reforming the insurance coverage for chronic acute conditions, which are critical for Vietnam, but also other transitioning countries which progress towards the introduction of universal health coverage and are similarly faced with the growing burdens of NCDs.

The patients' accounts throughout my thesis emphasise the important role of the peer support network in influencing and shaping the knowledge and experiences of breast cancer. The Courageous Women Club exemplifies the emergence of patient activism which unites women diagnosed with breast cancer across the country to come and work together and practice their new biological citizenship (Petryna 2013; Rose 2009). Through online platforms, notably Facebook, and offline activities, similarly to breast cancer movement elsewhere (see, for instance, Sulik 2010; Petersen, Schermuly and Anderson 2019), the support network in Vietnam has contributed to changing the way ill health is perceived by providing a public platform for discussing and sharing women's illness experiences and promoting biomedical knowledge surrounding the disease. The peer support group is also instrumental in forming a new social identity for the women patients, for instance, by normalising the mastectomised body in everyday life, thereby altering the cultural norms regarding the ideal female beauty and challenging the assumptions that perceive a breast loss as a "physical handicap." To show solidarity with their peers in a context where interaction with healthcare professionals and institutional protection are often inadequate, the network mobilises different forms of support for

their members or non-members, such as helping them navigate through complex biomedical spheres or via the provision of in-cash or in-kind assistance. Further research is recommended to explore the engagement of breast cancer activism with healthcare providers and its affects upon the delivery of breast cancer services.

Women's agency constitutes the final theme of my research. While reflecting the systemic constraints facing women's lives with breast cancer, throughout my thesis I emphasise the necessity to pay attention to their experience *in situ* and women's agency in responding to their illness. Women have shown that they are not passive recipients of biomedical information and always strive to carve out meaningful ways to make sense of cancer diagnosis, for instance, when encountering test results with complex unfamiliar medical terms and concepts while having insufficient explanations from their healthcare providers. Women often highlight themselves as active agents of their decisions despite the narrow conditions under which they can make choices. For example, many informants in my research speak of their self-detection of a breast symptom that led to breast cancer diagnosis and their urgent actions to seek medical care rather than depending on a structured screening program. Likewise, when constrained by inadequate insurance coverage and limited accessibility to breast reconstruction information and services, women still make the decisions about their mastectomised body as an autonomous act and with a sense of control — for them, forgoing reconstruction is a social action to challenge existing social gendered norms that objectify women and reinstate ownership over their bodies and sense of self.

Throughout their cancer trajectory, accounts in the preceding chapters suggest that women patients and their families do not lack the agency to act upon their treatment and resume control over their life. This is the most resonant in the circumstance of women patients “from the province” who take individual responsibility to purchase hormone medications from a local pharmacy. As such, they are able to maintain treatment compliance rather than depending on the dispense covered by public health insurance while simultaneously managing the financial risks associated with monthly long trips to the hospital. Additionally, to mitigate the enormous economic burden of cancer care that is beyond their affordability, others resort to pay a bribe or disclose their cancer status to people in their community in an attempt to make themselves qualified for some types of assistance as they navigate through the state's social protection scheme.

In illuminating the nuances of women's agency in breast cancer responses, I highlight that we must attend to and understand how women *act* rather than solely focusing on structural explanations and overlooking any agency assertion. In doing so, I do not however attempt to downplay the plight of women living with this malignancy. Women's coping strategies can only serve to obviate a modest fraction of their burden but cannot avert a crisis. Breast cancer is in the first place an acute condition that presents existential threats and enormous social and economic burdens to diagnosed persons rather than a cosmetically-oriented crisis or positively-transforming life experience – a discourse that has sometimes dominated the constructions of breast cancer knowledge and experience in Western societies (for instance, see Broom 2009; Sulik 2010; Gibson, Lee and Crabb 2014). The development of breast cancer and the rigorous treatment it necessitates to put cancerous cells under control causes psychologically and physically debilitating effects on affected women, rendering them vulnerable to multiple forms of suffering and vulnerabilities. For the women of this study, the pursuit of prolonged treatment to manage breast cancer deprives women of employment and income-generating activities and exhausts household's savings and assets, thereby plaguing their life with uncertainties and burdens. For those whose resources have already been constrained prior to breast cancer diagnosis, the unaffordability of cancer care renders a further form of suffering (Lora-Wainwright 2013) which leaves them with no choice but to resort to “detrimental coping strategies” (Nguyen, K. T. et al. 2012), such as loans with usurious interest rates or depending on social welfare benefits, or foregoing certain forms of treatment. In this respect, breast cancer traps affected families in a cycle of hardship and poverty.

My study has shown that even when treatment is completed and successful, the cost of cancer stays with individuals and families in the long term. As they attempt to prevent the malignancy of this acute condition from further growing, their life is simultaneously re-routed to other malignant situations: the malignancies of immense hardships, of financial catastrophe, and of persistent poverty. Considering this, my research emphasises the precarious status that encapsulates both the failing biologies of the diseased body and the lack of social and financial security shaping the life with breast cancer. The affected women's health precarity (Sargent and Kotobi 2017) is characterised by the unsettled possibility of cancer relapse or progression that pervades their everyday life. It is also determined by their lack of capacity in securing sufficient resources to cover substantial

cancer expenses, which threatens their maintenance of health and chance of survival. Such precariousness is conditioned and intensified by structural forces, including the unequitable distribution of health resources, a present but under-funded public health insurance, a stratified health system, and an erratic social safety net that provides meagre protection against income loss during ill health. Only by recognising the contextual factors that shape the differences in health outcomes and inequalities can we act to reverse their precarious situation, circumvent the malignancies from multiplying, and adopt an effective approach to health and social policy-making that widens the avenues of support for women living with breast cancer.

# Epilogue

I was fortunate enough to complete the last interviews in Hue and return to Australia in late December 2019, just a few weeks before COVID-19 pandemic struck the globe. This thesis was written up amid the swift evolution of coronavirus that has shaken and starkly revealed the multiple structural vulnerabilities in Australia, Vietnam, and the rest of the world.<sup>1</sup> As I am writing the concluding thoughts for my thesis, I look back to the context within which my PhD research was originally designed: it was carried out in response to Vietnam's recent epidemiological transition from communicable to non-communicable diseases. It has been more than 20 months since the first case of COVID-19 was detected in the Chinese City of Wuhan but we do not know how long the pandemic will remain and when countries around the world can return to their pre-COVID states. What we all know is that never before in our contemporary times have we seen such immense impacts on the global economy, healthcare system, and people's lives caused by a single infectious disease. It is also widely known that different governments have implemented unparalleled measures requiring enormous financial, technological, and human resources that have never been deployed to tackle any other communicable disease nor NCD. In this sense, the novel coronavirus pandemic completely reverses the nature of the recent epidemiological transition as this highly transmissible disease is regarded as a health threat that needs to be urgently addressed. In a developing country like Vietnam, managing a pandemic that is evolving rapidly on top of a long, slowly moving NCD epidemic that has yet been properly addressed produces tremendous impacts on the health system and those living with an unresolved NCD condition prior to and during this COVID-19 era.

In 2020, as its northern neighbour China and most countries in the Global North faced the devastating consequences of the pandemic on their economy and health systems, Vietnam prided itself on globally acclaimed success in controlling COVID-19 when only 4,378 cases and 37 deaths were recorded from March 2020 to early May 2021.<sup>2</sup> This resulted from the country's swift action to close its international border at the start of the pandemic, along with strict restrictions on domestic mobility and social distancing measures. However, by September 2021 when other Asian and Western countries are recovering, Vietnam is now crushed by the fourth outbreak starting in May 2021. In less

than four months, the number of total cases rocketed to over 645,000 people and over 16,000 lives were lost.<sup>3</sup>

As the situation worsens, lockdowns have been enforced across the country whereby some of Vietnam's largest regions, such as the Mekong Delta and Ho Chi Minh City with approximately 35 million people, are totally shut down.<sup>4</sup> Military troops are deployed in Ho Chi Minh City – Vietnam's largest financial and economic hub and the epicentre of the COVID Delta strain outbreak. People are ordered to stay at home and must not leave even when they need to shop for food.<sup>5</sup> In other cities where the outbreak is less severe, partial lockdowns are still enforced in certain suburbs, housing complexes, offices, and hospitals.

Such lockdowns and accompanying restrictions profoundly impact care-seeking behaviours and treatment compliance. People are requested to present various types of documentation to multiple checkpoints in order to prove the medical reasons that allow them to leave home. This is particularly challenging for patients from other provinces who need to seek care in a safe zone such as Hue City – where my ethnography was conducted - due to the fences and multi-layer checkpoints which are densely situated around each city and at every province's border, requiring more transits and a greater amount of traveling and waiting time for the patients. It is also likely that many patients cannot get to the hospital to receive medical attention and insured medications when their appointments are due or when they need to access specialised facilities and expertise because hospitals are forced into on-site quarantines sometimes lasting up to a month. The imposition of strict social distancing measures, such as limiting or prohibiting the number of caregivers at hospitals, inevitably disrupts patients' regular care routine given the importance of family members who often accompany them during hospital visits or provide inpatient care during hospitalisation as my thesis described.

Oncology care has been deeply affected during the pandemic. From May to June 2021, Vietnam's National Cancer Hospital in Hanoi, the largest centre for oncology care in Vietnam were put into quarantine after positive cases were detected among patients and medical staff. During this five-week period, all healthcare services, except for the emergency department, were on pause and all people who were visiting or undergoing treatment by the time of the quarantine announcement were banned from leaving the Hospital. Those staying at nearby guesthouses were also affected and locked down. Not only the National Cancer Hospital but also other tertiary and large provincial hospitals

across the country have become mass quarantine sites throughout the pandemic. For this period of time, stranded patients and their caregivers were provided with boarding and meals, but relied on charity donations when they needed nutritious food or other essential health and sanitary products. This was particularly the case of people from other provinces who had no close contact or support network in urban cities.

As the pandemic witnesses unprecedented redirection of healthcare resources to manage its spread, as in almost every other country in the world,<sup>6</sup> it comes with the cost of austerity applied to other medical services that are non-pandemic related such as oncology care. It is estimated that at the peak of the outbreak, over 14,500 medical staff from public hospitals in the Northern and Central regions, including National Cancer Hospital and Hue Central Hospital among Vietnam's largest national-tier hospitals, were deployed to assist medical facilities in Ho Chi Minh City and the Mekong Delta that were specifically built to treat COVID-19 patients.<sup>7</sup> In addition, the diversion of medical equipment, such as ventilators, that these medical staff brought with them to their assignments in COVID-19 struck regions, or funding re-routed from other areas of care to finance the emergent needs of tackling the pandemic has impacted the health system in general.

All these factors have compounding impacts on cancer patients' reluctance to seek care. Fears over transmission risks at overcrowded public hospitals or during their long trips to/from hospital via different modes of transportation were preeminent at the start of the pandemic. Their anxieties were intensified with known scientific findings suggesting increased risk of getting infected and suffering COVID-19 complications for immunosuppressed people or those with underlying conditions like cancer. Despite this, immuno-compromised people like those living with cancer are not regarded as a highly prioritized group in Vietnam's national vaccination programs, which leaves them with inadequate protection from catching the virus and their anxieties unsettled.<sup>8</sup> The occurrence of the pandemic aggravates their concerns to seek care in a timely manner, not only due to the difficulties of travelling and accommodation amid lockdowns and mobility restrictions, but also the stigma that is likely to incur to them when returning to their hometowns after travelling elsewhere to seek medical attention. This situation also has delay implications for people who develop early signs of cancer and require screening and diagnostic services, but reluctantly doing so to avoid visiting any medical setting during the pandemic.

As a result, during these days, public hospitals outside the epidemic like in Hanoi or Hue – my fieldwork site – are unusually quiet with a small influx of patients.<sup>9</sup> From conversations with some of my key informants who live in Hue, their follow-up appointments have become much less troublesome as there is no longer any queue at the reception areas or consulting department as the normal times before the pandemic. On the other hand, they have not seen many of their fellow patients from other provinces, some for more than six months.

As the accounts throughout my thesis have suggested, cancer patients heavily rely on their kinship networks who provide them with financial support to continue with costly cancer treatment and care. While unemployment statistics for 2021 have not been released, we can anticipate the immense loss of income for households, especially rural migrants and informal workers who work in cities like Ho Chi Minh City and Hanoi. During the tough lockdowns in those cities, open markets, street vendors, and taxi services were closed or had to limit their activities, and many factories stopped working due to the breakdown of the global manufacturing chains or when positive cases are detected and the factories became mass quarantine sites. In a context where institutional protection against health and economic shocks is weak, this undoubtedly will force thousands of families to live with hunger and housing insecurity, and stop the flow of remittances to financially support their loved ones back in their hometowns, let alone pay for expensive medical and travel costs to maintain compliance with something like cancer treatment.

As we have seen throughout my thesis, to cope with rigid regulations with respect to the dispensing of cancer medications covered by public health insurance, many women choose to purchase monthly hormone medications out-of-pocket in order to avoid the transportation costs to/from urban hospitals and many of them will have to do so during the pandemic when not being able to visit the hospital. But it is not the case for those who are prescribed with imported brand-name medicines, such as those for advanced-staged cancers. Missing a hospital visit will lead to a discontinuity of treatment because those medications are unaffordable. There are also circumstances that even when patients can afford and are willing to purchase medicines at a private pharmacy, it is impossible for them to do so without presentation at a hospital setting. Such is the case of certain palliative drugs like morphine which must only be prescribed by authorised physicians and can only be purchased at designated pharmacies at a limited dose (usually for ten

days), and the presence of the sick patient is mostly required to do so. During the pandemic when restrictions on mobility are tightened, when their stock runs out, patients and their families become powerless and have no other way but to turn to social media platforms, such as Facebook groups of cancer patients, and ask their peers for some spare drugs to help alleviate their excruciating pain at the end-of-life.

COVID-19 poses unprecedented challenges to the existing health system, but it also offers avenues for change. Hospitals around the country promptly responded to the swiftly evolving nature of the virus by embracing digital healthcare solutions. For instance, Hue Central Hospital where my ethnography took place has launched telehealth and virtual appointments to reduce the burden of traveling for patients from other provinces and to alleviate the overcrowding status at the hospital. With nearly 70 million internet users, online healthcare delivery is promising in Vietnam<sup>10</sup> and in this regard, the pandemic presents an opportunity for rapid reforms towards more efficient operation of the health system. However, to benefit from such reforms, patients critically need access to and basic skills to use computers or smart phones, as well as reliable and affordable internet data which still remain out of reach for a large proportion of the population, especially for low-income residents in rural areas like those who participated in my study. Considering their limited access to communicative technology, it is also challenging for the conduct of timely research to consider the impacts of COVID-19 upon their illness management and truly reflect the magnitude of the burden when living with a chronic acute condition throughout the pandemic.

With over 10,000 cases newly reported a day throughout August and September and the mortality rate of 2.5%,<sup>11</sup> among the highest in Asia and the world, and given Vietnam's vaccination progress among the lowest in South-East Asian region,<sup>12</sup> and a health system that is rapidly running out of resources, pessimistic forecasts of its collapse are growing. As we have seen throughout my thesis, despite Vietnam's remarkable economic growth in the past three decades and recent transition to a lower middle-income country status, its health system lacks the preparedness, resources, and capacity to cope with the changing burdens towards NCDs. Pre-existing challenges associated with infectious diseases of poverty have not yet been properly addressed while other health problems of a transitioning country have already emerged. The current Covid-19 crisis has further exposed the weaknesses of the current health system, extended the vulnerabilities for marginalised groups, and amplified structural inequities in terms of

healthcare access and resource distributions. As it is likely to remain, we therefore do not know when the system will be able to provide the pre-COVID-19 level of cancer care services but we are certain that cancer patients' life conditions and continuity of care will be more precarious and further deteriorated in the foreseeable future.

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<sup>1</sup> See, for example, Team and Manderson (2020); Manderson, Burke and Wahlberg (2021)

<sup>2</sup> Vietnamese Government Portal (2021) *Health ministry confirms 37th COVID-19 death*. Available at: <http://news.chinhphu.vn/Home/Health-ministry-confirms-37th-COVID19-death/20215/43818.vgp> (Accessed: 10 September 2021).

<sup>3</sup> See updates at the Ministry of Health's COVID-19 Portal at <https://covid19.gov.vn/>

<sup>4</sup> AP News (2021) *Vietnam puts southern region in lockdown as surge grows*. Available at: <https://apnews.com/article/health-coronavirus-pandemic-vietnam-958c8f737c497b2330f1af69c84bae18> (Accessed: 15 September 2021).

<sup>5</sup> Reuters (2021) *Vietnam deploys troops to enforce COVID lockdown in largest city*. Available at: <https://www.reuters.com/world/asia-pacific/vietnam-deploys-troops-enforce-lockdown-largest-city-2021-08-23/> (Accessed: 15 September 2021).

<sup>6</sup> See Manderson and Wahlberg (2020) and Greco *et al.* (2021)

<sup>7</sup> Tuổi Trẻ (2021) *Hơn 14.000 cán bộ, nhân viên y tế hỗ trợ chống dịch COVID-19 tại miền Nam (More than 14,000 medical staff assisting to curb COVID-19 in the South)*. Available at: <https://tuoitre.vn/hon-14-000-can-bo-nhan-vien-y-te-ho-tro-chong-dich-covid-19-tai-mien-nam-20210821193850542.htm> (Accessed: 15 September 2021)

<sup>8</sup> According to the Vietnamese government's vaccination rollout plan set out in Resolution 21/NQ-CP, people with chronic disease and people aged 65 and over are only ranked 9<sup>th</sup> out of 11 groups prioritised to receive COVID-19 vaccine. The first five groups are (1) medical staff, (2) government officers tasked with COVID-19 prevention and control, (3) military personnel, (4) police force, and (5) Vietnamese diplomats and their family members.

<sup>9</sup> This also impacts upon hospitals' revenues due to their autonomous status (see Chapter 3 on Vietnam's health system) which puts pressure on medical staff's income and other benefits, according to Van Son (2021) *Bệnh viện, nhân viên y tế cần hỗ trợ khẩn cấp (Hospitals and medical staff urgently need support)*, Tien Phong. Available at: <https://tienphong.vn/benh-vien-nhan-vien-y-te-can-ho-tro-khan-cap-post1373896.tpo> (Accessed: 15 September 2021).

<sup>10</sup> See Ho *et al.* (2021)

<sup>11</sup> Updates on Johns Hopkins's Coronavirus Resource Centre at <https://coronavirus.jhu.edu/data/mortality>

<sup>12</sup> As of September 17<sup>th</sup> 2021, the percentage of Vietnamese population who has been fully vaccinated is only 5.9%, the second lowest among 11 ASEAN countries, only higher than Myanmar (3.3%) and far below the world average (30%) and other countries. Updates at Our World in Data: Coronavirus (COVID-19) Vaccinations [https://ourworldindata.org/covid-vaccinations?country=OWID\\_WRL](https://ourworldindata.org/covid-vaccinations?country=OWID_WRL)

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# Appendix

## **Appendix 1.** Women presented in the case studies

### *Chapter 5.*

**Dương** (Hue City), 47 years old, was first diagnosed with stage II breast cancer in 2015. She lives in Hue with her mother Aunty Huỳnh, younger brother, husband, and two sons. **Dương** is a tailor and also opens a store selling plants and plant pots at home. She loves charity works, which, as she explained to me, is due to her strong beliefs in karma as a Buddhist. Despite her family's tight finance, **Dương** joined many Buddhist temples and via her personal network, donated to the provision of free meals and in-cash assistance to poor patients. Since her cancer diagnosis, she has become even more active after she joined the Courageous Women Club in Hue and serves as an organiser. **Dương** was recently a proud mother when her son achieved high scores to go to high school despite a hard year through the pandemic.

**Xuân** (from Khánh Hòa province), 46 years old, was first diagnosed with triple negative breast cancer in 2015. She did not know her stage at primary diagnosis and could not retrieve any medical records by the time she showed up at the hospital in 2019. Despite opting out of chemotherapy and all follow-up care until the time I met her during my fieldwork, all the tests and scans in 2019 suggested her stable condition and no sign of metastasis. **Xuân** was awaiting her the arrival of her daughter's baby, **Xuân's** first grandchild when I interviewed her for this research.

**Minh** (from Quang Tri province), 53 years old, was first diagnosed with stage II breast cancer in 2018. **Minh** has three grown-up children and has been working at the social policy department within the People's committee of her commune and has helped many war veterans and their families with their application for social security benefits. **Minh** completed eight rounds of chemotherapy at the same time of my ethnography.

**Châu** (Hue City), 41 years old, was first diagnosed with stage I breast cancer in 2015. Working as a teacher at a secondary school, **Châu** is also famous among her peer patients for having the fortune-telling ability. She is also a member of the Courageous Women Club in Hue.

### *Chapter 6.*

Khiêm (Hue City), 45 years old, was first diagnosed with stage II breast cancer in 2018. Despite her busy working schedule as a nurse at a large hospital, Khiêm actively got engaged in community service. Along with her friends and colleagues, she organised many activities raise fund and provided support to people, especially elders, students, and ethnic minorities living in remote, poor areas of Thua Thien – Hue province. Since joining the Courageous Women Club, she became one of its executive members in Hue, and also helped connect peer patients from other provinces with the network. Khiêm passed away in June 2021 after 18 months being treated for liver metastases, after two months since she turned 47. She is survived by her husband and two children.

### *Chapter 7.*

Hồng (from Ha Tinh province), 51 years old, was first diagnosed with stage II breast cancer in 2018. She has three children. Her daughter is married and gave birth to her first grandchild in 2019, by the time we met during my field work. Her two sons still go to school (one at high school and the youngest was about to go to secondary school). Hồng and her husband are farmers and they have orchards where they grow oranges and grapefruits. Hồng often insisted that I bring home some home-grown grapefruits she picked for me whenever we met at the hospital.

Long (from Dak Lak province), 35 years old, was first diagnosed with stage II breast cancer in 2011. Since her diagnosis, Long quit her accounting job and started working for a private beauty salon. In addition, she also ran her own beauty business from her home and was very passionate about giving beauty tips to her friends and peer patients. She passed away in July 2020 after six months being treated for brain and liver metastases, just a few days before her 36<sup>th</sup> birthday in August. Long is survived by her husband and a 12-year-old daughter.

### *Chapter 8.*

Hải-Anh (from Hải Dương), 37 years old, was first diagnosed with stage I breast cancer in 2016. Hải-Anh lives with her son and two daughters in a semi-urban district while her husband is often away as he works overseas. In her spare time, Hải-Anh loves singing karaoke with her siblings and daughters. Since her reconstruction surgery, she has made

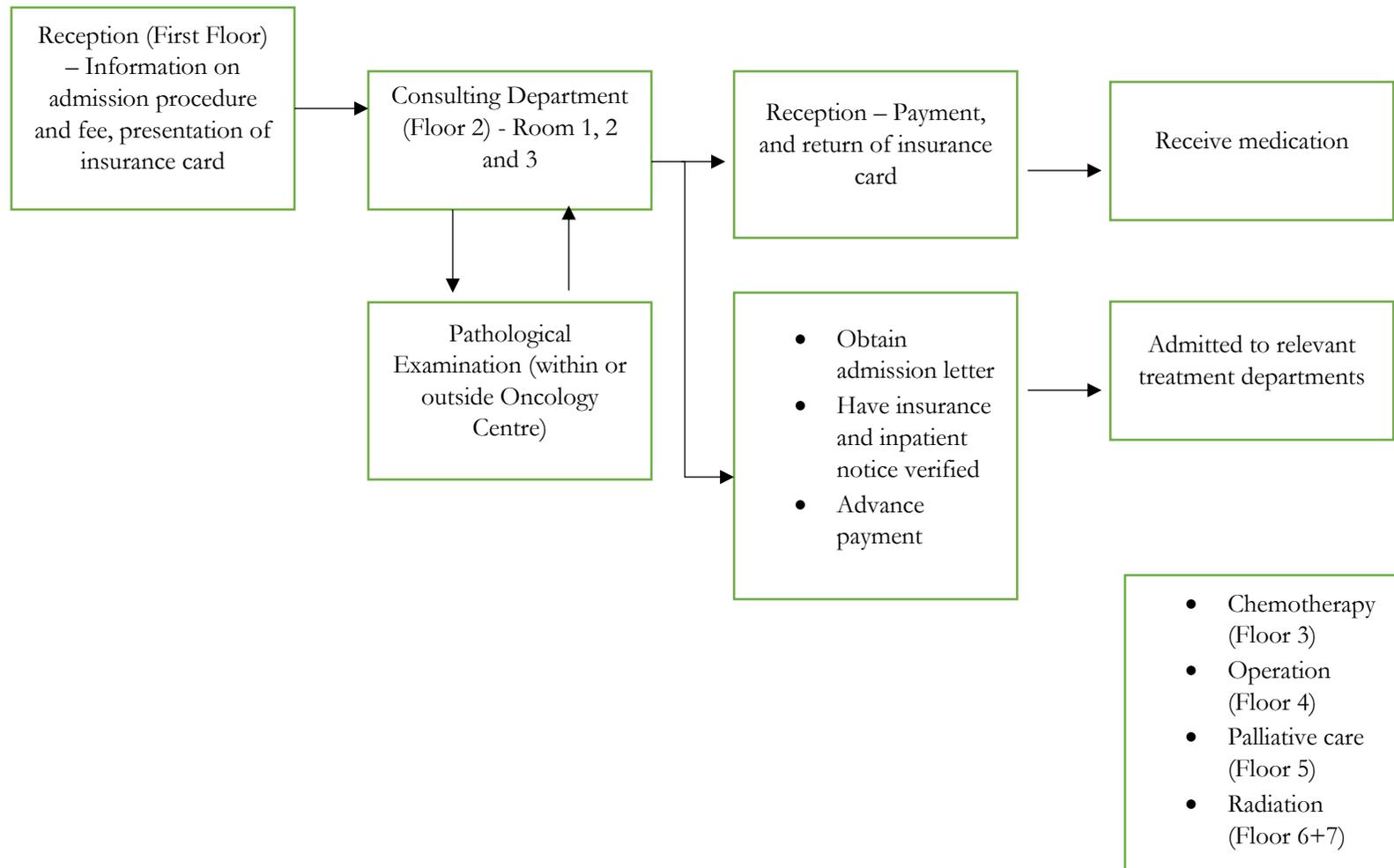
many friends with peers across the country and avidly shared her stories with anyone who is considering the procedure.

**Appendix 2.** Key performance indicators of Oncology Centre 2016-2018

<b>Number of enrolled patients</b>	<b>2016</b>	<b>2017</b>	<b>2018</b>
<i>Inpatients by department</i>	8,836	12,138	18,154
Surgery	1,424	1,715	2,650
Radiation	1,746	1,977	3,423
Chemotherapy	4,365	6,048	8,511
Palliative care	900	2,167	3,570
<i>Outpatients</i>	3,418	2,022	4,172
<i>Underwent treatment of breast cancer</i>			
Mastectomy and lumpectomy	271	294	255
Breast reconstruction	7	17	23
Chemotherapy		905	1,968
Radiation		186	392

*Source:* Oncology Centre (2019)

**Appendix 3.** Treatment and consulting procedure at Oncology Centre - Hue Central Hospital



#### **Appendix 4.** Five vignettes used in FGDs

*Problem statement:* In the second part of our discussion today, I would like to introduce some stories of the women and men I have recently met in my research at various hospitals. These people may remind you of people you know. Their names are changed but the stories replicate real people and situations.

##### **Story 1: Hòa and Cộng**

Hòa and Cộng who are both from the district of Hương Trà have been seeing each other since they went to university together. They have now graduated and found good jobs in Danang City. They plan to get married soon.

One month ago, Hòa's mother was suddenly diagnosed with breast cancer during a regular check-up. Cộng was told about her status but he is now confused as to whether or not he should tell his parents because they are planning his wedding.

*What do you think Cộng would respond when they are informed about Hòa's mother? Do you think they might change their mind about their son's marriage?*

##### **Story 2: Hạnh**

Ms. Hạnh is an officer in a public insurance agency. She is 36 years old and married with two children. Her daughter is 8 years old and now at Grade 4. Her youngest child is a boy who is 18 months old. Hạnh's husband works for the military. However, he can only visit her and the children every two months.

Two months ago while breastfeeding her youngest son, Hạnh discovered a small lump on her left breast.

*What would you advise her if you were her relatives or friends?*

Within two months, she visited the National Cancer Hospital for a check-up and was later diagnosed with breast cancer. Hạnh was shocked but the doctor reassured her that her cancer is not invasive and as the tumour was quite small, she could choose to have either: (1) a lumpectomy to remove the tumour and preserve her left breast or (2) a mastectomy to remove the whole breast. The doctor told her both options were equally effective in terms of removing the cancerous tumour.

Hạnh was confused and told the clinician that she needed to consult her husband and other family members.

*What do you think her husband Đức would advise her and react?*

*What would you advise Hạnh if you were her relatives or friends?*

### **Story 3: Xuân**

Ms Xuân, 53 years old, is married with two children. Both of them are grown up. She now resides in Phong Điền district with her husband.

Five years ago, Xuân was diagnosed with breast cancer and underwent a mastectomy to remove her right breast. Now her health is stable and she can live as normally as before her diagnosis. However, Xuân often feels insecure about her appearance because of the breast loss.

Her household is not very wealthy, but they can make ends meet. They have settled all the debts they previously borrowed to pay for Xuân's treatment.

Xuân heard that Hue Central Hospital has performed many operations to restore the breasts for breast cancer patients like herself. It costs around 45 to 50 million VND.

*What would you advise Xuân if you were her relatives or friends? Should she go for that reconstruction surgery?*

### **Story 4: Liên**

Liên, 28 years old, is married with a 3-year-old daughter. Last year, when she was in her fourth month of gestation, she found a lump in her breast. She went for a breast screening and was diagnosed with late stage breast cancer. She was advised to be hospitalised immediately and receive radical treatment. Her doctors also told her that if she continued to carry her pregnancy to full term, it would be dangerous for both her and the baby. However, Liên does not want to abort her unborn son and hoped she could still carry on until she goes into labour.

*What would you advise Liên if you were her relatives or friends?*

### **Story 5: My**

27-year-old My is an employee for a large textile factory in HƯƠNG TRÀ. My has a daughter who is 6 years old and about to start primary school. Three years ago, My went for a breast examination and was diagnosed with breast cancer. After successful treatment, including a mastectomy and several rounds of chemotherapy, My could go back to work. However, now she however continues to take hormone medications for at least another two years to prevent cancer recurrence.

Vũ, My's husband, is the only son in his birth family. Therefore, My's mother-in-law wants her to bear another son and continuously reminds her of this wish. However, for My, if she wants to get pregnant and give birth, she will have to cease the hormone medications, which will increase the risk of cancer relapse. My personally does not want to have more child and wants to focus on taking care of her only daughter and complete her cancer treatment.

*What do you think about her mother-in-law's wish and behaviour?*

*What would you advise My if you were her relatives or friends?*



**THƯ MỜI  
PHỎNG VẤN  
Nghiên cứu:  
Tìm hiểu về bệnh  
Ung thư Vú**

Trong thời gian này khi đến Trung tâm Ung bướu - Bệnh viện TW Huế, Ông/Bà có thể gặp chị Đỗ Thu Trang. Chị Trang là nhà nghiên cứu đến từ trường Đại học Tổng hợp Monash (Úc) và đang thực hiện Nghiên cứu cùng Cán bộ Y tế và Bệnh nhân. Được sự đồng ý của Trung tâm Ung bướu, chị Trang có mặt tại bệnh viện để tìm hiểu về quá trình thăm khám, điều trị cũng như những vấn đề mà bệnh nhân ung thư vú gặp phải.



**NGHIÊN CỨU VỀ VẤN ĐỀ GÌ?**

Nghiên cứu về *Cuộc sống của Bệnh nhân K vú* tìm hiểu quá trình điều trị và sống chung với bệnh ung thư vú, từ đó đưa ra những đề xuất cải thiện chất lượng cuộc sống cho bệnh nhân.

**AI CÓ THỂ THAM GIA?**

- ✓ Bệnh nhân Ung thư Vú hoặc người nhà của bệnh nhân Ung thư Vú
- ✓ Điều trị tại Huế
- ✓ Từ 18 tuổi trở lên

**TÔI SẼ THAM GIA THẾ NÀO?**

Trường ĐH Monash sẽ sắp xếp một cuộc phỏng vấn với Ông/Bà vào thời gian và địa điểm được Ông/Bà chỉ định. Sự tham gia của Ông/Bà là hoàn toàn tự nguyện và sẽ không ảnh hưởng đến kết quả điều trị của Ông/Bà tại bệnh viện. Tất cả thông tin Ông/Bà cung cấp sẽ được bảo mật theo đúng quy định của trường và chỉ sử dụng cho mục đích nghiên cứu mà không được phép tiết lộ với bất cứ một bên thứ ba nào.

Nếu Ông/Bà quan tâm và có thể tham gia vào Nghiên cứu, xin vui lòng nhắn tin hoặc gọi điện tới số điện thoại của chị Trang: 098 3988 815; hoặc có thể gửi email tới [thu.do2@monash.edu](mailto:thu.do2@monash.edu).

**Appendix 6.** Costs of major services related to breast cancer screening and diagnostic services offered at Hue Central Hospital (*As of November 2019*)

<i>Service</i>	<i>Cost (VND)</i>	<i>Remarks</i>
Consultation	39,000	
Ultrasound	44,000	both breasts
Mammogram	160,000	per breast
Biopsy	144,000	
Sentinel Lymph Node Biopsy	2,143,000	
Ultrasound-guided Biopsy	808,000	
Magnetic Resonance Imaging (MRI)	2,336,000	
SPECT/CT scan	886,000	per breast
PET/CT	20,114,000	

## **Appendix 7.** A snapshot of breast cancer treatment stages

This section describes the various stages of treatment for breast cancer stretching over long periods of time experienced by the patients I encountered during my ethnography. For a large number of my informants whose cancers were diagnosed mainly at stage II or III, a typical pattern of primary treatment started with a lumpectomy during which a specimen of the tumour was excised and sent for laboratory tests. Based on the test results, another surgery followed which might be a mastectomy or an extended lumpectomy in combination with lymph node dissection. After the mastectomy, patients were usually required to stay at the hospital for two to three weeks in the post-op department as inpatients.

Subsequently, most cancer patients enter several cycles of chemotherapy and each starts with a week of hospitalisation. On Monday, the first day of each cycle, the patient must register to be admitted to the Central Hospital as an inpatient if she is from a location apart from Hue City and does not have accommodation outside the hospital. This registration for hospitalisation often requires a patient to present themselves with necessary documents, most importantly their health insurance card and transfer documents approved by local levels. Patients must also pay an advancement to be admitted, part of which will be returned to them at the end of their stay should the factual medical and hospital costs be below the payment. After admission, the patient will have her blood sample collected, usually on Monday afternoon. Based on the blood tests, some patients will require an injection to boost their blood counts the next day which makes them qualify for receiving chemotherapy. Those who already have adequate blood counts will stay for a rest. Some of them might receive traditional herbal therapies at another department which help with muscle pain and insomnia. Wednesday and Thursday are the two days when chemotherapy is given, intravenously in most cases. On Friday, a patient is administered and if her condition is stable, she is allowed to leave the hospital upon the completion of all the administrative paperwork and payment. The same procedure is applied for those who have a place to stay during their therapy, for instance, residents in Hue, except for the first two days when they are not required to stay at an inpatient department. Some also choose to leave hospital during the night during Wednesday and Thursday. Then the patient goes back home and returns in two weeks for the next cycle. The interval between the two cycles is usually three weeks. Most patients I interviewed in my fieldwork underwent eight rounds of chemotherapy following mastectomy, which

altogether lasted for roughly six months. Several received four rounds and a few had chemotherapy prior to their mastectomy which helped reduce the size of the tumour before surgery took place.

Some patients are given radiotherapy at the time of the surgery while others need an additional period of hospitalisation to receive their full regimen which often includes five sessions of radiotherapy a week and lasts for up to two months. Again, patients from locations other than Hue mostly have to stay over the course of their therapies. Patients suffering burns or soreness as a result of radiation might need a longer stay at the hospital to obtain additional care.

When the primary treatment is completed, patients with positive-hormone-receptor breast cancer start to take oral medication every day for the next five to ten years. Younger patients who have not gone through menopause receive an injection that suppresses their ovaries on a monthly basis. Those who require targeted treatment due to their HER2-positive status, need to return to hospital back and forth for a year.

A follow-up care procedure is subsequently advised on a quarterly, semi-annual, and annual basis respectively in the first two, three, five years and thereafter since their primary diagnosis. For each appointment, a patient needs to present at the hospital for a day to take several tests (including physical examination, blood tests, chest and abdominal ultrasound, and X-ray) that help assess their overall health status and identify any sign of recurrence or metastasis. More specialised testing and examination might be required in certain cases depending on the patient's health status and in such cases, often require longer visits.