INDONESIAN WOMEN DIAGNOSED WITH BREAST CANCER: A HERMENEUTIC PROCESS

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Abstract

Breast cancer is a life-threatening disease that occurs worldwide. It has the potential to create disharmony and imbalance in the lives of people diagnosed with cancer and their family and friends. These experiences, however, differ across nations. In terms of presentation for diagnosis there is a great deal of evidence that women in developing countries present at the more advanced stages of the disease. In Indonesia, in 2012, breast cancer constituted 43.3% of diagnosed malignancies (Ministry of Health Republic of Indonesia, 2015). The delay in diagnosis also means late onset of treatment. Perceptions of illness and the impetus to act are indeed complex issues where symptoms may be perceived a normal event or a trivial process. Little is known about Indonesian women with breast cancer; how women come to seek treatment, the process of decision-making around treatment and the experience of being diagnosed with breast cancer. An assumption of this research was that the experience of breast cancer was interrelated with the social and cultural contexts wherein women are situated.

The purpose of the research was to construct a hermeneutic understanding of Indonesian women diagnosed with breast cancer. In-depth, audio-taped interviews were conducted with 28 Indonesian women with breast cancer. The tradition of hermeneutic theory, grounded in Gadamerian philosophy, guided the data generation, analysis and interpretation. The analysis engaged with the temporal interpretive processes central to hermeneutics. The interpretation centred on the positioning of the women participants in their worlds and how this shaped responses to self-expectations and the expectations of others. Underpinning this process were three related sub-interpretations: collective decision-making, social positioning of women, and changing identity. Further analysis was undertaken that generated an overarching interpretation: the temporal experience of breast cancer.

The analytical findings of this research generated a conceptual framework that illuminates the dimensions of the decision-making processes engaged by Indonesian women with breast cancer. The research findings emphasise the importance of bringing a lens that juxtaposes the social, cultural, and historical realms to the experience of Indonesian women diagnosed with breast cancer. Managing the broader implications of having breast cancer for Indonesian women based on cultural, historical, and traditional situatedness is recommended as a focus for future research.

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List of Abbreviations

CSG : Cancer Support Group

LGFB : Looking Good Feel Better

WHO : World Health Organisation

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Statement of Original Authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

QUT Verified Signature

Signature:

Date: 30 August 2017

Chapter 1: Introduction

1.1. Introduction

Cancer is a global disease and across the world it is estimated that, each year, more than 8 million people die from cancer and approximately 14 million people are diagnosed with cancer (WHO, 2015). In developing countries, where there are far higher mortality rates from this disease globally and in 2011, 508,000 women died of some form of cancer (Ferlay et al., 2014). Of relevance to this research is that breast cancer is the most common cancer experienced by women in both developed and developing countries (Ferlay et al., 2014). The research reported upon here explored, through a hermeneutics lens, the ways in which breast cancer was experienced by Indonesian women. This chapter addresses an overview of breast cancer in the Indonesian population and related health behaviours; thus, providing a rationale for the undertaking of this research. A brief description of the theoretical framework is provided and an outline of the research aim and research questions. The chapter also engages with the concept of researcher reflexivity as it related to the research, the significance of the work indertaken and finally, the contribution that the research makes to the development of knowledge around the phenomenon of Indonesian women diagnosed with breast cancer is noted.

1.2. Breast Cancer: A Global Perspective

In Indonesia, breast cancer is the leading cause of all female cancer related deaths and in 2014, these deaths reached 1.41% of total female deaths (WHO, 2016a). However, it should be noted that there is no cancer register in Indonesia and it is probable that the actual incidence of any type of cancer is understated. The incidence of breast cancer has generally been determined retrospectively through pathology reports and hospital admission databases. Based on an earlier audit of pathology reports by Tjindarbumi and Mangunkusumo (2002), the Indonesian incidence of breast cancer in the years 1988 and 1989 was found to be between 18% and 19% of all cancers. Breast cancer was identified as the most frequent primary cancer in women during this period, with the majority of cases in women aged between 40 to 49 years (Tjindarbumi & Mangunkusumo, 2002). In 2009, breast cancer became one of the top ten malignancies in Indonesian women and the cause of the most cancer related deaths of Indonesian women (Ministry of Health Republic of Indonesia, 2013).

Indonesian women frequently present with breast cancer at a late stage of the disease, which is termed Stage 4 or advanced metastatic disease. Stage 1 is the first and earliest stage of the disease process (Harmer, 2011). The finding on delayed presentation is the outcome of a study by the Dharmais Cancer Centre in Jakarta (2010), Indonesia, which examined the stage women presented with breast cancer. The study found that, in 2010, 32% of females presented at Stage 3 and 47.2% at Stage 4 (Dharmais Cancer Centre, 2010). The reason for ultimate presentation was the need for medical assistance for breast wound care of open, spurious (weeping/purulent/smelly), breast wounds (Dharmais Cancer Centre, 2010). In Indonesia, while breast cancer incidence is comparable to developed countries, the mortality rate is higher (Moore, Yoo, Tuncer, & Sobue, 2010). There are no clear or definitive documented reasons for why Indonesia woman present so late for a diagnosis of breast cancer. Late presentation may be due to a lack of general population health education about breast care/cancer; the absence of systematic cancer control programs, including mechanisms to ensure early detection of breast cancer; or a propensity to first turn to traditional health treatments before assistance is sought from more established Western medicine practice.

1.3. Indonesia (Background)

1.3.1. Demography

Indonesia is an archipelago country located around the equator in the Southeast Asian region. Countries to the north of Indonesia are Thailand, Singapore and Malaysia and to the South and South East are Timor-Leste and Papua New Guinea. According to the WHO (2016b), the Indonesian population was approximately 257.564 million in 2015, with females slightly underrepresented compared to males. The longevity of the population, however, favours women whose average life expectancy is 74 years compared with 68 years for males (Aziz, 2009).

Figure 0.1. The Map of Indonesia
(Source: http://www.worldatlas.com/webimage/countrys/asia/id.htm)

Indonesia is a democratic country with a secular elected government. It is rich in ethnicity, with more than 500 Indonesian ethnic groups. Indonesian women are a heterogeneous group based on ethnicity, education level, political interest/affiliation, and socioeconomic status. While there are many different languages indigenous to Indonesia, as well as hundreds of local languages, Bahasa Indonesia is the official national language. Moreover, the vast range of traditions and cultural values make it difficult to generalise anything meaningful amid such diversity. The largest ethnic group is the Javanese and these people tend to reside in Central and East Java. The second largest group is the Sundanese, located in West Java and other smaller ethnic groups reside in Celebes (Sulawesi), Sumatra, Bali, and Papua (Poerwandari, 2005). There are a few other ethnic groups amid the Indonesian population, with those of Chinese origin constituting the highest proportion, at approximately 1.2% (Ananta, Arifin, Hasbullah, Handayani, & Pramono, 2013).

In terms of religion, Indonesia consists of a plurality, with the majority of Indonesians identifying as Muslims (82%), and the remaining 18% made up of Protestants, Catholics, Hindus, and Buddhists (Central Bureau of Statistics Indonesia, 2010). These religious differences influence society's norms and values and make it particularly difficult to provide a single picture that represents the position of Indonesian women generally.

1.3.2. Cultural and Social Life

As evident from the above, Indonesia is one of the most ethnographically diverse countries in the world and it is therefore difficult to define an Indonesian culture. As a country rich in myth and legend, Indonesia possesses an extraordinary range of belief systems and material culture. These diverse cultures influence people's health and illness behaviours, such as how illness is perceived (Degner, Hack, O'Neil, & Kristjanson, 2003). In Indonesia, for example, it is common for certain foods, including eggs and fish, to be restricted when people have had an operation, because it is perceived that such foods will delay wound healing and overall recovery (Ranjabar, 2013). Thus in many ethnic groups, cultural beliefs influence health practices. These ethnic cultural beliefs can also attribute specific causes to some diseases. Some ethnic groups believe that disease is caused by supernatural or mystical beings and that treatments therefore must be based on the supernatural (Fanani & Dewi, 2014; Putriyani, 2013).

In some parts of Indonesia, there are also strong beliefs in traditional medicine. In Java, traditional healers are referred to as ‘dukun’ and the dukuns provide treatment with ‘jamu’ (herbs) that are sometimes combined with magical or spiritual activities (Rahayuwati, 2002). In many cases, where people have not made partial, or any, progress using traditional treatments, they will then seek treatment from more Westernised health professionals generally presenting at a more serious or later stage of an illness. It may be that this health-seeking behaviour is an important factor associated with the incidence of late diagnoses of breast cancer.

Indonesian culture is essentially collectivist in nature. The people have a shared communal life and value a sense of oneness, togetherness, and living in harmony (Rahardjo, 1994). The Indonesian lifestyle is strongly influenced by ethnicity and religion. This is reflected in everyday life, for example, in language. Different ethnic groups have their own dialects which are used for daily conversation. Ethnicity also influences diet. Muslims are forbidden, by religion, to consume certain items, such as pork and drinks containing alcohol as stated in the Qur’an Verse Al Baqarah 173 and ; Al Maa’idah 90 (Ministry of Religion Republic of Indonesia, 2006a, 2006b).

1.3.3. Women’s Movement

It is significant that in Indonesia and in the late 19th century, Indonesian women organised and institutionalised a movement focused on women’s rights. This movement has since evolved into a number of different movements that continue to be active in this country (Parawansa, 2009). The women's movements sought to influence policy agendas through involvement in the constitutional election debates, and as a result, women gained the right to vote in the first elections in 1955 (Bessel, 2004).

Following the Proclamation of Indonesian Independence on August 17, 1945, some political parties developed women's organisations (Bessell, 2004) which came to be of central importance in reifying nationalist ideology and sentiment. However, the government instituted regulations which did not favour women and women's issues became marginalised as a result. For example, in 1952, the government, through the Ministry of Religion, promulgated Regulation No 19 which strengthened the polygamy policy even though women engaged in street demonstrations and protested against this regulation and the practice of many years (Blackburn, 2004).

During the long period of authoritarian rule under Soeharto's New Order (1966-1998), the government played an important role in determining the status of women in Indonesia. The government propagated the view that ideal women were devoted wives and self-sacrificing mothers (Brenner, 2011). The role of a mother, or 'ibu', was a status symbol of priyayi (modern educated Javanese) women. As ibu (mother), a woman has dual roles that ensures she not only cares for her children but also participates in supplementing the family income and hance at the one time contributing to family and national productivity (Djajadiningrat-Nieuwenhis, 1987). Indonesian women were, therefore, considered good ibus (mothers) if they performed these dual roles (Pitaloka, 2014).

In the contemporary context, gender relations and patriarchal norms in Indonesia are shaped by social, economic, and cultural factors, or events that have converged with historical developments (Hapke, 2013). Patriarchy is a dynamic and complex entity and therefore has developed in different ways in distinct socioeconomic and political situations (Elboubekri, 2015, p. 27). Since, the fall of the Soeharto regime in 1998 followed by political transition, women have openly fought for representation within the formal processes of decision-making (Bessell, 2004).

According to the patriarchal tradition, male domination is legitimated in various sectors of life and legitimation of women very much occurs in domestic and household roles. The views derived from gender stereotypes and beliefs reproduce gender inequality in various sectors, both private and public. Women are identified with the private or domestic sector (Koentjaraningrat, 1985). While Indonesian women assume greater responsibility for looking after family members, those women have limited autonomy and less power (Adamson, 2007; Jejeebhoy & Sathar, 2001; Stoler, 1977).

Furthermore, the conditions that dominate the patriarchal tradition permeate decision-making. Decision-making about health programs and/or treatment is often a matter for all family members, not just the woman with breast cancer, not least because women are caregivers who are responsible for their family’s health (Sharan, Ahmed, & Strobino, 2005). A not uncommon story would be of a woman finding a breast lump a year or more before a formal medical diagnosis. The woman may know something is happening in her breast and conduct breast examinations regularly to monitor, or evaluate, any change to the lump. If it does not progress she may not worry. If there are changes to the lump and it appears to grow larger, she may feel afraid to visit the doctor to check on the status of the lump. Where the doctor alerts her to the status of breast cancer and that she should have surgery as soon as possible, she may be surprised. Any decision for treatment may then depend upon the woman’s mother and/or husband which reflects the patriarchal family system in Indonesia.

1.3.4. Breast cancer and West Java

West Java, the location for this study, has the largest population in Indonesia. Based on the population census of 2015, there were approximately 46.7 million inhabitants with 49.3% of women living in West Java (Statistic of Jawa Barat, 2015). Of concern is that approximately 0.5% of women have received a diagnosis of breast cancer and it is predicted that 9.6% of young women in West Java are at risk of developing breast cancer. During the year this study commenced, 2009, and in the Hasan Sadikin Hospital (900 bed capacity), which is the top referral location for breast cancer in the province, 6,170 women sought treatment for cancer and 613 (10%) of this group sought treatment for breast cancer (Hasan Sadikin Hospital, 2009).

In an attempt to address the issue of late diagnosis of breast cancer, in 2008, the Ministry of Health introduced a Breast and Cervical Cancer screening program in West Java (Dharmais Cancer Center, 2010). This was piloted in eight Districts at eight Primary Health Centres under the coordination of Dharmais Cancer Centre, Jakarta and the National Cancer Centre. The goal of this project was to increase the early detection of breast cancer and cervical cancer detection through a screening program. Findings from the pilot study of the program indicated that the majority of women with breast cancer who were seeking treatment were in the later stages of the disease. The outcome of this pilot led to the development of programs targeted at improving the prognosis of breast cancer patients, through earlier detection and treatment (Dharmais Cancer Centre, 2010). The result is that the Breast Health Foundation has developed and implemented a program in West Java designed to promote the early detection of breast cancer, with an aim of detecting the disease breast cancer at stages one or two, rather than at stages three or four, as is currently the case.

1.3.5. Indonesian Health Care System

In Indonesia, there are two pathways for seeking health care. One is for people employed by the government or from low socio-economic backgrounds. All health care for these people is free (Pinto, Masaki, & Harimurti, 2016). Those considered to be from high socio-economic backgrounds must pay for all their health care and there is no national health insurance scheme in Indonesia. However, the latter group has more flexibility in choice of health care including the privilege of choice of doctor and hospital treatment. This group of people can go either directly to a government hospital (and pay for care) or a private hospital. Those whose health care is free must initially seek medical assistance from their local community health centre and get a referral to a government hospital. As most women with breast cancer present at a late stage, often with open wounds, they place a significant burden on the health care system in terms of higher costs for the delivery of health care. Health care cost is obviously greater for treatment of advanced breast cancer where the condition is more complex than treatment for early breast cancer (Harmer, 2011).

1.4. Impetus of the Current Study

1.4.1. Researcher Perspective: Caring for Women with Breast Cancer

My interest in breast cancer was triggered, not only by the lack of local statistical data, but also my professional experience as a nurse caring for women with breast cancer. I have had four years of experience in the medical ward for women at Hasan Sadikin Hospital which is devoted to caring for people with chronic diseases, including women with breast cancer. Many of the women who presented for treatment were in the advanced stages of breast cancer. Some appeared with open, weeping, infected wounds and were diagnosed at advanced stages of breast cancer. These wounds limit treatment options. Infected, swollen wounds bleed easily and surgery is generally not indicated in these situations.

As a nurse caring for women with breast cancer, my duty was to care for those women during chemotherapy and radiotherapy and in the management of their breast wounds. Treatment was conducted in a general ward and not in a specialised cancer unit. A range of difficulties confronted these women, including treatment side effects such as nausea and bleeding, suppurating wounds that produced foul smelling odours. Sometimes these women conveyed to the staff caring for them that they were embarrassed and reluctant to interact with others due to a lack of self-confidence, physical exhaustion, nausea, vomiting, and gradual loss of hair. A number of women contemplated discontinuing treatment because of the distress associated with side-effects. Being witness to these problems and to the range of difficulties facing these women became the catalyst for my interest in researching this area.

As a result of caring for and knowing that women experienced breast cancer as a challenging life event, and my previous personal experience, my interest was in exploring the experiences of women diagnosed with breast cancer. In Indonesia, this is an area requiring urgent research,as many women are diagnosed at late stages with advanced disease.

Through a University of Padjadjaran Research Centre grant, I had the opportunity to conduct a qualitative study exploring the spiritual experiences of women with breast cancer in the Hasan Sadikin Hospital (Pahria, Agustina, & Kurniawan, 2007). Findings from this study revealed that the participants struggled with many aspects of their daily life. These included receiving a diagnosis of breast cancer, confrontation with their own mortality, changing family roles and relationships, reviewing their sense of self as a woman, and re-engaging with friends and the broader community.

1.5. Researcher Reflexivity

Reflexivity refers to “the process of continually reflecting upon our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings and our investment in particular research outcomes” (Finlay, 2003, p. 108). Reflexivity can also be understood as a potentially valuable tool in order to examine the impact of the researcher’s position and perspectives (Finlay, 2003). In other words, reflexivity means deliberately taking different positions during the process of the research to see what alternative conceptualisations might be possible to achieve during the interpretation process.

One important element of reflexivity is positioning oneself socially and emotionally in relation to participants (Mauthner & Doucet, 2003). Regular meetings with supervisors enhanced my ability to be more reflexive about what had been my response when encountering a problem during the research process. For example, it was important to acknowledge my insider status as an Indonesian woman during the analysis process. As Grosz (1995, p. 13) argued “the author’s intentions, emotions, psyche, and interiority are not only inaccessible to readers, they are likely to be inaccessible to the author herself”. Thus, in the research and in the co-construction of data, I was actively engaged with the participants and particpated in an ongoing dialogue with my pre-understandings as an Indonesian woman, with data, with existing literature and through discussions with supervisors. I interrogated every aspect of every phase, not simply assuming one position, but considering a number of different explanations for interpretations. In Gadamer's (2004) terms, the concept of fusion of horizon facilitates and reinforces a reflexive approach. I deliberately considered alternative interpretations rather than assuming a pre-understanding as an immediate lens to the interpretation. The process of considering alternative interpretations was facilitated through extensive reading on the relevant areas and issues (concepts) and also through regular meetings with my supervisors.

Furthermore, during the analytical process, I realised the importance of the concept of gender. It was because I was embedded in the Indonesian culture and considered my role as a woman in Indonesian society as the norm that I was not sensitised to issues surrounding gender early in the research. As such, I shifted my thinking a number of times during the research process. Previously and through my particular lens I could not see that how women's roles were constructed and acted out raised any serious issues because I had been exposed to this social phenomenon for a long time and, in fact, for the whole of my life. What I perceived was normal I assumed was a shared norm even beyond my cultural context. I had never faced a critical situation such as breast cancer that demanded that I make complex decisions. What I understand now is that different contexts will give rise to different meanings and interpretations. Even though the participants and I may have had things in common, such as a shared language, history and tradition, this did not necessarily translate into an in-depth understanding of being an Indonesian woman with breast cancer. Indeed, there must be bias in interpretation. Prejudice for Gadamer (2004) was inherent to interpretation. However, the hermeneutic Gadamerian (1976) framework sustained some coherent rigour in the research. For example, the role of pre-understanding is very important in the interpretation process and yet is also dominant in the interpretation process. In the application of the concept of the fusion of horizon, the researcher's pre-understanding fused with participant voices and also with other information to produce new understandings. Further knowledge that became part of the fusion of horizon was brought to the research process through extensive reading.

1.5.1. Theoretical Framework

A Gadamerian hermeneutical theoretical frame work underpinned this research (Gadamer, 2004). The key tenets of the framework are the concepts of proposition, hermeneutic circle, language, the fusion of horizon, and temporality. The theoretical lens was extended to incorporate the concepts of identity, gender, and culture which were perceived as important to an interpretation of the research context and focus.

1.6. Aim of the Study

The aim of this study was to construct an understanding of being an Indonesian woman diagnosed with breast cancer.

1.7. Research Questions

The central research question of this study was: What is the experience of being an Indonesian woman diagnosed with breast cancer?

Additional questions were used to guide the interview process:

How do women interpret being diagnosed with breast cancer?

How do women respond to the experience of breast cancer?

How do women perceive themselves as women with breast cancer?

What are the processes involved in constructing an understanding of being an Indonesian woman diagnosed with breast cancer?

How are the meanings and identities of a woman diagnosed with breast cancer shaped through the experience?

1.8. Significance of the Research

The findings of the study have the potential to provide new insights and understandings of the lived experience of being an Indonesian woman diagnosed with breast cancer, given that this area of research has not been undertaken previously.

A plethora of research has been undertaken on breast cancer and has concentrated primarily on the experiences of women in developed countries, without consideration of the social and cultural context as a main exploration of the research. Culture plays an important role in women’s health and their illness experience, and influences health beliefs and practices (Kleinman, 1988). There are no universal experiences for women with breast cancer; it can be influenced by gender, ethnicity, culture, race, and social class, which define social factors (Carver, Smith, Petronis, & Antoni, 2006). Little is known of breast cancer that is grounded in social and cultural issues in developing countries. Hence, there is a gap in our knowledge about the understanding of women who delay presentation when they have breast cancer, in the Indonesian context.

This research, therefore, also has the potential to inform Indonesian health care practitioners and health administrators working in this specialist area of clinical practice, and to prompt a review of current practices and health care policies for women diagnosed with breast cancer. The outcomes may also generate insight into the family context and inform future families about the treatment and recovery trajectory for a woman diagnosed with breast cancer so that women and families in the future may receive more developed support.

1.9. Definition of Terms

1.9.1. Breast Cancer

Breast cancer is a disease in which malignant (cancer) cells form in the tissues of the breast (National Cancer Institute, 2016). In general, there are two types of breast cancer; in situ and invasive carcinoma disease. Carcinoma in situ cells localise beyond the terminal duct lobular unit and adjacent duct, they do not spread to the basement membrane. Invasive carcinoma involve the vascular and lymphatic system and have the potential to metastasise to a secondary location (Grimsey, 2011). Invasive breast cancer ductal carcinoma is the most common type of breast cancer, it is found in approximately 85% of all breast cancer presentations (Dixon & Sainsbury, 1998).

1.9.2. Help-seeking Behaviour

Help seeking behaviour is complex process of seeking and obtaining health care once people have the symptoms of illness. Help seeking behaviour is also defined as a response to health changes, and is part of the broader process of health-seeking behaviour (O'Mahony & Hegarty, 2009). A broader definition of help seeking behaviour, as argued by Rickwood, Deane, Wilson, and Ciarrochi (2005, p. 4), is “the behaviour of actively seeking help from other people… it is about communicating with other people to obtain help in terms of understanding, advice, information, treatment and general support in response to a problem or distressing experience”. This behaviour relies on other people as a coping mechanism, and is operated based on both personal skill and social relationships (Rickwood et al., 2005). The concept of ‘help-seeking behaviour’ is important in exploring and understanding patient delay in seeking help (Cornally & McCarthy, 2011).

1.9.3. Hermeneutics

Hermeneutics, as defined by Ferraris (1996, p. 1), is “the art of interpretation as transformation”, in contrast to a view of theory as “contemplation of eternal essences unalterable by their observer”. Hermeneutics is the study of how people interpret their lives and make meaning of what they experience (Cohen, Kahn, & Steeves, 2000). It is associated with the theory and practice of interpretation.

Of significance to hermeneutics is a rejection of the “objectifying methods of modern science” (Gadamer, 2004, p. 312) and therefore the traditional and linear “gradatim” of much research. In the current research and contrary to method the interpreter or researcher was understood to belong to the tradition being interpreted and that understanding itself was a historical event. Understanding, therefore, was an ongoing dialogue between researcher, participants, the past, the present and perceptions of the future. All forms of data, whether interviews, literature or theory, were essential components of this ongoing dialogue.

1.10. Thesis Outline

This chapter has provided a brief overview of the background, rationale, and theoretical framework for this research. The research aim and questions were described and addressed were the significance of the study and key terms relevant to the research.

Chapter 2 engages in an overview of the literature concerning breast cancer and related issues, specifically in regard to the interrelationship of breast cancer and socio-cultural Indonesian perspectives. The chapter begins with a discussion of breast cancer and late diagnosis and extends to perceptions of bodily change, the socio-cultural context, advanced presentation, breast cancer, and treatments. The discussion then moves on to breast cancer and identity. Here, two conceptual ideas are explored; the redefinition of self and appearance and the changing body. The chapter draws to a conclusion with an exploration of breast cancer and the role of women. This last section overviews the complexities that women encounter for different reasons including the patriarchal social structure that prevails in Indonesia.

Chapter 3 explores and justifies the methodological approach underpinning this research. The chapter begins with an overview of hermeneutics, followed by the conceptual framework which draws on the work of (Gadamer, 2004). The discussion moves on to an exploration of the key tenets of Gadamerian philosophy, including the hermeneutic circle, language, fusion of horizon, and temporality. The chapter then turns to the concepts of self-identity and culture as they relate to context of Indonesian women.

Chapter 4 details and justifies the elements of the research process. This chapter begins with an overview of hermeneutic inquiry and a justification of the use of a hermeneutic approach as opposed to a predefined set of methods. In this chapter, the stages of the research are also outlined, beginning with participant selection, data generation, and the process of data analysis. Ethical considerations and maintenance of the rigour of this research study are also addressed.

Chapter 5 is the first of the analytical chapters and focuses on collective decision-making. This chapter begins with a discussion of the complexities faced by women with breast cancer. Delay in breast cancer presentation is a common concern presented in this research. Issues around delay are explored, including the choice of treatment, and the tension between the self and the values and norms of the family and society. A further aspect addressed in this chapter is the influence of religious beliefs on practices that contribute to the formation of a social identity, and in turn, how social identity binds people to a system of beliefs and practices. Thus, social practices are both determined by and determine decision-making.

In Chapter 6, the focus is on the social positioning of women in Indonesia. A discussion about the role of women from the perspective of the nationalist and Islam feminist movements in Indonesia is also presented. In the Indonesian context, discourse around the role of women cannot be separated from religion and culture, as gender ideology is embedded within these institutions.

Chapter 7 is the third findings chapter of this research. This chapter begins with a general discussion about the concept of identity, followed by a more specific analysis of the reforming of gender identity in relation to Indonesian women diagnosed with breast cancer. Reformulation of identity in this research refers to both individual and social reformulation.

Chapter 8 constitutes the final chapter of the thesis. This chapter explores the core interpretation of this research which is the temporal experience of women with breast cancer. Exploring the experience of breast cancer through a temporal lens allows the role of women and their changing identities to be understood. It also illustrates the complexity of the breast cancer experience, as women seek to determine appropriate responses. The implications of this research and for future research and public policy making are then argued followed by the conclusion.

1.11. Summary

This introductory chapter has demonstrated the necessity for breast cancer research in Indonesia. An account of the global incidence and prevalence of breast cancer was presented, along with some of limited statistical data available from Indonesia that highlights the seemingly higher breast cancer rates in this country.

Indonesia and its health care system were described in relation to breast cancer and the late presentation of women with breast cancer for treatment was highlighted.

The impetus for the current study was explained through the researcher’s experience and prior research with women with breast cancer. The chapter concluded by outlining the aim of the study, posing specific research questions and addressing the significance of the outcomes of the research and knowledge development concerning the phenomenon of being an Indonesian woman diagnosed with breast cancer.

Chapter 2: Contextual Review

2.1. Introduction

The purpose of this chapter is to review the literature relevant to the issue of the experience of breast cancer for Indonesian women and specifically as it relates to breast cancer diagnosis and treatment. A review of literature in hermeneutic research is an evolving process whereby ongoing interpretation brings new insights and thus new knowledge to the research. In this sense the review presented here is considered an integral component of the research interpretive process and therefore of understanding. As such, the review does not perform the traditional function of "gap spotting" but rather sets down the context of the research.

The review encompasses three main areas, the first of which is a consideration of breast cancer and late presentation. Second, the review addresses Indonesian culture and the significance of gender, and thus the social-cultural context of breast cancer within that setting. The review finally turns to breast cancer and identity. Thus, the works explored here relate to breast cancer and treatment (including the issues of late presentation and alternative therapy), breast cancer and identity, and breast cancer and the role of women. The concluding argument of the chapter is that a hermeneutic approach based on the work of Hans-Georg Gadamer (1900-2002) will allow for a greater understanding of Indonesian women's breast cancer experiences, and the cultural and historical factors central to that experience.

2.2. Breast Cancer and Late Presentation

While breast cancer is the most common cancer in women in both developed and developing countries (Ferlay et al., 2014), the latter countries have far higher mortality rates from this disease. Mortality reductions achieved in developed countries in recent decades have not translated to developing countries (Piñeros, Sánchez, Cendales, Perry, & Ocampo, 2009). The evidence is that the high mortality rate of breast cancer in low and middle income countries is significantly related to late presentation (Yip, Buccimazza, Hartman, Deo, & Cheung, 2015). It has been reported, for example, that Where presentation at stages 3 and 4 occur in up to 50% of cases in Mexico (Sánchez & Guerrero, 2006) in 42.5% cases in Iran (Harirchia & Moghimic, 2005), and 67% in Peru (Zaravia, Cabrera, Méndez, & Palomíino, 2000). In 2012, a report on Chiang Mai in Thailand concluded that 52% of women with breast cancer in that region were diagnosed at an advanced stage (Youlden, Cramb, Yip, & Baade, 2014). In Indonesia, in recent years, it has been estimated that 47% of women with breast cancer present at Stage 4 (where the cancer has metastasised), with many women presenting with open breast wounds (Dharmais Cancer Centre, 2010). By contrast, in developed countries, the majority of breast cancer is diagnosed in localised stages and more than 70% of breast cancer has been diagnosed at Stages 1 and 2 (Unger-Saldaña, 2014).

In general terms, the expression ‘delay’ is used to portray an elapse of time between the first symptom recognised and a diagnosis. Nonetheless, many definitions exist for breast cancer delay. A very early study in this area, by Pack and Gallo, in 1938, defined delay as when three months time or more had elapsed between the discovery of symptoms and a visit to a health professional. This definition has had remarkable longevity. For example, Yau et al. (2010) suggested that a delay in diagnosis refers to the time difference between the first symptom or bodily change related to breast cancer discovered by the woman, and the first visit to a health care professional about these symptoms. Similarly, Corner, Hopkinson, and

Roffe (2006) defined delay as an elapsed time of over three months prior to a woman with symptoms seeking help from health care professionals. Others have defined delay as the waiting time in the diagnostic process; between diagnosis and start of treatment (R. Andersen, Paarup, Vedsted, Bro, & Soendergaard, 2010; Arndt et al., 2002; Bairati, Jobin, Fillion, Larochelle, & Vincent, 2007; Facione & Facione, 2006).

The above definitions refer to total delay. In defining total delay, it is pointed out that the concept has two dimensions; patient and provider (R. Andersen et al., 2010; Angus, Miller, Pulfer, & McKeever, 2006; Chang, Chan, & Hartman, 2011; Unger-Saldaña & Infante-Castañeda, 2011). Patient delay can be described as the time elapsed between the first symptom discovered and the first point of contact with a health care system for this specific issue.Provider delay is the waiting time from the first consultation when a breast abnormality is discovered to a point when a diagnosis is established or therapy begins (R. Andersen et al., 2010; Chintamani et al., 2011). A number of studies have reported on total delay rather than patient delay or provider delay (Ramirez et al., 1999; Richards, Westcombe, Love, Littlejohns, & Ramirez, 1999; Unger-Saldaña & Infante-Castañeda, 2009).

In relation to the above, the Yau et al. (2010) study in Hong Kong found that the mean total delay (from first symptom to treatment) was 21.7 weeks, while the mean patient delay (from first symptom to first consultation) was 13.1 weeks and constituted the largest component (60%) of the total delay. Similarly, the Kumari and Goonewardena (2011) research concluded that 38% of breast cancer patients in Sri Lanka had a delay in presentation greater than 12 weeks. In terms of delay predictor, or how to identify women at risk of delay, Facione, Miaskowski, Dodd, and Paul

(2002) conducted a study in San Francisco and found that 23.7% (n= 166) of women reported a likelihood of patient delay.

However, this categorical definition of delay (patient and provider delay) does not readily accommodate for the social and cultural factors that also have a potential to impact on breast cancer diagnosis delay. Very few studies have explored social and cultural contexts in relation to this phenomenon (Angus et al., 2007; de Nooijer, Lechner, & de Vries, 2001; Lam & Fielding, 2003). The absence of broader inquiry is surprising, because the application of a narrow and rigid definition of delay ignores attributes that may explain delay, and suggests that both patient delay and provider delay are separate problems. In other words, social interactions between the patient and the provider are ignored (Unger-Saldaña & Infante-Castañeda, 2011). Indeed the two categories have been researched separately (Facione & Facione, 2006; Unger-Saldaña & Infante-Castañeda, 2011). A more persuasive approach would assume that there is no single, or discrete, factor that causes delay.

In light of the above, the current research was not concerned with a definition of delay, but rather with the experience of women in presenting with breast cancer in a particular cultural context. The research reviewed has restricted utility in directing an analysis process, because these studies did not recognise the social context in which delays occurred (Angus et al., 2006). The terms ‘patient delay’ and ‘provider delay’ are more likely to be used to look at individual sources or contributors to timely diagnosis of breast cancer. Yet, the assumption in the current research is that an experience cannot be reduced to a typology of independent factors. On the contrary, experience is both constituted by, and constitutes, the social and cultural worlds of the family, community, and national and beyond levels. Hence, the experience of coming to a diagnosis is interrelated with the social and cultural contexts in which women are situated. Research in this area, therefore, should explore these social and cultural dimensions. The following section moves on to literature around perceptions of the association of symptoms and bodily change that influence breast cancer delay.

2.3. Perceptions of Bodily Change

Recognition and more significantly, interpretation of symptoms, are issues integral to breast cancer delay. Psychological factors include fear, denial, and emotional distress (Mohamed, Skeel Williams, Tamburrino, Wryobeck, & Carter, 2005). Yet, fear as a social construct can manifest as shame where the breast is considered a restricted, sensitive, or taboo area and hence one that should not be investigated (L. Smith, Pope, & Botha, 2005). Delay has also been linked to the passive attitudes of a woman who assumes a ‘wait and see’ approach, rationalises symptoms as unrelated to a malignant disease, or self-diagnoses and self-medicates prior to presentation to a health care professional (Macdonald, Macleod, Campbell, Weller, & Mitchell, 2006; Mitchell, Macdonald, Campbell, Weller, & Macleod, 2008). Apart from, or in addition to, the above a reduced time to presentation can be influenced by the sanctioning of help-seeking by a family member or friend (Macleod, Mitchell, Burgess, Macdonald, & Ramirez, 2009; L. Smith et al., 2005).

It appears that perceived bodily change influences some women to take action some distance in time beyond symptom recognition. Thus, how symptoms are viewed will determine whether a woman acts to seek help or ignores symptoms. The way women interpret bodily signs or breast-related symptoms can range from not perceiving a serious threat, to interpreting the symptoms as a threatening disease (Corner et al., 2006). A further factor is the complexities inherent to the process, whereby a woman becomes aware of symptoms of breast cancer. Several studies have sought to address this issue. S. Scott and Walter (2010) argued that the process whereby women seek help from health care professionals reflects how women discover symptoms and how they perceive, interpret, appraise, and make decisions about symptoms. A lack of interpretation by patients regarding the serious nature of their symptoms is considered a predominant factor for cancer-related delay (Macleod et al., 2009). Other studies have also found that a prevailing reason for increased time to presentation is that women do not recognise or acknowledge the seriousness of their symptoms (B. Andersen, Cacioppo, & Roberts, 1995; Macleod et al., 2009; Ristvedt & Trinkaus, 2005). It has further been asserted that delay in presentation can be predicted through types of symptoms, and particularly if a symptom is atypical or vague in nature (Macleod et al., 2009). Where there is an absence of pain or any lump and a belief that the symptom will disappear, the risk of delayed presentation can be increased (L. Smith et al., 2005). Thus, the perceptions of women related to the monitoring of bodily abnormalities are important, because they directly affect actions.

However, even where symptoms are considered to be an indicator of an illness, there is no guarantee that a person will seek help (S. Scott & Walter, 2010). A qualitative study in Ireland that involved interviews with women who had self-discovered symptoms found that not all acted promptly in seeking advice from health professionals, and that delay ranged from one to three months and at times exceeded three months (O’Mahony, Hegarty, & McCarty, 2010). Therefore, it appears that recognition of symptoms is not simply a matter of knowledge or lack thereof. There may be other factors around social, cultural, and religious practices and associated beliefs and values.

Thus, a further possible contributing reason is social. R. Andersen et al. (2010) found that interpretation of bodily change as a symptom of a potential illness requires professional care, because bodily change interpretation is always framed within a social and cultural context. This suggests that women may not interpret a bodily sign as a symptom of illness alone, and that they may do so as a result of the involvement of a family member, friend, and network or community. In Hong Kong, for example, it was found that “women sought their partner’s or close relative’s opinions to help decide whether to seek a medical opinion” (Lam & Fielding, 2003, p. 132). Moreover, reducing time to presentation can be influenced by the sanctioning of help seeking by a family member or friend (Macleod et al., 2009; L. Smith et al., 2005). It is therefore assumed that the social and cultural dimensions of the family and society cannot be ignored as contributing to the response of women’s attitudes to symptoms and bodily change. R. Andersen et al. (2010) further argued that interpreting symptoms is not a linear process but rather, a dynamic interaction of factors related to a specific social life situation that accords with cultural values. These authors refer to this process using the concept of containment. This concept has been applied in a growing body of works as an appropriate frame for understanding patient delay, and in particular, why cancer patients have been reported to underestimate or consider symptoms to be normal (Corner et al., 2006; de Nooijer et al., 2001; S. Scott & Walter, 2010).

It can be concluded that perceptions of bodily signs as symptoms of health problems and as the impetus to take action or not act constitutes a complex process. It may involve the perception of symptoms as a normal event or as a trivial process. In the trajectory of health care seeking, it also involves an extended social group rather than simply patients as individual actors. The following section addresses the importance of the social and cultural context when considering presentation with breast cancer to a healthcare professional.

2.4. The Socio-cultural Context and Advanced Presentation

Socio-cultural factors have been found to play an important role in health-related issues, including breast cancer delay. Culture is defined as the shared beliefs, values, traditions, understanding, and behaviour patterns of a particular group (Deshpande, Thompson, Vaughn, & Kreuter, 2009). Williams (2006, p. 32) also pointed out that culture can be thought of as a "description of particular way of life, which expresses certain meanings and values not only in art and learning but also in institutions and ordinary behaviour". A more wide-ranging definition is that of Priyatna (2013, p. 99), who argued that culture is a broad term that refers to "the complex relations and attribution of language, knowledge systems, systems of social organisations, systems of technology and equipment, systems of livelihood, religious system and arts". This perspective considers how distinctions in the ways that one perceives the self and relationships shape, in turn, how health and illness are experienced and acted upon (Uskul, 2010). Moreover, how people perceive cancer is embedded in the social context in which information is communicated (Craddock-Lee, 2010). Thus, different people in varied contexts will produce different perceptions and interpretations of cancer which, in turn, will influence subsequent actions.

A number of authors referred to an early literature review by Facione (1993) who found that factors influencing the delay of women in seeking help for breast cancer symptoms were associated with socially normative, perceived demands arising from social roles, and a desire to devote time and attention to the needs of someone else. Other studies, noted earlier, also indicated that a woman's place in society can shape help-seeking behaviour by determining priorities (Bhakta, Donnelly, & Mayberry, 1995; Bottorff et al., 1998).

A qualitative research study conducted by Iskandarsyah et al. (2013), exploring psychosocial and cultural reasons for delay in seeking help in Indonesian women with breast cancer, found that some women believe that cancer is incurable, that cancer is a shameful disease, and that it can be passed down to family members. In this research, such beliefs appeared to influence perceptions of the appropriateness or otherwise of seeking medical help and commencing treatment in referral hospitals. Culturally, most Asian societies, including Indonesia, embrace a collectivistic set of beliefs, which means that people's decisions and actions are largely influenced by social and mutual obligations and the fulfilment of group expectations (Triandis, 1995). Thus, it is assumed that social and cultural factors strongly shape women's behaviour regarding their experience of breast cancer. This understanding gives support to the need for an in-depth exploration of breast cancer within the social and cultural context of Indonesia.

From the above, it can be seen that the advanced presentation of breast cancer is a multilayered issue. Hence, it is suggested that an understanding of any delay in the diagnosis of breast cancer cannot be generated from perceiving a woman as merely an individual, because the phenomenon of delay is multi-dimensional where a woman's socio-cultural context and individual characteristics interplay and are thus interdependent. The combination of these dimensions influence how women interpret symptoms and decision-making in the context of social networks, and also in terms of the types of support and health services available (Unger-Saldaña & Infante-Castañeda, 2011). In the area of breast cancer delay, most existing studies have not extended to an exploration of social and cultural aspects (Corner & Brindle, 2011; Revenson & Pranikoff, 2005). Yet, what is known is that women respond to health problems in different ways across cultural groups (Uskul, 2010). Thus, in terms of breast cancer delay, it may be that while women recognise the symptoms that they have, how they decide to act on that knowledge is a significant cultural issue. In order to understand the experience of breast cancer-related issues, therefore, it is important to engage in research that accommodates all of the dimensions that might influence women's experiences and their breast cancer experience (R. Andersen et al., 2010; Corner & Brindle, 2011; Unger-Saldaña & Infante-Castañeda, 2011). In summary, breast cancer is a feature of social communities in developed and developing countries. However, it has been demonstrated that experiences differ across nations, as do incidence and mortality rates. These differences also apply to the issues of presentation for diagnosis, as it is known that in developing countries women often present late. Even though a plethora of research has been undertaken to address specific health problems, the woman's experience in developing countries remains complex and explanations for the higher mortality rate in developing countries extends beyond economics and education.

Although some research with a cultural focus has been undertaken in the research area, most of the studies have been conducted in Western countries, such as the United States and Canada (Facione, 2002; Gates, Lackey, & Brown, 2001; Gorin, Heck, Cheng, & Smith, 2010; Gullatte, Brawley, Kinney, Powe, & Mooney, 2010; Kagawa-Singer, 1995; Kagawa-Singer M, 2010; Lannin et al., 1998; Lantz et al., 2006; Maly et al., 2011). The body of research has also been largely concerned with minority groups characterised by low socio-economic background and religious differences. Very few studies have addressed the dominant socio-cultural context of breast cancer, and no studies have been found with an Indonesian based focus.

Hence, as Indonesia is culturally and socially distinct, it might be assumed that an exploration of this context will contribute to the body of knowledge about women's experiences of breast cancer.

2.5. Breast Cancer and Treatments

Based on global standards, available treatment modalities for breast cancer are divided into local treatment, radiation therapy, and adjuvant systemic treatment (Senkus et al., 2013). Local treatments include forms of surgery such as mastectomy and breast conservation surgery. Radiation therapy can be applied to both invasive and non-invasive carcinoma and involves whole breast radiation therapy and accelerated partial breast irradiation. Adjuvant systemic treatments refer to chemotherapy, hormonal therapy, and targeted therapy. Such treatment modalities can be provided alone or as multi-modal treatments (Maughan, 2010). Treatment options are based on certain considerations, such as the type and stage of cancer (Harmer, 2011), a woman's age, and her personal preferences and decisions (Maughan, 2010). Moreover, the treatment of breast cancer is accompanied by unfavourable side-effects, in addition to the therapeutic effect, that creates further problems for women in this situation. These problems are amplified by social and cultural factors.

As has been emphasised throughout this review treatment delay , as an inevitable consequence of delay to diagnosis, is a further important issue in developing countries. Although breast cancer therapy standards are recognised worldwide, application across countries is not uniform because many factors influence conformity to such standards. A complex interaction of demographic, clinical, cognitive, behavioural, and social factors exists (Yusoff, Taib, & Ahmad, 2011). Yusoff et al. (2011) conducted a qualitative study to gain an in-depth understanding of delay around treatment for breast cancer in Malaysia. Ten women diagnosed with breast cancer who had experienced delay in accessing treatment and their husbands participated in semi-structured interviews. The study found delay in breast cancer as a result of four main factors. The first three were perceptions of symptoms, women appraising themselves as not being susceptible or at risk for breast cancer, and fear of surgery. The fourth aspect was help-seeking behaviour whereby women and their husbands sought advice from friends and relatives about treatment and particularly in relation to a choice between Western and traditional therapies. The authors also pointed to health care systems as a contributor to a delay to breast cancer treatment where there was ineffective communication between health care professionals and patients. In terms of religious and philosophical beliefs the women and husbands perceived that the illness was interrelated to God and fate and this contributed to a level of acceptance and positive thinking about their situations.

Given the increasing recognition of the importance of the social and cultural contexts in which women make decisions and take action around breast cancer, the current research sought to expand upon this area. Thus and as the current research evolved, a focus was on the processes whereby women decided and determined the treatment of breast cancer.

The popularity of alternative therapy among breast cancer patients around the world is considered quite high. According to Wanchai, Armer, and Stewart (2010), regardless of the type of alternative therapy, the use of other than medical treatment ranges from 36% to 83%, with considerable variation across countries. There is also abundant evidence on the strength of beliefs in traditional healers and the implications of this for patient behaviour and treatment decisions (Agarwal, Pradeep, Aggarwal, & Cheung, 2007; Hisham & Yip, 2004; Wanchai et al., 2010). Hence, many women have a fundamental belief in traditional healers and will use traditional therapies as an alternative, or complement to, or substitute for bio-medical treatment. Research conducted by Taib, Yip, Ibrahim, Ng, and Farizah (2007) in Malaysia, found that the motivation for women diagnosed with breast cancer to seek therapy outside a Western medical system was grounded in fear of surgery, influence of friends, an earlier negative hospital experience, belief in alternative therapy, financial difficulty, fear they would be unable to work after surgery, denial of cancer, and shyness about seeing a doctor.

The above study noted, in accord with a recent study by , that in Indonesia most women from one district hospital consulted a traditional healer after confirmation of a diagnosis of breast cancer. It appeared that access to traditional healers, for primary and not complementary therapy, was a common practice in some societies. Reasons proposed for this practice vary and include fear that surgery will disturb the cancer and cause it to grow larger (Leong et al., 2009), inadequate medical facilities in primary health systems, poor infrastructure and information systems (Pai, 2002), and lack of financial resources (Al-Adawi, 1993; Pai, 2002; Tovey, Broom, Chatwin, Hafeez, & Ahmad, 2005). All the above reasons have been posed as barriers to seeking what is considered effective medical intervention, and as facilitators in giving preference to traditional healers. Alternative therapy builds and develops along with the culture and tradition in a particular society.

In conclusion, it has been determined that decision-making surrounding breast cancer treatment is complex and cannot be viewed as separate from the social and cultural contexts in which women live. A woman’s very identity is similarly grounded and the interrelationship between identity and an experience of breast cancer has implications for decision-making.

2.6. Breast Cancer and Identity

A threatening illness, such as cancer, “produces discontinuities in a sense of identity” (Little, Paul, Jordens, & Sayers, 2002, p. 173). Identity is a broad concept that has been defined in various ways. It appears on a spectrum of perspectives from the social to the individual. Burke and Stets (2009, p. 3), in covering the spectrum, noted that identity is a “set of meanings that define who one is when one is an occupant of a particular role in society, a member of a particular group, or claim particular characteristics that identify him or her as a unique person”. Furthermore, identity formation is considered not entirely innate, but only partly given, and is a multilayered active process (Coulmas, 2005). In other words, identity formation is not a static process, but a social phenomenon that develops over time.

From the above, it can be seen that identity is dynamic and always changing and it occurs in a particular situation (Burke, 2006). Hence, “identities’ resistance to change gives them some stability; thus, change occurs only slowly in response to persistent pressure” (Burke, 2006, p. 92). Identity change is where change occurs in a situation that brings “situationally relevant meanings into alignment with the meanings in the identity, thus verifying and supporting the existing self-meanings” (Burke & Stets, 2009, p. 176). The level of change tends to be slower in decisions taken where the results will not be noticed until long periods of time have passed (Burke & Stets, 2009). Additionally, some situations that stimulate identity change may arise where there is a conflict between two (or more) identities, or a conflict between the meanings of the change. Based on identity control theory (Burke, 2006, p. 85), there are two general sources of systemic identity change, one that verifies a particular identity, and two, when “multiple identities” are activated at once.The concept of identity gives rise to the ways in which self-perception is a product of interacting that may change in situations, such as illness and health. The redefinition of self is considered the following section.

2.7. Redefinition of Self

A growing body of literature reports that a diagnosis with a life-threatening illness, such as cancer, will have a significant impact on one’s self (Johnston, 2013). Suffering a chronic illness represents an assault, on both the person’s physical self and sense of identity, calling into doubt the person’s self-worth (Charmaz & Emerson, 1983). Thomas-MacLean (2004) suggested that breast cancer diagnosis and its treatment disrupts self-identity, which involves sense of self, femininity, body image, and body integrity.

According to Charmaz (1987, p. 284), the concept of self is “an emergent structure or organisation as it may shift or change as the person reflexively interprets the identification it imagines that self or others confer upon him or her”. A further definition is that the self is constructed and reconstructed mainly through symbolic physical interactions with the world and others. Both definitions assume that alterations to the body may see a major restructuring of self; the perception of who one is and one’s capability (Corbin & Strauss, 1988).

In the terms of Thoits (1991), identity theory can be used as a framework to understand the identity reformulation process process experienced by women with breast cancer and breast cancer survivors. Thoits (1991) argued that the continuity in sense of self could be threatened when a woman has an extreme experience, such as a diagnosis of breast cancer.

In moving on from the above, a diagnosis of cancer, or in this case breast cancer, is accompanied by bodily and cognitive changes that challenge core values and beliefs. More specifically, Thoits (1991) emphasised that the cancer experience can be the cause of change to specific identity characteristics, or a salience identity hierarchy and as individuals reconstruct their identities after cancer, further changes occur to the salience of certain identity characteristics. In turn, the hierarchical changes alter aspects of a person's self-concept. This means that individuals are attached to a specific identity that will have been central to a person's sense of self prior to their breast cancer (for example, femininity, career, and spouse). Thus, when individuals are faced with cancer, these specific identities can diminish in salience and be replaced by other, more salient identity characteristics.

While breast cancer treatment, including surgery, chemotherapy, and radiation, can be lifesaving interventions, they are associated with multiple consequences for women, such as physical change in the form of the loss of the breast, hyperpigmentation or scarring of the skin, alopecia, disfigurement, weight gain, and muscle loss (Brockopp, 2010). These physical changes can disrupt the capacity of women to fulfil significant roles in the family and in society. A breast cancer diagnosis and treatment brings about significant changes for women, not only physiological, but involving all dimensions of their lives (Brockopp, 2010).

The experience of breast cancer experience is considered complex and a common descriptor of the jourbney is as life-changing (Brockopp, 2010). Mears (1997) suggested that when women complete treatment for breast cancer, they reformulate their personal biographies to include diagnosis and treatment. Mears (1997) further asserted that the reformulation comprises self-reconstruction (identity and body) and biographical time and takes place within a social context. In other words, women are faced with the continuing, or long term, effects of breast cancer. Some breast cancer research has demonstrated how the disease significantly influences the self and identity of women, as indicated in the following.

Piot-Ziegler, Sassi, Raffoul, and Delaloye (2010, p. 500) conducted qualitative research and interviewed nineteen women who had been diagnosed with breast cancer and had undergone a mastectomy in a Swiss university hospital. Body deconstruction was a central theme generated in the research. The loss of a breast challenged women's identities and relationships with others, gave rise to a re-evaluation of existential priorities and prompted "a re-positioning", as the experience of cancer provided a greater understanding of life. Similarly, Berterö and Wilmoth (2007) analysed the relationship between cancer and self. These authors reported that women redefined themselves in three ways. The first was through changes in the way women viewed their own bodies. No longer perceiving themselves as 'normal', the women saw themselves as no longer complete. The second defining feature was the limiting effect of lymphedema on physical function, including perceived and real difficulties with sexual function. The third was where women questioned their femininity and whether they were attractive and 'woman enough' (Berterö and Wilmoth, 2007, p. 200). Thus, Berterö and Wilmoth (2007) concluded that redefinition of self as a result of a breast cancer diagnosis and treatment includes not only physical redefinition, but cognitive component characterised by body picturing, physical functioning, and womanhood/femaleness.

The findings of Berterö and Wilmoth (2007) resonate with the early work of Bury (1982) who argued that chronic illness and its treatment was self-disruptive and required redefinition. Breast cancer disrupts the structure of daily life, and treatment induces not only changes in physical appearance, but also results in a change in a person’s sense of self-identity (Lam & Fielding, 2003). In other words, a breast cancer diagnosis and the impact of treatment cumulatively interferes with self-identity.

In addition, breast cancer and its treatment also has the potential to engender a sense of positivity. Hubbard and Forbat (2012) conducted an interpretive analysis of the written accounts of forty men and women who had been diagnosed with different types of cancer. Fifteen participants were women who had been diagnosed with breast cancer. Participants were asked to write about their experiences of living with cancer and to identify what was better or worse or remained the same. The analysis concluded that cancer is perceived as an ongoing physical and psychological disruption, a persistent threat, creating a heightened sense of mortality, and yet also contributing to positive changes to self. The implications of chronic illness on an individual’s biographical self-have been suggested as having (or not having) continuity and flow (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004) and being temporary or permanent (Charmaz & Emerson, 1983). Arman and Rehnsfeldt (2003) reported that after a diagnosis of breast cancer women revealed a common concept/theme of a ‘turning point’, which is referred to as occurring after diagnosis when the consequences of breast cancer on a woman’s life are realised. All of the above indicate that experiencing breast cancer brings about a range of notable changes, both positive and negative, to the lives of those diagnosed with breast cancer.

A number of strategies have emerged in order to address the consequences of these changes. In medical terms, undergoing a breast reconstruction is a known intervention for women post mastectomy. In Western society, breast reconstruction surgery is a standard intervention for breast cancer. The primary goal of breast reconstruction is to recreate the appearance of a breast (or breasts) that is satisfying to the patient (Fingeret, Nipomnick, Crosby, & Reece, 2013). Breast conserving surgery is also a now routine approach in western countries and considered important, because it leaves a woman's body, and therefore the woman's body image, largely intact (Al-Ghazal, Fallowfield, & Blamey, 2000). In America, 66.7-75.7% of women who are post mastectomy will undertake breast reconstruction surgery (Holland, Archer, & Montague, 2014). Ideally, the purpose of breast reconstruction surgery is to improve cosmetic outcomes for women with breast cancer and mitigate the negative effects of breast cancer on women's sexual well-being (Rowland et al., 2000). It is assumed that physical improvements through breast reconstruction will be followed by psychological effects and also influence the reshaping of identity.

As a follow up to the breast reconstruction surgery intervention, research has been undertaken to evaluate whether this intervention influences the shaping of self-identity. Al-Ghazal et al. (2000) reported that women experienced less body image distress immediately following breast reconstruction surgery than women who delayed. R. Sugrue, MacGregor, Sugrue, Curran, and Murphy (2013) argued that a patient receiving breast conservation surgery experienced better short-term psychological outcomes compared with those who had had a modified radical mastectomy. Conversely, the breast reconstruction surgery appeared to have less influence on long-term psychological states. Sugrue et al. (2013), conducted an evaluation of patient reported outcomes following breast reconstruction and found no significant differences between post reconstructive outcomes and pre-operative perceptions in terms of satisfaction with breasts, psychosocial, and sexual well-being. Ucok (2002) suggested that for a woman with breast cancer, it is not only important to deal with of the reconstruction of the body but just as important is the intersection of social and cultural discourses surrounding the diagnosis, as well as issues of femininity, masculinity, ethnicity, sexuality, agency, and age (Thorne & Murray, 2000). Research considering social and cultural perspectives for women's experience with breast cancer is important.

2.8. The Changed Body

The changed body not only represents the physical signs of cancer, but also the social presence and representation of cancer. Rasmussen, Hansen, and Elverdam (2010) conducted a study to explore how cancer survivors with different types of cancer and cancer treatment experienced and handled their changed bodies, especially when meeting others, and how this influenced their everyday lives of survivorship, long after treatment has been completed. Changed bodies as a result of cancer and treatment was the main finding of this study (Rasmussen et al., 2010). When women participants met others, they perceived that they were avoided or approached, in particular ways because of their altered bodies.

A further issue, interrelated with identity, is that where changes are visible, cancer survivors seek to hide them in various ways, such as under the clothes they wear, or through the use of prostheses or wigs. For the individual cancer survivor, the concern is not only outwardly visible changes. Bodily changes that are invisible to others but nonethelss hidden are also a cause for concern. The Sekse, Raaheim, Blaaka, and Gjengedal (2010) hermeneutic phenomenological study interviewed 32 women with various gynaecological cancers who had all undergone surgery. The study findings indicated that the women's feelings of femininity appeared little affected by treatment. Femininity was reflected upon in relation to physical looks and related to the age. Hence, removal of a breast was likely to cause a greater loss of femininity. Sekse et al. (2010) further explained that the removal of reproductive organs engendered some concern about the consequences for sexual relationships but appeared to have only a minimal effect on the sense of femininity. Feminity was defined more in terms of explicit relations with others and physical appearance. The removal of a breast was perceived as a greater threat to femininity and the women focused on the fact that reproductive organs were invisible.

2.9. Breast Cancer and Women’s Role

There are four interrelated factors that underpin a woman’s role in Indonesia; religion, history, culture, and the government. The following discussion constitutes a review of research situated broadly around those factors that may influence an Indonesian woman’s role in relation to breast cancer experience.

As a part of an Asian society, Indonesian women have multiple roles as wives, mothers, daughters, and daughters-in-law, and consequently, women are responsible for many role related tasks. For example, women are not only expected to fulfil their roles as good wives and mothers within the families but also to contribute to local development and to fulfil social obligations at the socio-cultural level, to fulfil emotional, physical, and financial needs, and to engender harmony and progress in the community (Niehof, 1998). Hence, when women are sick, the stability of the family is affected, because women are perceived to be the guardians of harmony in families. This situation is a reflection of a patriarchal tradition where women are positioned as subordinate to men in the broader social environment and also in the family. Women have considerable responsibility but limited or no power and rights. Women are expected to participate and be productive but also to be invisible to some extent. It has been determined that in South Asian societies where women suffer serious illnesses significant issues arise over who will assume responsibilities for the their families and the mainetenance of their proper place in the community. This concern may lead women to a decision to put others first and delay engagement with the health care system (Bakht & Najafi, 2010; Bottorff et al., 1998).

Additionally and as Hubeis (2010, p. 260) suggested; “the roles of individuals also need to be considered as family is one consideration and also the associated rights and obligations of belonging to a family, for example, as daughter, wife and mother, each of which have a role and obligation embedded”. Hence, women are expected to meet their responsibilities based on specific and relation-oriented roles (Tsai, 2001). Conflict may arise in regards to fulfilment of the role expectations of the self and families or significant others.

The collectivist culture in Indonesia is strong and is said to distinctively reside in “the sense of a shared communal life, as a sense of oneness, togetherness and harmony” (Rahardjo, 1994, p. 495). There are some famous metaphors that describe how togetherness is so important. For example, the term “gotong-royong” (mutual burden sharing) means mutual assistance between people in the community to attain a shared goal, such as building bridges or improving roads (Sinha, Alatas, & Bun, 2007). A further example is the term “mangan ora mangan kumpul”, which similarly means being together either with eating or not eating. It is not uncommon, therefore, for many people to visit an ill person and to bring healers or information regarding treatment or therapy for a disease.

2.9.1. Women and Islam

Islam is the religion of the majority of the Indonesian population and Indonesia is the largest Muslim country in the world. Hence, the study of issues surrounding gender in Islam has evolved significantly in Indonesia. This is because any discussion of gender issues in Indonesia cannot be separated from the role of religion. Although gender issues may not necessarily be religious in nature, many activists have found that in the context of Indonesian society, any discussion of gender, morality, or family life cannot be separated from religion, because a purely secular approach would not gain public attention and support (Brenner, 2011).

In the colonial era, Islamic society developed and conducted education based on an Islamic though institution name *Pesantren,* which refers to a traditional Javanese Islamic boarding school. *Pesantren* operated and followed colonial state rules that only boys had access to the *Pesantren* (B. Smith & Woodward, 2014). Meanwhile, girls and young women from families of high economic status received informal education from a male teacher at their homes. In the early 1930s, some Pesantren agreed to admit girls to study but very few, if any, girls joined the Pesantren at that time (B. Smith & Woodward, 2014).

Religion is used to give legitimacy to patriarchal practices, whereas patriarchy is not particularly associated with the religion. Hence, there are many cases where men and women are treated unequally and purportedly in the name of Islam. Polygyny is an example of Islamic influence on the constitution of the 1974 Marriage Law which involved critical debates between Muslims and Christians, although with notably little involvement from women, that reflected some comprises but failed to erdicate discrimination of women in marriage. The Marriage Law permitted polygyny where a wife was unable to perform her duties as a wife, suffered from physical defects or incruable disease, and/or was incapable of having children (Nurmila, 2009). By contrast, in the case where a husband was sick, it was not acceptable for a woman to leave her husband or to divorce. The practice of polygyny is acceptable in terms of religion but was not commonly praticed. Nonetheless, the power differences between men and women do give rise to issues, including domestic or spousal violence, that may go unaddressed because they are perceived as "properly belonging to the private sphere" (Brenner, 2011, p.482).

Hence, women's decisions in life are influenced by a complex mixture of religious, social, and cultural understandings in the community. Through a combination of Islamic religious views and a patriarchal tradition, women's roles in Indonesia have become prescribed as part of a collective ideology (Pinagara & Bleijenbergh, 2014).

2.10. Summary

The purpose of this capter was to construct the context of the research reported upon in this thesis. It was noted at the outset that the review took shape as an evolving structure that was an integral component of the hermentic process of interpretation. As such the chapter addressed literature concerning breast cancer-related issues and specifically as breast cancer relates to the socio-cultural Indonesian perspective. The review has demonstrated that breast cancer treatment delay is an ongoing issue across countries and is most prominent in developing countries. It is also the case that delay in breast cancer diagnosis and treatment can not be explained by a definitive set of factors and nor by discreet factors.

The chapter brought focus to the multi-layered social and cultural processes that are integral to any decision making around breast cancer diagnosis, treatment and future. There have been some attempts to determine, using scientific methods, what comprises the decision-making of women with breast cancer. Yet the risk of trying to grasp what is complex and dynamic through a set of methods risk reducing that complexity to a typology of "barriers and facilitators" that assumes a given and appropriate path, and in the case of this reresearch, for women in Indonesia with breast cancer. This research, therefore, sought to explore the experiences of

Indonesian women who had been diagnosed with breast cancer within an hermeneutic framework that emphasises the process of coming to understand through iencounters between interpretations, history and place. Thus, the experiences of the women participants and the researcher encountered the social, cultural, and historical features of the context in which the research took place. Hermeneutic enquiry promoted a constantly moving and iterative exploration of the lives of the Indonesian women with breast cancer. The following chapter explores the key concepts that informed the theoretical framework of the research.

Chapter 3: Theoretical Framework

3.1. Introduction

This chapter presents the theoretical framework, grounded in the hermeneutic work of Hans-Georg Gadamer (1900-2002), that informs this research. The chapter begins with an explanation of the hermeneutic approach and its focus on understanding and interpreting experience. The Gadamerian theoretical framework articulated here is organised around the key tenets of proposition, the hermeneutic circle, language, the fusion of horizon, and temporality. The latter part of the chapter extends the framework to the concepts of identity, gender, and culture, which were deemed important to gain an in-depth understanding of the research context and focus. The chapter concludes with a justification of the choice of hermeneutics as an approach to the explication of the meaning of being an Indonesian woman diagnosed with breast cancer.

3.2. Hermeneutic

The word hermeneutics derives from the mythical Greek God, Hermes, the fabled messenger (Finch, 2004) whose responsibility was to transform the ”unknowable”, or the ineffable, into a form that humans could try to comprehend and understand (Walsh, 1996, p. 233). The word is grounded in ‘”hermeneuein”, which simply means to interpret (Van Manen, 1997, p. 179) and thus refers to an explanation or translation (Crotty, 1998).

More specifically, the term ‘hermeneutic’ is associated with the theory and practice of interpretation. The proposition of hermeneutics as a practice and a historically conscious practice, is central to Gadamer’s (2004) repudiation of the positivist view that knowing can only come through isolated, replicable, empirical experiments. For Gadamer, “the truth is never to be methodised, because, the truth as a product of infalliable method ignores truths of experience enshrined within a common cultural tradition” (Lawn, 2006, p. 41) Hence, Gadamer rejected a dependency upon the conception of method that is acquired from the natural sciences (Lawn, 2006). On the contrary, knowing or understanding is a deciphering process that takes the object of inquiry as far more subtle and complex than scientific analysis allows. Yet, despite a distance, there is an assumed commonality between the researcher and individual or text that makes understanding possible. Thus, where scientific research treats the object as natural and set apart from the researcher, a hermeneutic perspective sees the researcher both set apart from and linked with that which is being studied. This simply means that there is no expectation that everything can be known.

Furthermore, hermeneutics is largely about language. In Gadamer’s (2004, p. 470) words; “Being that can be understood is language”, which makes it clear that language is the medium in and through which one has a world. Language constructs all situations and experiences; and hermeneutics thus promotes the human potential for understanding the meaning of language to expand the infinite possibilities of human thought (R. Palmer, 1969).

From the hermeneutic viewpoint, it can then be seen that understanding is always coupled with a perspective and interpretation. For Gadamer (2004), understanding must be interpretation, where indeed “understanding occurs in interpreting” (Gadamer, 2004, p. 390). Furthermore and because the world is constructed through language (McLeod, 2001, p. 58), the basic argument of hermeneutics is that to be human is to live in an “interpreted world”.

Just as importantly, meaning and understanding are always arising from contextual and historical features (Finlay, 2009). Understanding is historical and the preconceptions that we all carry around are a product of historical contexts. Gadamer defined these preconceptions as “prejudice”. Prejudice, however, is not something to be set aside to allow the truth to be grasped, but is a necessary condition of understanding. Hence, the researcher is always involved in the pre-understandings or prejudices that derive from being a member of a culture and a user of language (McLeod, 2001).

In his major work, *Truth and Method*, Gadamer (2004) thus set down the fundamental ideas that constituted his understanding of the hermeneutic pursuit. The first is that hermeneutic reflection refers to the complex process that is set in motion when we encounter something or somebody new and strange, which, or who, we seek to understand, such as somebody with whom we find ourselves in conflict (Buckley-Zistel, 2006). Second, once understanding has been accomplished, the shared meaning about an issue at stake is no more ‘true’ than the assumption we had before the encounter (Buckley-Zistel, 2006). Rather, this newly acquired truth is merely different, and there is no hierarchy of different truths. Third, and as a result, hermeneutics opens the door for a pluralism of interpretations and the competition of different truths.

Gadamer, as a former student of Heidegger, agreed that hermeneutic inquiry shifted interpretation from its original meaning and biblical contexts “and entered into the realm of human experience” (Laid law, Bennett, Dwivedi, Naito, & Gruzellier, 2005, p. 200). In recent years, hermeneutics has become and can be seen as a broad range of theoretical and practical approaches in terms of research inquiry.

The following discussion explores the understanding of Gadamerian thought relevant to this research.

3.3. Gadamerian Thought

Gadamer (2004), as did Heidegger (1962), conceived of hermeneutics as the science of interpretation; not only a method of determining truth, but also an activity in order to understand the conditions that make truth possible. As noted above, the pre-understanding, or “fore-structure”, is integral to interpretation. Fore-structure is a term that reflects pre-understanding or prior knowledge, and hence, is not conceived as something to be put aside, reminiscent of Husserl’s (2012) bracketing, but an inherent element of understanding. For Heidegger (1962), the process of interpretation invariably operates in the fore-structure. For Gadamer, fore-structure is the so called prejudice or pre-understanding, and prejudices are present in all understanding (Lawn, 2006). In research terms, this means that the position of a researcher is a legitimate and inevitable part of research (McConnell-Henry, Chapman, & Francis, 2009), because interpretation of data is reliant on previous knowledge (Mackey, 2005).

From the above, it is clear that the ultimate goal of hermeneutics is to gain understanding and that pre-understanding is critical to this process. In the words of Gadamer (2004) “understanding is essentially a historically effected event” (p. 299), “all understanding inevitably involves some prejudice” (p.272), and prejudice is not a false judgement, but a condition of truth. Therefore, for Gadamer, the importance of prejudice is that the interpretation of texts involves a process of becoming aware of our prejudices and being open to the horizons of understandings of the past, or of others (Röing, Hirsch, Holmström, & Schuster, 2009).

A further important Gadamerian tenet is the rejection of the notion of subject-object. As Gadamer wrote:

> The purpose of my investigation is to discover what is common to all modes of understanding and to show that understanding is never a subjective relation to a given ‘object’ but to the history of its effect; in other words, understanding belongs to the being of that which is understood. (Gadamer, 2004, p. xxviii)

In other words, inquiry is not about exploring subjective intentions as the object of research. This is because the objective point beyond history cannot be achieved because we are already there, in the time that we attempt to grasp at understanding something. Hence, the historical effect is inevitable whether we are released from it or not and it exists in all understanding (Phillips, 2007).

In further explaining these general propositions, there are four key concepts that underlie Gadamerian philosophy; the hermeneutic circle, fusion of horizon, temporality, and language. These concepts are not independent nor mutually exclusive, but rather complementary and interrelated. Each concept is addressed in turn in the following discussion.

3.3.1. Hermeneutic Circle

The hermeneutic circle is used to describe the movement between the whole and the part during the process of interpretation. This means that we must “understand the whole in terms of the detail and the detail in terms of the whole” (Gadamer, 2004, p. 291). The movement starts from the researcher or interpreter’s pre-understanding to confront the “other”, or the text in the hermeneutic process. It is a dynamic movement from a whole to the parts, alternating continuously until understanding is determined. For example:

> The interpretation of a text invokes a circular movement between its overall interpretation and the specific details that a particular reading offers. The new details potentially modify the overall interpretation which in turn sheds light on new parts significant for understanding. (Buckley-Zistel, 2006, p. 11)

Thus, the parts and the whole of the text constitute an entity, whereby the parts might be a projection of meaning and the whole an anticipation of meaning (Gadamer, 2004).

The hermeneutic circle is further described as the form in which “the interpretation which produces understanding is accomplished” (Gadamer, 1988, p. 71). The structure of hermeneutical understanding is “the circular relation between the whole and its parts: the anticipated meaning of a whole is understood through the parts, but it is in light of a whole that the parts take on their illuminating function” (Gadamer, 1987, p. 126). The consistency of shifting between the parts and whole, therefore plays an important role in order to understand the experience. Thus, the emphasis in hermeneutic understanding is on the synthesis of information and the process always resembles a spiral (hermeneutic spiral), rather than a hermeneutic circle. The outcome of the process of intepretation is not a definitive finding or answer. In hermeneutics, interpretation never ends. Nonetheless, a researcher will reach a point in the analysis where a persuasive and legitimate interpretation has been developed that will provide an in-depth understanding of the focus of inquiry.

Importantly, and as Gadamer (2004) explained, in moving back and forth between the whole and the part and back to the whole again, the hermeneutic reading of the text will show how experiences change over time and how earlier experiences shape understanding in the present and beliefs about the future. For example, when one begins interpreting a body of work that may be ‘gaining an understanding of the experience of breast cancer', the interpretation might start from the interview transcript (individual) as a part of the text, and then move to the whole, which means examining the interview transcript in relation to the cultural, social, and historical contexts and in accordance with a temporal frame. The importance of temporality from this perspective is in the relationship between the past, present, and future. This relationship creates a tension, because the language of contemporary times will differ in meaning from earlier historical moments, but at the same time it will be part of those times. This brings the discussion to a further concept central to the interpretation process, which is language.

3.3.2. Language

It was made clear from the outset of this chapter that language is an essential concept in the hermeneutic tradition. As Heidegger argued, the role of language is integral to understanding because, "(t)he intelligibility of something has always been articulated, even before there is any appropriative interpretation of it" (Heidegger, 1988, p. 234). To put this another way, it is in language that our world is structured, and thus disclosed to us. From a hermeneutic perspective, the world is therefore impersonal and presents between individuals (Holroyd, 2008). This is so, because human beings are constituted in language, engaged in society, and these in turn are situated within place, time, and history (Preston, 2009). Moreover, the key of Gadamer's (2004, p. 387) concept of understanding is by means of language, in which "mastering the language is a necessary precondition for coming to an understanding in conversation".

Furthermore, in the process of achieving understanding during the interpretation process, language plays an important role as the medium through which both people and the world become apparent as distinguishable, meaningful entities. For Gadamer (2004, p. 440), “no world” exists outside of language: …language - view is a worldview. Language is not just one of man’s possesions in the world; rather, on it depends the fact that man has a world at all. The world as world exixts for man as for no other creature that is the world.

Hence, achieving an understanding is a process that must succeed or fail in the medium of language. For Gadamer (1990) and Gadamer (2004, p. 440) “language is orginally means at the same time that man’s being in the world is primordially linguistic”. Thus, language is situated as a core of understanding, and in so doing, our whole experience of the world is made possible from “language as a medium” (Gadamer, 2004, p. 453). As a result, language enable reflection on past experiences and is the medium through which past and present understandings fuse to enable the development of understanding (Spence, 2004, p. 142).

To take this a step further, Gadamer’s (2004) view of language points to something transcendent, where language has the power to create and recreate a different world from that which existed. For Gadamer (2004, p. 553);

> …[language is not limited] to a stock of words and phrases, of concepts, viewpoints, and opinions…language is not its elaborated conventionalism, not the burden of pre-schematisation with which it loads us, but the generative and creative power to unceasingly make this whole again fluent.

Thus, language assumes an essential role in the hermeneutic process as the medium for shared understanding among people about the world and its existence. The linguistic tradition enables the ‘handing down’ of traditional information of relevance to the interpreter’s frame of reference and how what is read, written, spoken, or heard is interpreted (Gadamer, 2004). Language therefore enables the information process to become ontologically specific to the interpreter, depending on the culture (*Bildung*) to be shared, learnt, and accommodated (Gadamer, 2004).

Thus, a key element is that language is “I-less”. In the words of Gadamer (2004, p. 278); “The focus of subjectivity is a distorting mirror. The self-awareness of the individual is only a flickering in the closed circuits of historical life “.

The challenge then lies in how the researcher properly understands the language of the text, and how the researcher might write appropriate words to capture the meaning of a particular phenomenon. Yet, it is assumed that the words will always be limiting and reduced during the interpretation process. Hence, a further concept that is directly relevant to this tension and to the interpretation process, is the fusion of horizons.

3.3.3. Fusion of Horizons

The concept of the fusion of horizons is deeply embedded within Gadamer’s (2004) work and refers to the things that are within our immediate world and are the activity of understanding. For Gadamer, horizon refers to “the range of vision that includes everything that can be seen from a particular vantage point” (Koch, 1996, pp. 176-177). Gadamer (1976, p. 10) pointed out that horizons are always in motion and have a temporal base, and that “a person does not have a closed horizon”. This means that the past and the presen always re-shaped of knowledge and understanding constantly (Coleborne, 2009). Our horizon, in turn, always moves with us, and thus, there is “an infinite capacity to refine and to extend our understanding of things” (d. S. Turner, 2003, p. 7). The final understanding, however, can never be achieved, because the experiences a hold multiple meanings (Ricoeur, 1976). Similarly, as Gadamer (2004, p. 389) explained:

> …conversation, like real conversation, finds a common language, and that finding a common language is not, any more than in real conversation,

> preparing a tool for purpose of reaching understanding but, rather, coincides with the very act of understanding and reaching agreement.

The fusion of horizon in this research is thus the fusion of pre-understanding and the horizon of the interview text. According to Gadamer (2004, p. 305), “the horizon of the present cannot be formed without the past. There is no more an isolated horizone of the present in itself than there are historical horizons which have to be acquired”. In other words, perceptions of the world are never unmediated, and hence, there cannot be a view of the world as definitive and nor purely subjective. As Gadamer noted, “we all have limited horizons and preconceived ideas and we bring pre-judgements (i.e. expectations, bias, anticipations) to our interpretations” (Trede, Higgs, & Rothwell, 2008, p. 4). Thus, a fusion of horizons and a deeper understanding can be achieved through engaging in dialogue with text. As such, the function of the fusion of horizon in this study is the coming together of the researcher’s horizon and the horizon of the interview text and contextual knowledge. In the process of this dialogue, the researcher’s horizon, which consists of my knowledge, life history, and experience as a nurse in relation to breast cancer, is fused with the text’s horizon, which is the interview transcripts and other sources of data, including previous studies and other literature. The fusion of these two horizons produced a broadening of my own horizon as researcher.

Furthermore, to Gadamer (2004), the process of interpretation is dialectical and characterised by active questioning and answering to the text. The dialogue process actively in which also occur between interpreter and the reader, as Alvesson & Skoldberg (2009, p. 101) argued that “we enter into an imagine diaolgue with the reader of our interpretation”. The dialogue occur is dialectical means that the dialogue moves circularly and centrifugally in order to achieve understanding

(Jahnke, 2012). Gadamer’s central concept of fusion of horizons is the hermeneutic circle process; the movement starts from our horizon of understanding, our prejudices in confronting the “others”, and ultimately, the fusion occur through exchange, facilitating our horizon of understanding through exchange opinions and facilitaing the expandsion with the horizon of the other who is to be understood (Jahnke, 2012).

Understanding of experience can be explained through the concept of horizon. As such, “understanding is already placed in history and tradition, and it can understand the past only by broadening its horizon ti take in the thing encounter” (Palmer, 1969, p. 183). For Gadamer, “the past, the other horizon, is always shaping our conciuosness of the world and it too changes since we are always interpreting the past from the horizon of the present” (Moules, et.al., 2015. p. 47). As a result, understanding will appear through the fusion of the horizons of the language of the participants and researcher. For Gadamer, “tradition and history are never settled or correctly interpreted but understood by the interpreter’s ever changing horizon” (Regan, 2012, p. 298). However, as the horizon of the present is in continuous development, understanding of the participants and researcher will merge into a new understanding. Understanding unfolds when a fusion of horizon of past and present, which is always a constituent feature of the future, occurs (Gadamer, 2004). As the interpreter or researcher makes sense of the text through changing their horizon; the horizon, adjusted and then fused, becomes the fusion of horizon. The process of fusion points to the important concept of temporality.

3.3.4. Temporality

Temporality refers to consciousness of time through the experience of being in time and as such, a person is temporally located in the world. Heidegger’s (1962, p.

39) philosophy conceives of time as “the horizon for all understanding of being and for any way of interpreting it”. Hence, the interpretive tradition considers that the experience of time is fundamental to understanding of being, and ways of being, and how all human experience is rooted in time (Mackey, 2005). Gadamer connected the experience of understanding and time, and placed time in the centre of his description of the experience of understanding (J. Robinson, 2006).

Here, temporality refers to a concept of time that is based on history, rather than clock time. The focus on history means looking at the ground in wherein the past and the present come to be situated, or at the customs and tradition that help understand what the present (and indeed future) itself is in the text. An interpreter’s own historicity and temporality affect all interpretations of speech and text (Gadamer, 2004). As Merleau-Ponty (1962, p. 415) claimed, a concrete structure of subjectivity can be accessed through time, and time is “not an object of our knowledge, but a dimension of our being”. In other words, he suggested that time is not an objective flow external to our experience, but rather it is constituted relationally between the subject and the world. Time establishes or mediates the relations between the perceptual subject and the world at large, making subjectivity and temporality inseparable:

> We are saying that time is someone, or that temporal dimensions, in so far as they perpetually overlap, bear each other out and ever confine themselves to making explicit what was implied in each, being collectively expressive of that one single explosion or thrust which is subjectivity itself. We must understand time as the subject and the subject as time. (Merleau-Ponty, 1962, p. 422)

Merleau-Ponty (1962) further suggested that when we reflect on our existence in the world, we find ourselves at the intersection of multiple temporal dimensions.

Thus, subjectivity is always a condition of "now", pushed by the past and pulled by the future to create an ever flowing present.

The above demonstrates that awareness of temporality is at the centre of situating and developing understanding during the fusion of the horizon. The whole of understanding is then realised in terms of temporal parts in the unity of past, present, and imagining the future (Gadamer, 2004). Hence, understanding is a result of history, what is happening now, and what may be perceived to happen in the future. To take this further, Gadamer pointed out as cited in Regan (2012, p. 299) that:

> What has gone before and how the present is interpreted affects Dasein's temporal future and being authentically aware means engaging with past reflective experiences and opening up retrospective analysis to inform not only Dasein's past but the present and future life.

Gadamer agreed once more with Heidegger in arguing that temporality becomes the basis of events in which the process of the past and present is grounded. Time is the productive feasibility of custom and tradition that aids comprehension through enlightening what presents itself (Heidegger, 1962; Gadamer, 2004). In other words, understanding the present is important because it is always constituted in terms of past meanings and future anticipation (Toombs, 1990) and all past experiences are filtered through the present moment (Dahlberg, Nyström, & Dahlberg, 2008). Thus, interpretation must consider the historical context, including past and present and future, because meaning comes from the past and is also bound to the present, and inevitably the future (Dahlberg et al., 2008).

In keeping with Gadamer's philosophy, "this is where we connect back to what tradition does for us and what tradition means that, interpretively, we do" (Pickering, 1999, p. 180). Tradition "is not over against us, but something in which we stand and through which we exist; for the most part it is so transparent a medium it is invisible to us- as invisible as water to a fish" (Palmer, 1969, p. 177). As noted above, language is perhaps the most crucial medium through which we exist in this way, and so come to any historical encounter; meaning that the boundary limits of our historicality are the boundaries of our language (Pickering, 1999).

The above demonstrates that understanding or interpretation can only be achieved through time and similarly, human existence cannot be meaningfully understood without time (Mackey, 2005). The notion of time always sits together with the concept of space (situated or location). Hence, the notion of being in the world is integral to the conceptualisation of time and space where everything (phenomena) in the world belongs (is situated) somewhere.

Thus, tradition, history, and temporality are inter-connected. Tradition and history are never settled, or correctly interpreted, but rather understood through the interpreter's ever changing horizon (Gadamer, 2004). The profound concept of historicity and understanding is that we are thrown into a world that has a historical context, which becomes better understood as Dasein matures in time (Gadamer, 2004). Not only a foundation of culture and a personal sense, tradition also shapes the internal world of understanding and also feelings and thoughts (Dahlberg et al., 2008). We are always connected with the past because we are part of the history (Dahlberg et al., 2008) and unavoidably not of our own making (Regan, 2012). Where history is important, the past cannot be seen solely as it is (the past), because historical understanding is always involved in the production of our present and future, as well as our past (Pickering, 1999). As such, the hermeneutic goal is to understand the human experience (Laverty, 2003) in terms of a person's background or history and the social context of the experience (Benner, 1985; Draucker, 1999).

In other words, gaining an understanding of the meaning of human experience is a complex process that always involves the background, knowledge, culture, and the history of the person who has the experience being studied.

Both history and tradition, therefore, play an important role in the hermeneutic process: they strongly influence the understanding process. Thus, understanding the breast cancer experience for women is strongly influenced by where those women are situated because history and tradition vary across locations or places. As such, and even though much research has been undertaken around the experience of breast cancer across locations and countries, the outcomes will not necessarily contribute to the understanding of the experience of breast cancer for women in Indonesia.

The discussion now turns to three further theoretical concepts that allowed for a consistent and coherent interpretation in this research; identity, gender, and culture. As Alvesson and Sköldberg (2009) pointed out in relation to hermeneutic interpretation, such interpretation must be externally consistent which means that it should be understandable. These concepts are explored below.

3.4. Self-identity

Definition of self is “an individual’s reflexive sense of his or her own particular identity, constituted vis-à-vis others in terms of similarity and difference, without which she or he wouldn’t know who they are and hence wouldn’t be able to act” (Jenkins, 2004, p. 27). Furthermore, Jenkins explained that identity is a reciprocal understanding of our self and other people, as well as other people’s understanding of themselves and others (Jenkins, 2004). Moreover, a life-threatening illness threatens an individual’s ‘integrity of self’ and greatly interferes with everyday life (Charmaz, 1995). For women diagnosed with breast cancer, where the experience of body change may be inevitable, the integrity of self-identity is challenged.

Indeed, woman diagnosed with breast cancer experience vulnerable encounters that might engender a diminished sense of self. Breast cancer is a potentially deadly disease, and is a life-altering experience that disrupts the fabric of daily life and may alter a woman's self-identity (Cheng, 2010). Self and identity are complex multidimensional concepts. Nonetheless, the concepts of self and identity as they relate to illness have been well argued and researched, by, for example, Bury (1982);(Charmaz, 1987, 1995, 1999); Conrad (1987); Corbin and Strauss (1987). Although many of these studies are grounded in the symbolic interactionist tradition, in the current research "self" and "identity" were considered within a hermeneutic frame. Hence, self and identity were explored from the perspective of health and illness as they are bound to society and culture in their temporal forms.

Thus, as Gadamer argued, identities are formed in a "circular process between past, present and future as well as the experience of otherness" (Buckley-Zistel, 2006, p. 3). In other words, identities consist of the hermeneutic tenet; the hermeneutic circle and temporality that aim to understand others and the experience of others. Buckley-Zistel (2006) asserted that a changing identity is key to hermeneutics and reflects the accomplishment of understanding among others (texts) to a conversation. This reflects Heidegger's stance on interpretation that was subsequently taken up by Gadamer. This encounter may challenge our existing assumptions, which may then be modified.

According to Gadamer (2004, p. 295), the true point of "hermeneutics is the in-between". For example, by analogy, the time and space after a breast cancer diagnosis for the women in this research can be described as the time 'in-between': in-between pre diagnosis and post diagnosis, in-between self and family, and in-between traditional and Western treatments.

3.5. Culture and Indonesian Women

Culture is traditionally understood as a system of values, beliefs, judgments, and behavioural compasses for setting norms and shaping our feelings of shame, guilt, remorse, pride, honour, disgust, taste, and social worth, shared in “the moral circle” (G. J. Hofstede, 2009). Moreover, there are four proposed characteristics of culture. The first refers to that which is learnt from birth through the processes of language acquisition and socialisation. The second charactised that which is shared by all members of the same cultural group The third is adaptation to specific environmental and technical conditions and the fourth is that culture is a dynamic and ever-changing process (Singer, 2012). However, understanding a complex phenomena such as the experience of breast cancer requires an ever moveable view of culture. As Anderson-Levitt argued (2012, p. 451), it is “a messier and more complicated notion of culture as the contested process of meaning making”. Hence, this thesis takes a view of culture as a dynamic and ever changing process, as Dallmayr (2009, p. 24) asserts, is “internally diversified and unfinished, that is, always evolving and on the move”. Through culture, people build the sense of existence and create and and recreate culture within the dynamic interplay of social and environmental forces (Morssink, 2012).

In addition and to construct an understanding of being an Indonesian woman diagnosed with breast cancer, both of the above views of culture need to be extended. This is because understanding of the phenomenon (breast cancer experience) not only includes process but incorporates context. Context comprises the beliefs, practices, and views that characterise a particular group of people such as tradition, traditional healers, women’s roles, and patriarchy. Throughout the life-course, some cultural beliefs can not only be instructive or protective, but can also inadvertently be detrimental to health outcomes (Kostick, Schensul, Singh, Pelto, & Saggurti, 2011).

In keeping with the hermeneutic approach, when reading text or language, understanding occurs when one situates oneself within the context (or tradition) of which that language is a part. The process of situating the self in this way is about opening up to what the text has to say, and thereby changing one's own understanding. This means an openness to history and culture. Hence, hermeneutical views, the understanding of a situation from an interpretation based on cultural traditions of meaning.

Furthermore, culture shapes people's behaviours and plays an essential role in response to health and illness and in decision-making about medical treatments (J. M. Anderson, Blue, & Lau, 1991). More specifically, cultural beliefs and values influence a person's health practices in terms of how a person defines illness, how treatment is explained and managed, how quality of care is perceived, and how a person responds to and copes with an illness (J. Anderson et al., 2003; Fitch, Gray, Franssen, & Johnson, 2000; Klawiter, 2004; Lam & Fielding, 2003). In other words, culture is a key concept that gives guidance to interpreting the world and how people's responses to their worlds are shaped. Culture is therefore central to an understanding of the health practices and experiences of Indonesian women diagnosed with breast cancer.

A majority of Indonesians embrace a patriarchal family system that determines women's roles. The everyday lives of Indonesian women are exposed to patriarchal values reflected, not only in the private domain, but also the public domain. In the words of Priyatna (2013, p. 102), ”cultural values, given the gender ideology, are biased and conflict with women's desire for advancement outside the domestic domain".

As noted, in Indonesia, the majority of the population is Muslim (84%) (Central Bureau of Statistics Indonesia, 2010). A traditional Muslim belief is that illness is a test imposed by Allah (God). If one accepts an illness, then one will be rewarded and the reward may be in the form of forgiveness for sins. In other words, those who suffer illness have been chosen to receive forgiveness for all of the mistakes they have made in the past.

All of the above noted factors influence illness experience, illness behaviour, and the outcome of the illness itself. Culture in all its myriad of forms shapes health beliefs and practices which, in turn, affect a woman's health experience. For Indonesian women, reconstruction of self-identity due to the experience of breast cancer is impacted by the importance placed on family and also surrounding people (friends, neighbours, key persons). Hence, to gain an understanding of the experience of breast cancer and the implications for the self-identity of Indonesian woman it is important to integrate feminist concepts and a Gadamerian approach into the context of historicity, temporality, and tradition. The following section turns to gender and feminist views and how they might inform a hermeneutics framework.

3.6. Gender and Gadamer

Gadamer's work does present difficulties for those who engage with gender. Criticism of his work has been raised by feminist scholars who argue that hermeneutics does not sit comfortably with feminist work because it reinforces the power of tradition and prejudice that presumably includes gender prejudice (Warnke, 2003). Yet, it is also argued that aspects of Gadamerian hermeneutics can be retrieved that resonate with contemporary feminist work (Code, 2003). Thus, although recognising that Gadamer's work is essentially conservative, the way that Gadamer writes about historically locating the process of understanding fits with a framework that seeks to give prominence to the concept of gender.

Importantly, feminists support a hermeneutics of suspicion where text is forced to show a different side of the reality it wants to present. In this way, as feminists would propose, power relations can be uncovered that are largely unknown to the text makers, or in the case of the current research, the researcher. Yet, Gadamer rejected this form of hermeneutics and in so doing , as Fleming, Gaidys, and Robb (2003) argued, revealed a fundamental conservatism. Inherent to Gadamer's work, therefore, is a lack of critical engagement with power and gender, and an absence of what Ricoeur (1974, p. 323) termed "a hermeneutic of suspicion" in relation to traditions of knowledge. In the words of Jantzen (2003, p. 290):

> If Gadamer is right, then it is hard to see how anyone could escape from being locked into tradition, since it is only within traditions and as a result of them that fore-understandings are formed. But if our fore-understandings are already shaped by the tradition, then how can they ever challenge that tradition? The conservatism of Gadamer's position runs very deep.

However, according to Alcoff (2003, p. 232), Gadamer's philosophical hermeneutics is useful to feminist theory, particularly in its epistemology and also in some of the key propositions which she refers to as "nascently feminist". Hence, Gadamer's philosophical hermeneutics offers features that are useful for feminism, including an openness to alterity, or a state of being different, known as interpretation and hence, historically and culturally located; and knowledge as contextual, and thus there is no independent reality (Alcoff, 2003). Although a weakness is an assumption of a single coherent tradition that obscures the existence of different traditions, Gadamer’s work provides a useful basis for interpretation that incorporates the factor of gender.

A plethora of research has been undertaken within the breast cancer area. Within this realm it is generally agreed that research on women with breast cancer cannot be separated from the concept of gender. As Eisenstein (2001) pointed out, political, social, cultural, gender, and race factors intersect in the research around breast cancer and these factors should be incorporated and recognised in any research surrounding the disease. Similarly, Stoppard and McMullen (2003, p. 4) noted that, “in conventional approaches to research and diagnosis, the social context of people’s life circumstances and every day activities are stripped away as unnecessary details in a process that ‘de-contextualises’ their experiences”.

As such, woman diagnosed with breast cancer experience disruption to their everyday lives which is an integral part of the social and cultural contexts. To understand the experience or research in the field of everyday life, such as that of breast cancer, therefore requires the achievement of an account through a process that ‘contextualises’ rather than ‘de-contextualises’. Further to this, Gadamer’s view demands not just a contextualisation but a re-contextualisation as central to the hermeneutic process of understanding of the experience of women diagnosed with breast cancer.

From a feminist viewpoint, that seeks to reveal systems of privilege, transform systems, and emancipate oppressed individuals, gender is the main category of analysis (Breitkreuz, 2005). This means that “by making visible previously invisible female experiences, feminist works aim to correct both invisibility and distortion of female experience in ways relevant to ending women’s unequal social position” (Lader, 1991, p. 71). Thus, it appears that in emphasising the connection between individual experiences and social contexts, feminist concepts can be validly applied in research around women who are oppressed by social, cultural, and religious cultural values and practices.

The task of hermeneutics is “not to develop a procedure of understanding, but to clarify the conditions in which understanding take place” (Gadamer, 2004, p. 295). Hence, for Gadamer, “any understanding of our social, cultural, and historical situation, as well as of ourselves, is possible only because we possess a pre-understanding and pre orientation towards that which we are trying to understand understanding” (Warnke, 2003, p. 58). This means that, in relation to women who experience breast cancer, understanding should be based on the object, which in this case is in the context of Indonesian women that might be culturally, socially, and historically different from other places.

Generally, feminist theory has its origins in the west and as such does not readily or necessarily translate to other, quite different cultures. On the one hand, as noted above, Gadamer’s philosophical view of gender is not an immediate or comfortable fit with a Western feminist position. On the other hand, it appears applicable, particularly in relation to the Gadamerian assertion that understanding is always embedded within the context of the subject being explored. Hence;

> Meaning is neither absolutely subjective or objective: there can be no dialectical interplay between an interpreter and the intrinsic meaning of the text or object, because there is no intrinsic meaning. There is also no pure subject because the subject shares a common tradition with the text and is therefore not autonomous and apart. (Code, 2003, p242)

In other words, gender is an interpretation and a fusion of the historical situation of the people who are part of the stories about Indonesian women with breast cancer and the history of interpretations of gender (Jantzen, 2003). This process can never be a complete, because knowledge of oneself and of others can never be complete. Thus, whether an interpretation or understanding is adequate must rest on the hermeneutic circle and the extent to which parts of the text are interpreted in terms of the whole and the whole in terms of the parts, in a coherent way (Gadamer, 2004).

Furthermore, a discussion on gender is an interesting agenda, and in the context of Indonesia, cannot be separated from culture and religion. It is complex process because of the multiplicity of cultures and religious values ingrained in local perspectives and practices (Priyatna, 2013). A majority of Indonesians embrace Islam and thus gender in this context is largely influenced by the teachings of Islam. Religion is parallel with culture in the practices of people’s lives. Moreover, it is known that Indonesia is a very diverse country consisting of many ethnic groups, and thus, is far from homogenous. This diversity, in turn, brings a “dynamic” to gendered practices, as religion and ethnicity exist as gender variants. To better understand the experience of being an Indonesian woman diagnosed with breast cancer, feminist concepts become an integral feature of the research, in addition to social, cultural, and identity concepts. Hence, all of these concepts are explained through the Gadamerian hermeneutic approach.

3.7. Summary

This chapter provided an in-depth examination of the fundamental theoretical concepts that underpinned this research. The chapter first explored the traditional features of Gadamer’s work and how they could and would inform an interpretation of being an Indonesian woman diagnosed with breast cancer. The exploration was extended to include further theoretical concepts that were relevant to the research and compatible with the hermeneutic frame of Gadamer. It was argued that these latter theoretical ideas of identity, gender, and culture, provided a structure for data interpretation. The concepts were not arbitrarily selected, but arose through what Heidegger and Gadamer referred to as the hermeneutic circle. The following chapter outlines and justifies the methods that were applied in this researched study.

Chapter 4: Methods

4.1. Introduction

This research sought to construct an understanding of the experience of being an Indonesian woman diagnosed with breast cancer, as informed by the lens of Gadamer's (2004) hermeneutics. Gadamer's work, as influenced by Heidegger, presents a broad analytical framework that seeks to connect understanding and time where the latter is defined as the conditions of language, history, and tradition (J. Robinson, 2006).

Research methods are generally understood to be systematic steps applied during a research process as a mechanism for answering a research question. For Gadamer (1989) however, the objective of research inquiry was to clarify the *conditions* that lead to understanding, rather than focus on procedures and processes that may constrain the possibilities of research. As Gadamer (1989) argued there is no method available for a hermeneutic approach that directs a human science investigation. Unlike traditional research methods (such as the natural sciences), which take on the appearance of standard designs or approaches to a problem, interpretive hermeneutic researchers argue for freedom from a strict method and the development of a conceptual framework. Yet, it is fair to argue that while Gadamer was clear that method should not dominate, he was not completely dismissive of method. Hence, the research methodology applied in this research assumed that the objective was not (and could not be) to achieve certainty. On the contrary, not all could be known, because human life is fluid and contextual (Jardine, 1990).

This chapter presents a detailed overview and justification of the hermeneutic approach applied in the research. The chapter begins with a discussion of the Gadamerian premises of hermeneutic inquiry that underpinned the research and informed the research process to produce understanding. The chapter then turns to an outline of the research design and a description of the phases of the research, including sampling, data generation, and data analysis. The chapter concludes with an examination of ethical considerations and highlights the need for a hermeneutical form of rigour to be integral to the research process.

4.1.1. The Hermeneutic Approach

The intent of hermeneutic inquiry is to generate an understanding of the experienced phenomena through the interpretation of a text and not through understanding the author of the text, in this case the participants, directly. Interpretation refers to a "basic action of human thinking; indeed, existing itself may be said to be a constant process of interpretation" (R. Palmer, 1969, p. 9). Hence, the interpretation of text is the point of departure in the hermeneutic process (Alvesson & Skoldberg, 2009), and the aim of interpretation is to understand the phenomenon and the meaning of the text (Geanellos, 2000). Thus, for Gadamer, the importance of interpretation and communication of the human condition must be foremost in the research process.

As noted above, Gadamer does not offer a particular method or a set of rules for research to follow (Austgard, 2012; Fleming et al., 2003; P. J. Wood & Giddings, 2005); the process is purely philosophical in nature (Austgard, 2012). In other words, and for Gadamer "… hermeneutics is not a method but a fluid set of guiding principles aiding the human search for truth in the concealed forgetfulness of language" (Regan, 2012, p. 291). Drawing on method alone, that is method not grounded in a philosophical tradition, is inadequate to produce any level of intelligibility (Gadamer, 2004).

A lack of articulated methods may be a challenge for the interpretive hermeneutic researcher (Holroyd, 2008). Yet, in structuring methods, or in assuming a uniformity, one can minimise the possibility of an “open dialogue between the researcher and the research participant that would help to clarify the conditions for understanding, as well as to expand each individual’s horizon of meaning” (Holroyd, 2008, p. 134). Researchers or philosophers who situate themselves within an interpretive paradigm seek to explore a phenomenon and openly assume that knowledge or knowing is necessarily fluid and incomplete. The method is then an openness and an encounter with the phenomenon as it presents itself (Gadamer, 2004).

The focus of hermeneutics is thus on the phenomenon and not on method (Moules, McCaffrey, Field, & Laing, 2015). Truth is unable to be reached methodically but is grasped directly through a dialectic in response to questions about the actual encounter or subject (phenomenon under study) in the hermeneutic process (R. Palmer, 1969). Hence, “interpretation is framed around careful attention, creative construction of possibilities, and grounded in experience” (Venturato, 2015, p. 5). Through the lens of interpretive hermeneutics, the researcher is given an opportunity to move beyond assumptions and purported truths associated with a phenomenon to a point where alternative possibilities and understandings are allowed to appear.

To accommodate the hermeneutic task, it is therefore essential that hermeneutic researchers engage with the philosophical underpinnings that shape their visions of the world and focus on how they can work towards an interpretation and communication of the human condition (Caelli, 2001). Rather than a prescribed set of methods, and to enable the above, the conduct of research based on Gadamerian principles thus requires a philosophical rather than technical rigour. The central tenets of temporality, language, fusion of horizon, and the hermeneutic circle, as explored earlier, can be understood as the nexus between Gadamerian philosophy and a research approach to interpretation of text (Austgard, 2012). Hence, in this research, the application of Gadamerian hermeneutics is through deciphering (converting, elaborating on) its key concepts.

In its unfolding, an interpretation process begins with a reading of the text and grasping the meaning as a whole. The interpretation then proceeds to a deeper understanding by identification of the relationship of the parts to the whole. In any reading of text, the reader (or researcher) carries expectations or anticipations of the meaning and as such holds some pre-understanding. Thus, this dialogic process of back and forth movement occurs between the researcher and the parts (a significant statement within the text) and the whole (the text as a whole). As Moules et al. (2015) pointed out, the hermeneutic process is neither inductive nor deductive. Rather the iterative process, back and forth between the general and the particular, is referred to as the hermeneutic circle. Moreover, the hermeneutic circle involves not only movement of the parts and the whole, but also movement between pre-understanding and understanding itself. The interpretation process, in which the researcher has a superficial grasp of the whole of the text, then moves forward to a deeper understanding, where the researcher understands the parts of the text in relation to the whole and the whole of the text in relation to its parts (Ricoeur, 1988). As such and as a result of both of these movements, an interpretation appears with a confirmed understanding and a final interpretation will be confirmed by the process of the hermeneutic circle (Geanellos, 2000).

A further dimension involved in the interpretation process is the fusion of the horizon. The process of fusion of horizon is based on the pre-understanding or prejudices by which the horizon of the interpreter is fused with the text in some sense. Yet the fusion of horizon also ends with new meaning, or understanding. Through dialogue and applying questions directed to the whole and to the parts, the two "hermeneutic currents" can cross and enrich each other (Alvesson & Sköldberg, 2009, p. 104). As a result, during the dialogic process, pre-understanding will transform into a new understanding of a phenomena.

The hermeneutic approach was considered appropriate to this research, because, as argued in the previous chapter, understanding the experience of breast cancer involves an interpretation of sociological, cultural, gender, and historical considerations, all of which are intertwined in complex ways. The hermeneutic approach enabled the generation of a new understanding of the complexities of being an Indonesian woman diagnosed with breast cancer. The broad framework that provided the parameters of the research is outlined below.

4.2. Research process

The goal of the research was to explore the actual experience and to gain an understanding of how Indonesian women with breast cancer gave meaning to living with a diagnosis of breast cancer.

4.2.1. Research Sites

The primary site for data generation was the Cancer Support Group (CSG). The CSG was a not for profit organisation established specifically to support cancer patients and survivors. The stated role of CSG is to provide a physical space for sharing experiences and information about cancer. Those working for the CSG also visited cancer patients who were undergoing treatment and organised recreation and sporting events. Membership of the CSGwas voluntary, free of charge, and not limited to cancer patients and survivors. For example, doctors who were interested in cancer management were also members. At the time of data generation, the majority of CSG members (70%) were patients and survivors who had received a diagnosis of breast cancer.

The CSG was located in Bandung, capital of West Java, Indonesia. Bandung is located 263 km north of Jakarta, the capital of Indonesia. In 2015, the population in Bandung was close to 2.5 million people, and in greater Bandung was approximately 8 million people. The majority of Bandung's population are of Sundanese descent. Javanese constitute the largest minority member of which aremostly from nearby Central Java and the eastern part of Java. Other minorities include Minangs, Malay, Batak, and Chinese. International minorities include Koreans and Indians.

4.2.2. Sampling

Within the context of hermeneutic inquiry, selecting appropriate participants is crucial. Van Manen (1997) proposed that certain considerations be taken into account when selecting participants for a phenomenological or hermeneutical study. The aim of sampling in this research was to determine and reach participants who had experiences of breast cancer and indeed who represented a specific population to enhance the possibility that the complexities of the phenomenon under study would be captured. Hence, recruitment of participants was confined to those who had lived the experience, who were willing to share their experience, and who were diverse enough from one another to increase the likelihood of rich and varied stories of the experience. Thus the sample criteria ensured a full exploration of the study phenomena. In keeping with these directives, the inclusion criteria for participant selection was for women who:

1. had been diagnosed with breast cancer;
2. had completed a course of treatment or therapy for at least one year; and
3. were willing to share their experiences of living with breast cancer.

Exclusion criteria were women who:

1. had secondary or metastatic cancer; and
2. were currently undergoing a course of treatment.

The exclusion criteria reflected the sensitivity of the research focus and recognition that women who were undergoing treatment at the time of the research and/or had been diagnosed with metastic cancer, may not be at the point where they could reflect fully on, or make sense of, their experience with cancer.

4.2.3. Recruitment

4.2.3.1. First recruitment phase

All participants were recruited through a process of purposive sampling. Purposive sampling involves selecting participants who can provide rich, in-depth, descriptions of their experiences of the phenomena under study (Patton, 2002). A decision about the research population was important, and influenced by many factors, including the research aims, access, and feasibility. In this research, access to a potential research population was initially pursued through contact with the National Cancer Centre (Jakarta), by way of email. Following some discussion about the research, a referral was made to a cancer support group in Jakarta. Contact was made with the Chair of the CSG, who was very supportive of the research and offered an invitation to attend a regular CSG meeting.

The Chair of the CSG used two methods to inform potential participants about the study. One method was information sharing at the routine two monthly BCS meeting. At such a meeting the Chair of the CSG distributed research participant information sheets and consent forms (see Appendices C and B) to those members who met the research participant criteria. Just two of the 20 people present expressed an interest in participating in the research. This was clearly not an effective method of recruitment. In reflecting on the recruitment method, the CSG Chair noted that many requests had been made of CSG members to participate in research studies.

It was determined that a further recruitment method was required to recruit participants from the CSG. The CSG Chair contacted other members of the CSG identified as potential participants, who had not attended the information meeting. The individuals were contacted by telephone and the research and potential involvement was explained in detail. All were informed that with their agreement, the researcher would make contact for further explanation. A further ten potential participants were identified through this process, and three women from this group agreed to participate in the study. Individual and initial meetings were arranged with the additional three women, and on each occasion a description of the purpose of the study and the level of participant involvement was fully explained, both verbally and in writing. Following recruitment of these participants, a mutually agreed place and time for each individual interview was arranged.

Although there are no definitive rules around sample size in qualitative inquiry, there are some key considerations. These include obvious factors, such as what the researcher wants to know, the purpose of the inquiry, what will be useful, what will have credibility, how to ensure credibility, and what can be done within the available time frame and with the resources on offer. More interviews were necessary to develop a meaningful understanding of the experience of woman with breast cancer.

The researcher subsequently sought support from current study participants to identify and recruit other women with breast cancer. Thus, the recruitment now turned to snowball sampling. Snowballing, as Liamputtong (2013, p. 17) put it, “requires researchers to initially select a few research participants and to ask them if they know others who meet the criteria of the research and who might be interested to take part”.

It was first determined whether the women who were the focus of the snowball method met the selection criteria for the research, and whether they were comfortable with being contacted by the researcher by telephone. One participant knew a number of women diagnosed with breast cancer and agreed to contact these women to determine 1) their eligibility for the research, 2) their interest in participating if they met the inclusion criteria, and 3) whether they would consent to be involved in the study. Through this method the researcher was able to recruit a further four women. On completion of recruitment in this first interview phase, a total of nine women had agreed to participate and were interviewed. Table 4.1 below provides the geographic details for this group of women.

4.2.3.2 Second recruitment phase

The approach to a second phase of interviews was premised on the need for further exploration of provisional analytical outcomes generated from an analysis of interview data. As mentioned above, the key recruitment site was the CSG and a similar process was again followed with this organisation, resulting in consent from a total of 14 further participants.

Table 4.1. A demographic summary of the first research phase participants

No	**Pseudonym**	**Years of diagnosed**	**Treatments**	**Stages of cancer**
1	Murni	2008	Mastectomy Alternative therapy	III
2	Eki	2009	Mastectomy, Alternative therapy	II
3	Yuni	2010	Mastectomy, Chemo	II
4	Maryam	2009	Mastectomy	II
5	Evi	2010	Mastectomy	III
6	Indri	2009	Lumpectomy Alternative therapy	II
7	Yeni	2010	Mastectomy	II
8	Neneng	2011	Mastectomy	I
9	Juju	2009	Mastectomy, Hormone	III

Additional participants were recruited from an oncologist private clinic in Bandung, Indonesia. Access to the oncology clinic was secured through communication with an oncologist who ultimately provided a list of names and telephone numbers of potential participants. The oncologist first contacted potential participants. With the consent of the participants the oncologist provided the names and contact numbers to the researcher of those women who expressed interest in the research. The researcher contacted the women by phone and invited them to join the research study. Five women agreed to be interviewed as a result of this recruitment approach.

Nineteen participants were thus recruited for the second phase and were subsequently interviewed. Table 4.2 outlines the participant background and general demographic information in relation to the second sample of participants.

Table 4.2. A summary of participant demographics for second phase interviews

No	Pseudonym	Years of diagnosed	Treatments	Stages of cancer
1	Zubaidah	2012	Mastectomy Alternative therapy	III
2	Erna	2004	Mastectomy, Alternative therapy	II
3	Mastiah	2008	Mastectomy, Chemo	II
4	Maysaroh	2008	Mastectomy, Alternative therapy	II
5	Dewi	2011	Alternative /Herbal therapy	II
6	Yuli	2011	Mastectomy	I
7	Diyul	2011	Lumpectomy	I
8	Mutia	2006	Mastectomy	II
9	Erna	2006	Mastectomy, Hormone	II
10	Eli	1996	Chemo, Hormone Radiation, Alternative therapy	I
11	Shabilla	2005	Mastectomy, Chemo, Hormone, Alternative therapy	II
12	Nabilla	2005	Mastectomy	II
13	Desy	2009	Lumpectomy	I
14	Ratna	2009	Mastectomy	I
15	Sari	2010	Mastectomy, Hormone	II
16	Zaskia	2010	Mastectomy	II
17	Wendah	2007	Mastectomy	II
18	Ummi	2008	Mastectomy, Chemo, Hormone therapy	II
19	Fitria	2011	Mastectomy, Hormone	II

At the conclusion of the recruitment process, which occurred over a nine-month period, 28 participants had consented to be interviewed for the research and had participated in an interview. The nine months included the period of initial data analysis.

Table 4.3. Demographic and clinical characteristic of participants

Characteristics	N (%)
Age range	
- 30-39	3 (10.7)
- 40-49	11 (39.2)
- 50-59	12 (42.8)
- 60-69	2 (7.1)
Marital status	
- Married	20 (71.4)
- Never married	2 (7.1)
- Widow	6 (21.4)
Education	
- Junior	7 (25)
- Senior	9 (32.1)
- University	12 (42.8)
Employment	
- Housewife	10 (35.7)
- Private	15 (53.7)
- Government	3 (10.7)
Stage of breast cancer at diagnosis	
- 1	6 (21.4)
- 2	18 (64.2)
- 3	4 (14.2)
- 4	
Treatment	
- Western medicine	17 (60.7)
- Traditional medicine	1 (3.5)
- Traditional & Western medicine	10 (35.7)

4.2.3.3. Informed consent

Prior to an interview, the respective participant was given a comprehensive outline about what was involved in participation in the study, both verbally and in writing. This procedure ensured that participants understood the research and possible benefits and risks of being involved. Information provided to participants included the objectives of the study, the process of information gathering, assurances of anonymity and confidentiality, level of participant involvement, and the right of participants to withdraw at any time from the study without any consequences. Written permission was secured before each interview. An informed participant information and consent form prepared in the Indonesian language was provided for each participant (Appendices E and D).

4.2.4. Data Generation

The interview is the art of questioning and interpreting answers and is considered a useful way to learn about the world of others (Qu & Dumay, 2011). Kvale (2006, p. 480) stated that "qualitative research interviewing has become a sensitive and powerful method for investigating subjects' private and public lives and has often been regarded as a democratic emancipating form of social research". The product of each interview was a narrative description of the participant's experience of the phenomenon under study (Dahlberg et al., 2008; Lopez & Willis, 2004).

In this research, data were generated through semi-structured, individual, face-to-face interviews. This form of interview not only allowed participants to talk freely about their lives in their own words (Ajjawi & Higgs, 2007), but also provided broad parameters to ensure that the interviews produced rich and in-depth accounts of the phenomenon under study. Moreover, the semi-structured interview is human conversation based, thereby allowing the interviewer to modify the style, pace, and ordering of questions following responses from a participant (Qu & Dumay, 2011).

Apart from the above, if a researcher wishes to develop an understanding of an individual's experience, both researcher and participant must be willing to engage in a dialogue where each individual's current knowledge and understanding of the experience, in this case the experience of a diagnosis of breast cancer within a particular context, is challenged and expanded upon through social interaction (Holroyd, 2008). Moreover, this understanding can be reached more effectively through an interactive interview process, rather than simply observing the participant under study. Hence, semi-structured, individual, face-to-face interviews were utilised to generate data that fulfilled the research aims of this study.

4.2.4.1. First interview phase

The first phase of interviews explored the ways in which women with breast cancer understood and gave meaning to their experience. Open conversation and the use of a dialogical approach are important techniques when undertaking research interviews. In practice this means that inquiry, using Gadamerian hermeneutics, becomes a dialogue rather than an individual narrative and as such, interpretation permeates all activities involving researcher and participant with their associated social, cultural, and gender implications (Koch, 1999).

The researcher, while engaging in conversation, assumes a reflexive stance where the researcher is cognisant of the need to bring alternative views to the conversation, and not to, in the words of Alvesson and Sköldberg (2009, p. 291), "get stuck in a particular paradigm", or assume a presumed degree of authority over the research subject. The researcher and participant have equal power in the interview process. This data generation approach was appropriate and utilised because the process was congruent with the theoretical framework of hermeneutics. In the words of Gadamer (2004, p. 387), research:

> Is a process of coming to an understanding. Thus, it belongs to every true conversation that each person opens himself to the other, truly accepts his point of view and valid and transposes himself into the other to such an extent that he understands not the particular individual but what he says. What is to be grasped is the substantive rightness of his opinion, so that we can be with each other on the subject.

The task of the researcher during the interview was to facilitate the sharing of experiences by the participants, which meant that the researcher actively engaged with the participant, and importantly, was focused on the phenomenon under study. The interviews were conducted in open dialogue and commenced with a central open ended question to facilitate the participants to articulate their experiences (Dahlberg et al., 2008, p. 185). The central question posed at the start of each interview in this research was:

Can you talk about your experience of being diagnosed with breast cancer?

Additional questions were posed for the purpose of clarification and elaboration where indicated during the interview. For example, the researcher used questions such as the following to encourage participants in sharing their experiences: *Can you tell me more about that? What did you mean when you said…? Tell me more about what you mean by that point?*

Each participant was interviewed individually and all interviews were audio-recorded. The interviews were conducted at various venues where the participants felt comfortable, including a mosque, café, or in the participant's home. It was important to ensure that the interviews took place in secure settings, as it was anticipated that the women would talk about very personal issues. The duration of the interviews ranged from 60 to 127 minutes.

4.2.4.2. Second interview phase

As noted above, following the first interviews, it became evident that further exploration of the research phenomenon was required. Hence, a second interview phase was undertaken to explore and ascertain a better understanding of the impact of cultural and social traditions for Indonesian women who had experienced a breast cancer diagnosis.

The second interview phase focused on the meaningful analytical outcomes identified from the first interviews. There were three main areas of focus that required further exploration. The first was a broadening of the exploration of women's understandings of the breast cancer experience. The second area was the decision-making processes inherent to the situations of women, and a third focus was the positioning of women as a consequence of their diagnosis and the experience of a changing identity.

Seven questions were formulated to explore the dimensions of culture and social tradition during the second phase interviews, as follows:

1. Can you tell me about your earliest memories of hearing/knowing about cancer?
2. How did you come to know and what did you think about cancer?
3. What do you think are the key influences on the ways in which women in Indonesia experience breast cancer?
4. What changes in the roles of Indonesian women have you observed in your lifetime?
5. How do you think religion has influenced the roles of women in Indonesia?
6. How have your views changed about cancer over your time?
7. Can you talk about what has influenced your view of cancer?

4.2.4.3. Interview transcription and translation

The translation process was undertaken from the premise of Gadamer (2004, p. 387) that a translation "cannot be simply a re-awakening of the original process in the writer's mind; rather it is necessarily a re-creation of the text guided by the way the translator understands what it says". The translation process sort to minimise the "fundamental gulf" (Gadamer, 2004, p. 387) between the two languages in drawing on the strategies outlined below to ensure that the translation language was "proportionate to the original" (Gadamer, 2004, p. 389).

There are a range of approaches in cross-language research translation where a translator is involved at some stage during the research process. These include back translation, partial translation, parallel translation, and simple translation. Back translation refers to a process whereby a document is translated into another language and an independent person translates the document back into the original language. Parallel translation is where two or more independent translators conduct translation of the same document of data. Simple translation is where one person translates data and this is considered potentially the weakest approach.

This research applied a mix of partial, parallel, and simple translation. Back translation was not used nor deemed necessary. This was first, because all interviews were conducted in Bahasa (Indonesian language) and subsequently transcribed in Bahasa by the researcher. Translation of only a small portion of the interview transcripts (Gadamer, 2004), by an Indonesian professional translator, was undertaken for the purpose of scholarly review and discussion with the researcher's supervisors. Second, the translation process adhered to the criterion of conceptual (rather than lexical) adherence (Jandt, 2015). In this sense, the translation of words into English remained fluid (van Nes, Abma, Jonsson, & Deeg, 2010) and was the subject of ongoing discussion between the researcher and supervisors. The third and most significant reason for not engaging with back translation was that the analysis up to the point of theoretical writing was conducted in Bahasa by the researcher, who was fluent in this language. Conceptual outcomes and data excerpts were then translated into English by the researcher and again as the outcome of meaning considerations. It was assumed that the researcher's translation was part of the analytical process, and hence, was not a neutral exercise. As such, elements of data analysis were undertaken in either, or both, Bahasa and English. The process of data analysis as outlined below does not, however, indicate the shift from one language to another. The focus of interpretation was not ‘fact’ nor ‘data’, but the meaningful symbols or signs (Alvesson & Sköldberg, 2009) reflected in the text. In summary, the focus was on the theoretical rather than lexical dimensions of the analysis. As Alvesson and Sköldberg (2009) pointed out, text in isolation holds no meaning but must be theoretically contextualised in the process of analysis for understanding to occur.

4.2.5. Data Analysis

It has been argued above that a hermeneutic interpretation of data is not based on predetermined steps of analysis, but rather the intent is to understand the human phenomenon as openly as possible. The main objective is to focus on data as a whole and as a part of the entire lifeworld (Dahlberg et al., 2008). In order to gain an understanding of certain phenomena, however, Gadamer (2004) offered valuable insight into how to develop a deep understanding. As Gadamer (2004) noted, the task of hermeneutics is not simply a set of constraining techniques that are designed to produce a consensus or uniformity of outcomes. Rather, hermeneutics is a progressive learning process (Dallmayr, 2009) which may be transformative in the sense that we can experience otherness. This is critical, because individuals understand a phenomenon or text in different ways, and these understandings vary at different time points (Dahlberg et al., 2008). Hence, a prerequisite for progressive understanding is a desire to engage with diversity in such a way that transcends “our separate minds (worlds)” (G. Palmer, 1987, p. 98). The figure below depicts the iterative theorising hermeneutic process.

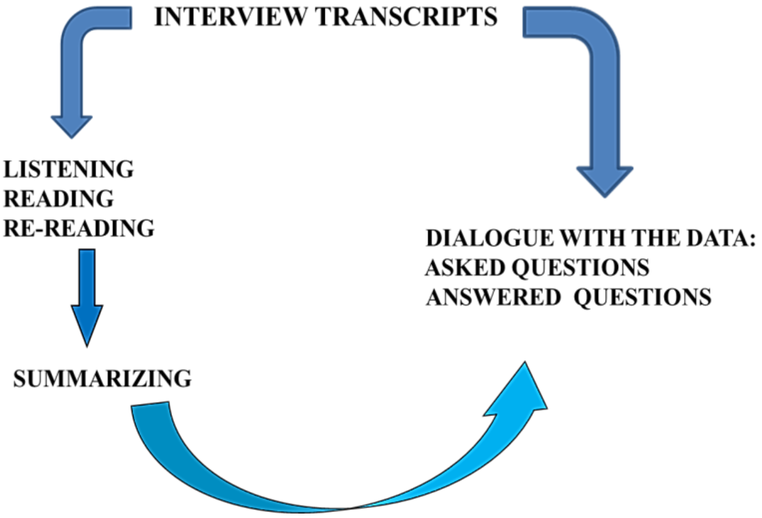

Figure 4.1. Basic process of the hermeneutic analysis
(Adapted from Alvesson & Skoldberg, 2009)

A more detailed explanation of the data analysis is presented below. The analysis was organised around two processes; initial data analysis and secondary data analysis, as reflected in the interview phases.

4.2.5.1. Initial data analysis

The focus of the first phase of interviews was the ways in which women with breast cancer understood and gave meaning to their experience following a diagnosis of breast cancer. General inductive analysis was undertaken at this stage. The analysis generated a broad overview, or picture, of the discovery of abnormalities or signs of breast cancer that was reflected in the processes of seeking (or not seeking) diagnostic confirmation, deciding upon (or not) a treatment, and finally moving towards a state of recovery physically, materially and emotionally.

The initial theorising was extended for an in-depth exploration and examination of the concepts of culture and social context that became the focus of the second interview phase and related data analysis.

4.2.5.2. Second phase data analysis

As noted above, the focus of the second phase of analysis was to explore the cultural and social dimensions of the experience of Indonesian women diagnosed with breast cancer. All second phase interview data were initially subject to interpretation similar to the first phase, with a subsequent analytical process undertaken, as explained in the following section. At this point, the first and second phase interview data were assimilated and analysed.

4.2.5.2.1. The general hermeneutic analysis process

Data analysis was grounded in the analytical processes drawn from the principles and processes of hermeneutic inquiry, as informed by Alvesson and Sköldberg (2009) and Dahlberg et al. (2008). The analysis consisted of three key levels of hermeneutic inquiry, where the focus was not limited to searching for meaning, but extended to a search for explanation (Dahlberg et al., 2008). In so doing, data analysis moved from a preliminary understanding (the beginning of the process of understanding) to a pattern of interpretation and on to a sub-interpretation. At this final level, a new horizon was conceived that explained the theoretical ideas about the experience, in this case, Indonesian women with breast cancer. The levels of hermeneutic analysis utilised in this research are expanded upon in the following sections. The following figure 4.2. depicts the processes of hermeneutic analysis.

Interpretation is synonymous with hermeneutics, and vice versa and thus the analysis in this research was interpretation. In the words of Moules et al. (2015, pp. 117-118) “interpretation occurs throughout the multifaceted engagement with a topic via literature and research interviews, transcribing the interviews to text and reading and re-reading them, developing interpretive conjectures and writing about them”.

Hence, the application of hermeneutic analysis required the researcher to simultaneously engage with the interview transcripts in a number of ways.

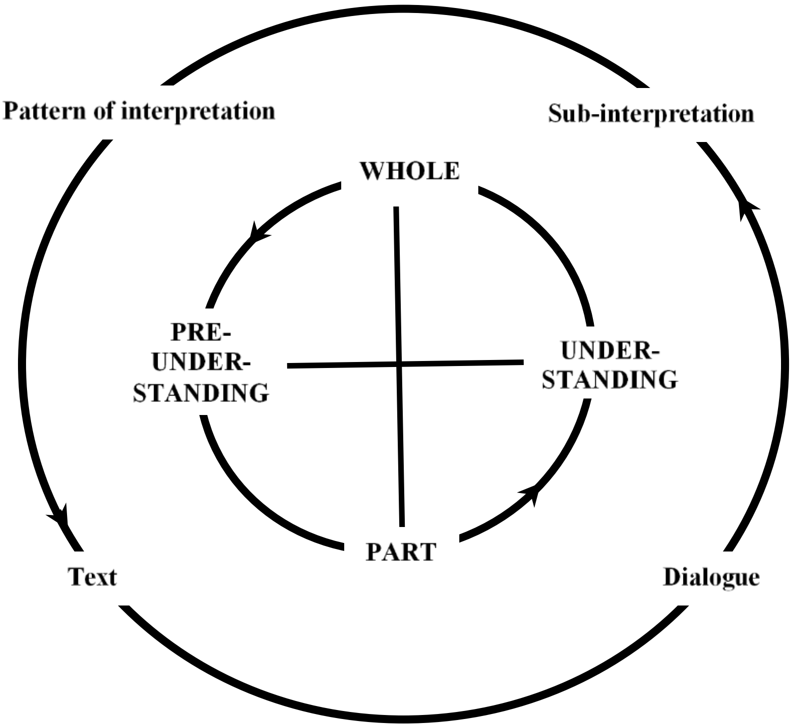

Figure 4.2. The hermeneutic analysis process
(Adapted from Alvesson & Skoldberg, 2009)

The process involved reading and re-reading of transcripts, posing questions, and bringing questions to the literature and back to interview transcripts (Moules et al., 2015). Integral to the analysis and dialogue with text was both a focus on data and an openness to new ideas (Alvess & Skoldberg, 2009; Gadamer, 2004). From this stage, the hermeneutic process moved to an initial analysis known in this research as preliminary understanding.

4.2.5.2.2. Pattern of Interpretation

Preliminary Understanding

While the concept of dialogue generally refers to conversation between two people, in this research, dialogue occurred between the researcher and text. The form of dialogue refers to a way of engaging with text by focusing on significant statements. There was, however, a resistance to the reductionism of a thematic analysis, where it is assumed that frequency informs significance. On the contrary, hermeneutic analysis is interested in both the particular and indeed the extraordinary (Moules et al., 2015) and the world. In the words of Alvesson and Sköldberg (2009, p.121) "Every interpretation is historical, relative, in the sense that it always presupposes historically transmitted preconceptions…". Understanding is thus grounded in both tradition and dialogue and this is how the hermeneutical conversation with text can transform our horizons.

The hermeneutic process involves an initial or preliminary reading of text. The aim of this reading is to grasp a first impression through reading a text as it presents (Röing et al., 2009). This preliminary reading provides clues about what is going on and contributes to sense-making about the unknown with what is more familiar (Dahlberg et al., 2008). Preliminary or pre-understandings play a necessary role in understanding and making sense of the world. Without pre-understanding there can be no understanding of the world, because there would be an absence of anything to reflect upon. As Gadamer (2004) posited, prior researcher experience plays an important role in the process of interpretation of the meaning of the phenomenon under study.

In order to arrive at a preliminary understanding, the researcher determined a form of structure within the data, through the identification of patterns within the text. This began with an identification of the pre-understandings of the researcher about the experience of caring for, or knowing, women with breast cancer. Prejudices or pre-understandings are necessary conditions for our understanding of the present context (Dahlberg et al., 2008; Debesay, Nåden, & Slettebø, 2008). This means that we not only meet the world with prejudice, but also with preconceived expectations based on our prior experiences. In application, this meant that during the hermeneutic process, the researcher (interpreter) was involved in the generation of new understanding through a transformation of the researcher's own frame of reference. Thus, in bringing the above principles to hermeneutic analysis, engagement with differences, ambiguities, and relationships identified in text will yield a deeper understanding beyond what is immediately provided by simply reading through the text (Alvesson & Sköldberg, 2009).

Pre-understanding for this study was about the experiences of women diagnosed with breast cancer in Indonesia. For the researcher, previous knowledge had arisen from the research literature around experiences in caring for breast cancer patients and through discussions with people who had expertise in the area of breast cancer. This pre-understanding, therefore, informed an initial interpretation in the analysis process. This is quite different from the tenets of phenomenologists, such as Husserl, where it was proposed that previous understanding be put aside or suspended in the research process (Gadamer, 2004). The assumption in the current research was that understanding required dialogue and conversation with the text, and that this dialogue can only take place if those engaged brought some information and knowledge about the phenomenon.

While reading the interview text, the researcher analytically noted significant statements (Alvesson & Sköldberg, 2009) and identified and marked sections of text that stood out as part of the experience of breast cancer. In so doing, the researcher focused on significant words or statements that were close to the context of this study. Nonetheless, while the text was reduced in this process, there was the potential to lose important parts or words. The researcher was therefore vigilant when cutting or reducing parts of the text or words from the text.

Table 4.4. Example of preliminary identified significant statement

Woman's statement from transcriptions	**Significant statement**
I asked my husband for his permission and whether he would allow me to ask my friends for help, because he is my husband and I didn't want him to lose his dignity.	*Asked my husband for his permission* *I didn't want him to lose his dignity*
…after it was found to be malignant, with her husband's permission, it was removed. She did not know that it was to be removed. After the surgery, it was gone, and she was down, very stressed and resentful.	*She did not know that it was to be removed. After the surgery, it was gone, and she was down, very stressed and resentful*

As noted above, interpretation is accessed through the text (the narrative of interview). Indeed, initiating a dialogue with text is an established hermeneutic procedure (Alvesson & Sköldberg, 2009). Hence, the use of a question framing approach can be a free and open way to manage data. As Alvesson and Sköldberg (2009) argued, 'knocking' at the text, which means listening or asking questions of the text, is important. By constantly posing questions, new knowledge is created and new questions arise so that the process can recommence (Alvesson & Sköldberg, 2009, p. 122).

In posing questions, the researcher considered what was going on and what it meant. An example is as follows:

> *I wish I knew earlier and went for treatment immediately. It would not have been like this. It's wasted… If we had money, we would seek treatment straight away. If we had money, for any illness that we experience. (02_P04)*

It may be that the above comment referred to financial difficulties in accessing treatment. It may also reflect a process of making sense of, or rationalising, late presentation to the hospital. Understanding this required that this partial text was connected to other text or statements so that it could be interpreted within context.

Importantly, however, context extended beyond what was immediately read to a unity in terms of its historical, social, and cultural context. During this interpretation process, text is transformed and takes on an appearance that delivers understanding. This means that text cannot say or deliver anything before it is interpreted. Because research text stands on the boundary between the expressed and unexpressed, it therefore requires interpretation of both the expressed and unexpressed to reach understanding (Geanellos, 2000). In the words of Gadamer (1989, p.41):

> The interpreter's task is to intervene when the text cannot be heard, when it is not doing "what it is supposed to do," so that "whatever is alienating in a text, whatever makes the text unintelligible" can be "overcome and thereby cancelled out." Once the text is heard, the interpreter's only remaining function is to "disappear completely to the achievement of full harmony in understanding.

Thus, interpretation began with a reading of the text and a grasping of the meaning of the parts and proceeded to a deeper understanding by identification of the relationship of the parts to the whole, which incorporated the full context.

Fusion of Horizons

As has been noted, an integral component of the interpretation process is the fusion of the horizon. For Gadamer, the fusion of horizon occurs when our own horizon (knowledge, pre-understanding within the context of tradition and history) is understood in order to understand that of another (text within the context of tradition and history) (Turner, 2003). This process is based on pre-understanding or prejudices, whereby the horizon of the interpreter is fused with the text in some sense. The questions glides back and forth between the 'old' assumptions imposed on the text in the shape of pre-understandings and new understanding.

Table 4.5. Example of pattern of interpretation

Pattern of Interpretation	
Significant statement	**Preliminary understanding**
- There are plenty of people who have succeeded in herbal medicine. - Then I went to a herbalist again. - Even people who have been diagnosed with cancer do not want to go back to a doctor. - We are traditional people. We still believe in something like that... up until now, well. I think that it will always come back to God's will. - I did not get operated upon right away and I did not take any medicine, - I will not let you be operated upon, - I heard that when the lump is operated on it grows again. - Even though the husband has already asked to for the operation to go ahead, the wife doesn't agree then the operation cannot be done. A decision is supposed to be made by the person effected.	A. Surgery as the last choice of treatment. - Double delay (diagnosis and treatment). - Choice of treatment. - Surgery vs traditional healers. B. Accessing health care facilities - Collectivist - Interpreting risk - Social punishment

The process began with a reading of the whole in order to gain a preliminary understanding of the experience and context before various parts in the text came into focus (Dahlberg et al., 2008). The questions directed at the whole also alternated with questions directed at the parts. In this way, the research problem could be transformed during the process, while at the same time the transformation was influential. As argued by R. Palmer (1969, p. 14), "the task of interpretation must be to make something real, near and intelligible". The fusion of the horizon, therefore, come to an end with new meaning or new understanding (Alvesson & Sköldberg, 2009).

In this research, fusions of horizon occurred on multiple occasions, following the hermeneutic circle of questions, posing and moving from parts to the whole and back again. In other words, during the process of initial interpretation, the researcher's pre-understanding and new understanding fused with the text (parts and whole). This dialogue continued until all data of general importance for the research question was covered (Dahlberg et al., 2008). The process occurred again and again in this research until a broad understanding of the phenomenon under study became known.

Using the example of the participant text above, an analysis involved previous text, the following statement within the text, and the end of the text, all of which contributed to preliminary understanding. Furthermore, understanding was not limited to the whole of the interview text, but extended to other, external knowledge. Thus, the whole consisted of the interview scripts and other sources, such as theoretical and research works (Alvesson & Sköldberg, 2009).

Hermeneutic circle

The hermeneutic circle is a metaphor that refers to an ongoing process of conceptual understanding and interpretation (Moules et al., 2015). Hence, this hermeneutic research sought to construct meaning and transform those meanings, so that the unknown became something that could be understood by the researcher. The iterative process of dialogue, back and forth, occurred between the researcher and the parts (e.g., a significant statement within the text) and the text as a whole (Ricoeur, 1988). The hermeneutic circle involves not only movement of the parts and the whole, but also movement between pre-understanding and understanding itself. Thus, as a result of both these movements, interpretation appeared as a confirmed understanding and the final interpretation was confirmed by the process of the hermeneutic circle (Geanellos, 2000). All of this interpretative activity means that the hermeneutic circle is "not a method for uncovering meaning, but rather a description of how human understanding can be created from a stance of focused curiosity and reflexive attention to different standpoints and ways of seeing a topic" (Moules et al., 2015, p. 122).

Comprehending that the dialogue used in the hermeneutic circle, which brings the parts and the whole together, does so in a way that can never be finished, is also of importance. Furthermore, for dialogue to occur, there must be a process of shared understanding. For Gadamer, this shared understanding is progressed where dialogue ascends to a higher universality that overcomes, not only one's own particularity, but that of the other (Roy & Starosta, 2001).

A further and critical point is that understanding and dialogue are shaped by history and tradition. What we understand can never be described outside of one's historical and personal context. History and tradition in everyday life incorporate norms, attitude, and values, which shape our view of the world. Nonetheless, history and tradition are not immovable forces. Where dialogue in the present time can bring about revision, so that revision may result in a reinterpretation of history and tradition. This is the hermeneutic circle. In moving from a preliminary understanding in hermeneutic analysis the construction of a tentative interpretation formed the next level of analysis.

Tentative interpretation

A tentative interpretation means to construct a framework or to communicate the essence of what data reveal. A tentative understanding is thus arrived at through an explanation of the meaning and the relationship of different parts of the texts drawn from the preliminary understanding (Dahlberg et al., 2008). Moreover, "the explanation must be within the contextual frame and background, by using the pre-understanding in order to understand the phenomenon under study in a new way" (Dahlberg et al., 2008, p. 283). The explanation of the interpretation that is generated can be derived from existing knowledge or from prior research findings in the field (Dahlberg et al., 2008). However, as Dahlberg et al. (2008) pointed out, and as is the practice in the varied iterations of interpretative research, bringing existing knowledge to theorising is best not employed in the initial process of interpretation, because this may disturb, rather than enhance the interpretive process. As such, the function of theorising in the interpretation process is "to help us see data and its meaning better" (Dahlberg et al., 2008, p. 284), rather than impose predetermined concepts on interpretation.

In the current research, the significant meaning relevant to the breast cancer experience, and thus 'the whole', was constructed as a contextual frame that incorporated culture and socialisation. This level of interpretation raised the analysis to the next level, where understanding was situated within the cultural and social context. Tentative interpretations were generated from this point.

The next level of hermeneutic analysis consisted of a new approach to the interpretation of text. The goal was to arrive at a main interpretation of the phenomenon being studied by connecting previous interpretations and identifying any patterns that may not have been obvious in the early stages of analysis (Dahlberg et al., 2008). This level of analysis is termed sub-interpretation.

Sub-interpretation

In order to explain an interpretation comprehensively, tentative interpretation must be raised to a higher level of abstraction, and in turn, becomes the main interpretation (Dahlberg et al., 2008). This process involves the application of tentative interpretations to construct a broader framework and comprehensive explanation. This is the point at which these early interpretations are assimilated into a logical explanation. A comprehensive interpretation that binds together previous interpretations, and at the same time is congruent with existing knowledge or theories is considered a "reasonable" interpretation (Dahlberg et al., 2008, p. 285). Interpretations that cannot be theoretically grounded must either be developed further or removed from the findings. Hence, not all tentative interpretations are guaranteed to elucidate the complexities that represent the research phenomenon as a whole.

Furthermore, in order to arrive at a main interpretation, the dialogue with text/data continues throughout the interpretation process. In the elaboration of all sources of data, such as previous research or theories, the researcher must make sure a focus is maintained on the research issue and the participant experience. For Palmer (1969), "a fundamental problem in hermeneutics is how an individual's horizon can be accommodated to that of the work" (R. Palmer, 1969, p. 25).

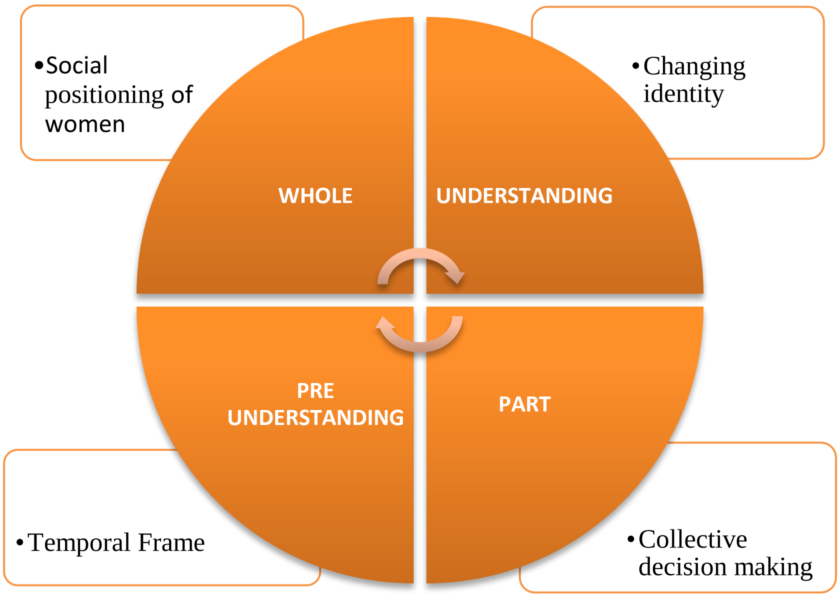

Figure 4.2. Higher level final analysis of the hermeneutic process

In other words, researchers cannot be inflexible in adhering to pre-understanding, but should be ready to experience new information and new understandings as an outcome of the process of hermeneutic analysis. The final analysis concluded with a new horizon that developed from the interpretation process. The new horizon formed the basis of further abstraction and exploration of the theoretical concepts that comprised the experience of breast cancer in the context of culture, society, and history. An example of the higher level analysis within the hermeneutic process which led to a main interpretation, is depicted in Figure 4.3. above.

Table 4.6. A summary of the outcomes of a hermeneutic analysis of the experience of women diagnosed with breast cancer in Indonesia

Preliminary understanding	Tentative Interpretation	Main interpretation
A. Positioning surgery as a last choice - The double delaying - Turning to traditional therapies - Rationalising decision B. Collective - Fate and bargaining - Accessing resources	Collective decision-making	
Women's movement - Gendered practices - Gender and community - The contemporary context	Social positioning of women	Temporal experience of breast cancer: Remaking a future
A. Changing gender identity - Normalcy B. Changing community identity - Stigma and cancer - Disclosing vs concealing -Social punishment - Metaphors and cancer - Salient identity	Changing identity	

The complexities of the experience of the women participants were ultimately explored by engaging with the particular meanings of decision-making, women's roles and changing identity through a temporal lens. In the application of the concept of temporality the issues that constituted the experience of breast cancer for the women participants were interpreted within a frame that gave emphasis to a juxtaposition of the elements of the experience rather than producing a narrative that assumes a linear progression from diagnosis onwards.

4.3. Ethical Considerations

Ethical considerations are critical to the undertaking of any research where research procedures must ensure the safety of participants involved in a study (Rogers, 2008). Therefore, for any research to be ethical, it is expected to comply with appropriate ethical regulations issued by ethics committees (M. Fox, Green, & Martin, 2007). In the current research, ethical approval was obtained from the University Human Ethics Committee at the Queensland University of Technology and the approval number is 1100000313 (see Appendix A). In conducting research with human participants, a number of ethical principles apply. The principles concern consideration of the level of risk involved, upholding confidentiality and anonymity, gaining informed consent, and ensuring correct procedures of data management.

4.3.1. Risk

A level of low risk was identified in this research. The assessment of low risk was made on the basis that the information communicated by participants was at the level of everyday conversation. Nonetheless, the interviews were focused on the experience of being survivors of breast cancer, which may have resulted in some level of discomfort in talking about a personal and sensitive experience. To manage this risk, participants were notified that if they experienced any sense of discomfort at recalling very personal information, the interview would be stopped and the participant given an opportunity to withdraw or to debrief. If a participant expressed a wish to discontinue an interview, the researcher would ensure that the decision was respected and the interview would be terminated. However, in the current research the interviews did not result in any requests to withdraw and there was no sense of discomfort displayed or noted by participants.

4.3.2. Confidentiality and Anonymity

Confidentiality and anonymity of participant information was maintained throughout the study. Confidentiality is concerned with protecting the information provided by participants (Ezzy & Liamputtong, 2005). Confidentiality is maintained as a means to secure privacy and to protect the research participants from harm (Kaiser, 2009). In this research, confidentiality was achieved by ensuring that no person would have access to interview tapes or transcriptions apart from the principal researcher and her supervisors, for the purpose of monitoring the research process, and in particular, the process of analysis. The information provided by participants was used only for the purposes of this study. Participants were also individually identified by a code and pseudonym, rather than name, for tracking interview data.

Even though the concepts of confidentiality and anonymity are commonly used interchangeably (Saunders, Kitzinger, & Kitzinger, 2015), anonymity is in fact a part of confidentiality and refers to the act of “keeping participants’ identities secret” (Saunders, Kitzinger, & Kitzinger, 2015, p. 617). There are six key areas of anonymising: people’s names, places, religious or cultural background, occupation, family relationships and other potentially identifying information (Saunders, Kitzinger, & Kitzinger, 2015). Thus, changing participant names is one process of anonymisation. As C. Scott (2005) pointed out, anonymity constitutes a continuum from fully non-identifiable to nearly identifiable.

In this study, anonymity of the participants was maintained through the following process. Prior to respective interviews participants were asked to nominate pseudonyms by which they would be known in the research. Such a precaution ensured that anyone accessing the interview tapes would not be able to identify any of the participants. Any information that may have led to the identification of participants was not included in the final research report. The individuals who assisted with the recruitment processes were not provided with the names of participants who expressed interest, nor were they informed of those individuals who ultimately took part in the study.

4.3.3. Data Storage

All information pertaining to the study was protected for current and future access. Social science data are seen mainly as a potential resource to generate new hypotheses, findings, and theories (Parry & Mauthner, 2004). Yet, the theoretical assumptions underlying qualitative research are not always explicit (A. Broom, Cheshire, & Emmison, 2009). Hence, datasets should be secured and arguably not used for secondary or further analysis by others than the researcher.

In this study, datasets remain non-identifiable and all hard copy documents were destroyed upon completion of analysis. Electronic records have been retained, secured by password protection and in accordance with the University data management policy. The researcher is the only individual who has access to the datasets.

4.4. Rigour and Transferability

Rigour is a problematic concept, particularly in interpretive research. There are those who consider rigour to be an essential aspect of qualitative research (Caelli, Ray, & Mill, 2003; Morse, Barrett, Mayan, Olson, & Spiers, 2002; Trainor & Graue, 2013) and others who reject any attempt to set down uniform criteria upon which qualitative research might be judged (Pierre & Jackson, 2014; Seale, 2002).

Generally, rigour is understood to be “the degree to which researchers hold themselves to standards of inquiry that address challenges to the credibility of a study’s findings” (Armour, Rivaux, & Bell, 2009, p. 102). What those standards might be is open to question, as evidenced in the numerous frameworks suggested for the purpose of giving methodological legitimacy to qualitative inquiry. Nonetheless, despite the variation in approaches to rigour, there is a prevailing requirement that qualitative research be shown to be accountable, systematic, and high quality (Morse et al., 2002). As has been well noted in this research, Gadamerian philosophy is not associated with definitive methods. Nonetheless, there are general guidelines that may be applied (Moules et al., 2015). The guidelines have the function of ensuring that a researcher is oriented and makes responsible, reliable, and defensible decision (Moules et al., 2015). Thus, to avoid problems inherent in general and paradigm specific criteria and techniques that assume a uniformity across qualitative research (Armour et al., 2009), this research argues the importance of demonstrating a level of methodological thoroughness and consistency. Moules et al. (2015) referred to this as being methodical.

Rather than aspire to rigour, a methodical stance in hermeneutics is demonstrated through the persuasiveness of argument around the philosophical research underpinnings and a congruence with the research approach. Therefore, the researcher developed an adequate understanding of the philosophical principles and the interrelationship between philosophical underpinnings and any methods employed (Maggs-Rapport, 2001). In order to answer the research question, the philosophical underpinnings in the current research drew on the application of Gadamerian hermeneutic analysis, as outlined by Alvesson and Sköldberg (2009) and Dahlberg et al. (2008).

A methodical approach also relates to the treatment of generated data. The processes of data generation should be described and recorded in such a way that enables others to trace the research process if desired. As Trainor and Graue (2014, p. 270) also stated; “data collection or analysis strategies can be internally evaluated in terms of whether the procedures make sense or align with the research questions or methodological tradition”. For this study, the methods of data generation have been outlined in detail and their application clearly demonstrated. Furthermore, data analysis has been described, and examples of the levels of interpretation provided. Hence, the outcomes of this study are auditable.

Transferability is a further concept generally associated with rigour in qualitative research. It refers to the importance of producing theoretical knowledge that may be available to apply to other similar individuals, groups, or institutions (Padgett, 2008; Sandelowski, 2004). In hermeneutics, rather than transferability that suggests the imposition of knowledge, a more appropriate concept is relevance. The perception that knowledge is relevant to a context or situation may precipitate dialogue, and therefore raise further questions and an ongoing process of interpretation.

4.5. Summary

The purpose of this chapter was to provide a detailed description and justification for the data generation and analysis approaches applied in this research on the experience of being diagnosed with breast cancer. In order to gain an in-depth understanding of the contextual meanings of the experience of being diagnosed and living with breast cancer in Indonesia, the data generation was undertaken in two phases. The initial phase was exploratory, and sought to elicit significant analytical understandings to be further explored and contextualised in the second phase of data generation. The interview frame in the second phase broadened the parameters of the research to the social, cultural, historical, and traditional realms. The processes addressed included criteria for study participant recruitment, data generation, and data analysis.

The data analysis, which included patterns of interpretation and sub-interpretation, was also explained in detail. The patterns of interpretation generated preliminary understanding and three tentative interpretations were subsequently generated; *collective decision-making, the social positioning of women, and changing identity*. A sub-interpretation produced the main (core) interpretation; the temporal experience of Indonesian women diagnosed with breast cancer: *remaking a future*. The chapter concluded with a discussion of ethical considerations and processes for establishing rigour throughout the study congruent with Gadamerian hermeneutics. The following chapter explores one of the interpretations generated in the research, the concept of *collective decision-making.*

Chapter 5: Collective Decision-Making

> *They trust their friend more, except if they meet people like us, who have experienced the disease and they see that we are like this, healthy again, We slowly gain their trust because they still don't believe it. The relationship among Indonesian is too close so when someone is ill we visit them, saying this, saying that, so the person is sometime confused.* 15P_05A

5.1. Introduction

The assertion of this chapter is that decision-making is an important component of the breast cancer journey and in large part determines the outcome and success of treatment. Furthermore, there is a complex assemblage of interrelated factors that influence decisions over breast cancer treatment that fall within the social and cultural realms. These factors shape not only access to, but the form of knowledge that leads to choices and decisions. An understanding of this process is critical in determining how and why women delay diagnosis and elect a form of treatment.

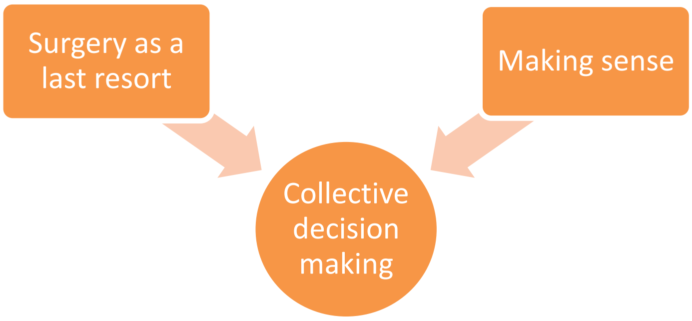

Figure 5.1. First Analytical Finding

In addressing the above, this chapter presents an exploration of the first of three tentative interpretations generated through data analysis. The chapter first explores the complexities that surround the *collective decision-making* of women diagnosed with breast cancer in the research context. Underpinning this process are two related sub-interpretations; the first of which is *positioning surgery as a last choice,* which includes the double delay of diagnosis and treatment, choice of treatment, and Western versus traditional medicine. The second sub-interpretation is *cultural mapping,* which incorporates bargaining with fate and social punishment.

5.2. Positioning Surgery as a Last Resort

5.2.1. The Double Delay (Diagnosis and Treatment)

Regardless of the dominance of any one factor in a particular context, there are many interrelated dynamics associated with a reluctance to seek medical advice in the first instance that, in turn, lengthens the period to cancer diagnosis (Gold, 1964; Gullatte et al., 2010; Simon, 2006). Indeed, delay following the appearance of breast cancer symptoms means that advanced presentations and large tumours are very often apparent at the time of diagnosis (Elzawawy, Elbahaie, Dawood, Elbahaie, & Badran, 2008). When the research participants first detected alterations to their breasts, they sought information and intervention from family members, friends, neighbours and others and only as individual situations worsened did the women turn to biomedical health care. Most of the women, therefore, presented to health care services for treatment at more advanced stages of breast cancer. How a process of delay in seeking medical treatment unfolded for the women in the research is reflected in the following participants’ comments:

> *When I was diagnosed as having cancer just like that... I was not ready to go through with medical treatment. I heard that if I followed medical treatment I would risk all sorts of problems. It was all negative information. And so I went to find herbal treatment. On my friend's advice I made a concoction of red betel myself, and I tried this herbal potion for 3 months.* 1P_01B

> *I was told it had to be operated on but I didn't do anything. Just acted as usual. It took a long time. Yes, I don't know, in my head I just did not have a disease.*
> 1P_04B

As noted in Chapter Two, breast cancer related delay in diagnosis and treatment exists as a major global public health challenge. Delay continues to occur despite advances in diagnostic science, research and technology that have significantly improved cancer care and treatment. The result of advances in diagnosis is better outcomes and increased survival for women with breast cancer (Rajaram & Rashidi, 1999) and when surgery is performed for breast cancer in a timely manner the outcome is generally positive (Han, DelaMelena, & PA-S, 2011).

There are, however, notable differences across nations in terms of incidence and outcomes of breast cancer and in broad geographical terms between developed and low and middle income countries (Unger-Saldaña, 2014). An estimated 80% of people with cancer present in developing countries at an advanced stage (B. O. Anderson et al., 2006). Where breast cancer is concerned, lower and middle income countries have a lesser, although increasing, incidence and much poorer outcomes than developed countries (B. O. Anderson et al., 2006). The disparity is also reflected in the substance of the research on breast cancer diagnosis where a dominant focus in developing countries is on patient delay and in developed countries is more often on issues related to health care system delay (B. O. Anderson et al., 2006; Freitas & Weller, 2015). Nonetheless, a significant proportion of research in all countries around breast cancer delay has focused on screening. The obvious assumption is that early detection will result in early diagnosis and treatment and will therefore ensure an optimal therapeutic outcome. In developing countries, however, not all women can rationalise the advice of health professionals or doctors and hence early diagnosis does not necessarily lead to the most efficacious treatment.

Beyond the screening issue, research on delay in seeking medical intervention has identified a complex mix of socio-economic and psychological contributing factors (Bish, Ramirez, Burgess, & Hunter, 2005; de Nooijer, Lechner, & de Vries, 2003; Macleod et al., 2009; O'Mahony, Hegarty, & McCarthy, 2010). As a result there are varying interpretations of the processes underlying delay. In this area, research in developing countries is broadly focused (Freitas & Weller, 2015) and concludes that, apart from the psychological dimension, social and cultural factors strongly influence delay by breast cancer patients in seeking health care interventions (Harirchia & Moghimic, 2005; Norsa'adah, Rampal, Rahmah, Naing, & Biswal, 2011; Taha, Al-Qutob, Nyström, Wahlström, & Berggren, 2012). Notions of illness causation (Hunt, 1998), life biographies and expectations (R. Andersen et al., 2010), misconceptions about cancer treatment and strong beliefs in traditional treatments (Iskandarsyah et al., 2013) are all culturally embedded processes that contribute to delay in breast cancer diagnosis.

> Hence, issues related to delays in breast cancer diagnosis are not confined to adequate or inadequate screening or to level of knowledge; the treatment of choice is also a crucial issue. In this research, treatment of breast cancer appeared a multi-faceted issue. An exploration of this complexity and how it relates to late stage presentation is best undertaken from not only an individual perspective but incorporating social and cultural views. The concept of culture, as noted earlier, defies a unified definition. The work of Clifford Geertz (1973) has been significant in bringing an emphasis to meaning rather than definition. As Geertz (1973, pp. 4-5) argued:
>
> Believing with Max Weber, that man *(sic)* is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the

> analysis of it therefore not an experimental science in search of law but an interpretative one in search of meaning.

Culture, from the above, is broadly perceived as webs of shared and learned attitudes, values, beliefs, and practices within and across a social group as well as the human capacity to classify and interpret experiences. Culture is thus not a static state and nor something that is simply externally imposed. Rather, culture is an active process whereby people and groups of people interpret, interact and act in certain shared ways within their worlds. Based on the above, it is clear that late stage presentation is not the outcome of a definitive number of well-defined causes (Elzawawy et al., 2008). On the contrary, the phenomenon is part of arbitrarily constructed and shifting systems of meanings that are integral to beliefs and behaviours.

It is important to note that the women participants in the current study presented late for both diagnosis and mainstream Western medical therapy. Thus an issue beyond delay was that, following diagnosis and having received medical advice, the women reflected upon and questioned medical guidance and whether it was the most appropriate or effective way of addressing the cancer.

> *… even for people who have been diagnosed with cancer, they don't want to go back to the doctor and many of my friends think and act like this.* 1P_20B

> *The diagnosis of cancer was confirmed on 31st December. I then sought a second opinion. However the result was the same. The verdict was that it must be breast surgery. But I rejected surgery. I am sure by praying that God will help me. It should disappear and I am hoping for a miracle.* 1P_03A

> *I was hoping that if I did this it would go away. I was massaged twenty seven times. It was very painful when my breast was being massaged. I didn't mind because I was hoping the lump would go away. The lady who massaged me told me to go to a doctor on the twentieth or twenty first time. She said "It won't*

> *disappear. You should go to a doctor". But I still didn't want to go. I finally went because I was very sick.* 15P 11B

The phenomenon reflected in the above was also evident in the research of Iskandarsyah et al. (2013) in Indonesia which found that women participants delayed treatment from four months to four years after receiving a diagnosis of breast cancer.

Three broad factors appeared to shape the decisions of the women participants in relation to both diagnosis and treatment. The first was the manifestation of fear of surgery. Second and related, women turned to traditional healers as the primary therapeutic sources for their disease journey. A third factor was related to the concept of self-identity and a salient social view that a woman who loses a breast is incomplete. These factors were interrelated in positioning surgery as a final choice of treatment for the women participants.

Treatment of choice

Participants turned to traditional healers as the first choice of treatment in preference to the alternative of surgery which would have involved a lumpectomy or mastectomy. Surgery was perceived as something to be avoided, a reason identified as a treatment delaying factor and thus the reason for early scepticism around medical advice (Iskandarsyah et al., 2013). The women participants struggled with a "to go or not to go" attitude to medical treatment and particularly around surgery. In contrast to traditional therapies, surgery was equated with the risk of trauma and dying as expressed by the following participant:

> *I was afraid because of the surgery. I imagined being in surgery.., oh.., stop..stop.., surgery just scared me. So it was just like that, moving back and forth, an inner battle.* 1P_02B

As the above suggests, what manifested was uncertainty related to fear. Breast cancer for any woman is considered a profound stressor associated with suffering, pain and death (Fu, Xu, Liu, & Haber, 2008; Perreault & Bourbonnais, 2005; Taleghani, Yekta, & Nasrabadi, 2006). Furthermore and as (Sinding et al., 2010) point out, decision making in cancer treatment for women is mediated by social phenomena such as the positioning of women and doctors in the organisation of health care and in society. As such, an ambivalence around, or indeed fear of, surgery for the women in the current research must be understood more broadly as interrelated with the social conditions that shaped decisions. The experience of fear is expressed in the excerpt below:

> *When I heard the word "operation" I was very scared. I could not imagine being operated on. This was even though my relative kept saying you would not feel anything, you would be under an anesthetic*. 2P_01B

For the women participants there existed the mutual impact of avoiding surgery and seeking an alternative or traditional therapy. The challenge in this thesis, therefore, was to explore the social processes that underpinned the ways in which the women perceived treatment and the social and cultural bases for their reactions and actions. From this perspective, the following discussion is organised around illness behaviour and choice of cancer treatment.

5.2.2. Treatment Choice

As has been argued above, perceptions around illness are understood as socially and culturally embedded (Olafsdottir, 2013) which means that these phenomena are to be explained from the perspective of an individual as part of a broader community and within the webs of shared, internalised and taken for granted systems of meanings. It is the case, therefore, that while the world may be understood as socially constructed the concept of culture provides a means of exploring immediate context.

The concept of cultural mapping, as argued by Olafsdottir (2013), is relevant to this analysis. This concept refers to the identification of “cultural boundaries by showing how individuals discriminate between different providers” in the health care sector (Olafsdottir, 2013, pp. 48-49). The focus moves on, therefore, from simply understanding whether individuals endorse particular health care resources to the ways in which people discriminate across a range of culturally “legitimate” sources of care (Olafsdottir & Pescosolido, 2009). In other words, decision-making involves assessment of a cultural repertoire, or tool box (Pescosolido & Olafsdottir, 2010), of what are considered appropriate treatments.

From the above and in relation to the women participants underlying the process of treatment choice was what Gadamer (2004, p. 278) refers to as tradition or a commonality which means that “long before we understand ourselves through the process of self-examination, we understand ourselves in a self-evident way in the family, society, and state in which we live”.

The impetus for women diagnosed with breast cancer to engage with therapeutic options other than biomedicine, at one level, may have been a response to fear of surgery. Yet, importantly, the impetus was also situated more broadly and involved a mix of influences including the views of the community and family and friends, a cultural understanding of cancer and a hierarchy of treatment options that might be tried and exhausted. A process of determining a hierarchy of options whereby decisions are made and discarded if ineffective is evident in the experiences of the participants below:

> *… then somebody said ‘are you really ready?’ ‘Are you ready for the risks of being operated upon?’ ‘What happens after the operation?’ I was thinking what is the risk? Then I said, it is better than being like this, burdened by a disease. It was so big that I had to use a carrying cloth (gendongan). It was just like carrying 3 kg of rice.* 3P_01B

> *So I was treated, by everyone and everywhere, to traditional medicine. I tried over and over again. I asked a friend whether they had tried this medicine (traditional medicine). Then , I drifted away for too long … So it was like that, moving back and forth, an inner battle.* 2P_02B

> *I did anything that people said because I didn’t want to go to a doctor. I was afraid the doctor would sentence me with cancer. When I heard the word cancer I was very afraid. It was like a scourge. I was like this because I saw what my sister went through until she died.* 1P_11 B

Thus cultural conceptualisations of illness will, in the words of Charmaz (2006, p. 30), “shape the responses of people in managing an illness, or the cause of their illness shapes what they believe they must do about it and the measures and markers they invoke”. Reported reasons for rejecting medical treatment include a desire for control, fear of adverse effects, perceived outcomes and toxicity and a belief in holistic therapy as a viable alternative (Charmaz, 2006; Citrin, Bloom, Grutsch, Mortensen, & Lis, 2012; Montbriand, 1998; Morris, Johnson, Homer, & Walts, 2000; Shumay, Maskarinec, Kakai, & Gotay, 2001; Sirois & Gick, 2002; Taib et al., 2007; Verhoef, 2008). Although such responses are globally shared among women with breast cancer, there were reactions and actions that distinguished the research participants from women in Western societies. In contrast to the current research, in Anglo-Western contexts, women generally comply with a more interventionist approach towards breast cancer treatment options and in particular biomedical and technological treatment. The biomedical model emphasises individual responsibility for risk detection and adopts quite radical detection and treatment regimes (Wong & King, 2008).

In turning to the second factor it is noted that while treatment protocols based on the biomedical model are well established there are also many kinds of therapy that exist as alternatives to standard therapy. The popularity of alternative therapies among breast cancer patients around the world is high and regardless of the type of therapy ranges from 36 to 83 % with considerable variation between countries (Wanchai et al., 2010). Reasons for embracing traditional therapies are varied and include prevention of recurrence, improvement in quality of life, boosting of the immune system and prevention of psychological distress (Han et al., 2011). The Iskandarsyah (2013, p. 4) study noted that participants held strong beliefs in traditional healers that "seemingly influenced participants' treatment decisions; they perceived the traditional therapy as an alternative solution for their health problem or as a complement to medical treatment". Yet and importantly, the current research focus was not just on the point at which traditional therapies were located on the treatment trajectory but how and why women came to give primacy to traditional healers in the broadest sense.

A concept compatible with cultural mapping and of relevance to the issue of treatment choice is ethno medicine which can be used to explain the tendency of people to turn to traditional healers. The concept refers to local ideas and behaviours surrounding maintenance of good health treatment of sickness (Manderson, 2011). In Indonesia, traditional healers are referred to as 'dukun' and the 'dukun' provide traditional medicinal therapies (jamu) that are at times combined with magical or spiritual activities. The origins of jamu predate any form of modern medicine and hence jamu has been practiced for centuries in its various forms. It is estimated that currently around 75% of 200 million Indonesians consume jamu products regularly (Torri, 2013). Thus the production and consumption of alternative therapies has evolved and developed as a constituent part of culture and tradition in Indonesia. In other words, jamu is a given, a therapeutic approach already strongly situated in the community. Added to this situation was the fact that traditional healers remained unregulated. Yet, where uncertainty surrounded surgery, other less confronting substitute therapies were readily available and economically more feasible.

Hence and while there is a lack of comprehensive research on the safety and efficacy of medicinal traditional healing and an absence of regulation of traditional remedies (Torri, 2013), there is a historical and deeply embedded trust of these therapeutic forms reflected in the ongoing growth of the sector in Indonesia (Torri, 2013; Vickers & Cassileth, 2001). Thus where traditional healing approaches are entrenched within a community there will be considerable familiarity and acceptance by community members. Overwhelmingly, the various forms of jamu are readily available in Indonesia where they are produced largely in household industries and are perceived to be natural therapies and hence without risk. It is also the case that this phenomenon is bound up with the collectivist tradition and social networking where people rely heavily on unofficial information from family, friends and neighbours (Torri, 2013). The significance of the social and cultural context is evident in the explanation of the following participant:

> *We Sundanese, most of us, especially my mother, do not really trust the hospital. So my mother said: I will not let you be operated on, it will not be right, it will be worse. Just put curcuma on it, shred it and put this in the area of the disease. That's what my mother said. So I just did what my mother said.* 2P_04B

There are two central concepts relevant to the above; a lay model of sickness which is referred to as a response to illness based on a patient's perception, experience, and expression of coping with symptoms and a health professional model of sickness that refers to a disease as cellular or organ pathology. This study points to the interrelationship of both models of sickness although with an emphasis on the women's experiences rather than cellular or organ pathology.

The above excerpt emphasises the authority of prevailing social rules that were deeply embedded in the research context. An exploration in greater depth of a reluctance to undergo surgery and a preference for traditional therapies evoked a sense of a fusion of horizons where the decisions of the present were inextricably a part of the past and where the past was being revised as a result of the present. This is an expression of Gadamer's (2004) argument that the world is given to us and we are composed of this world and thrown into a world. Moreover, "we are born with the past even as we begin to know we exist and we have the ability to think and wonder adapting to the world as it is" (Regan, 2012, p. 298). Historicity and tradition are essential parts of our lives: they are an inevitable feature and must be taken into account in an interpretation process. Hence, in order to understand the experience of women diagnosed with breast cancer, the present needs to be accounted for by understanding how the past appears in the present. Cultural predispositions that manifest in communities always contain the threads of the past.

Furthermore, when a woman experiences breast cancer it not only impacts upon the self but also on those who constitute the woman's social world. Indeed, the social worlds of the women participants were critical to decisions on treatments. Women sharing information through informal dialogue about breast cancer and its treatment often serves as the main source of information, or the motivation to discriminate among treatments, in any given community. The description offered by one participant of her encounter immediately following diagnosis provides some insight:

> *I met somebody when I was on the way home, and she said " an operation is not necessary, my friend and my relative have already recovered, so it's better you go to Mr. Cecep (herbalist)".* 1P_18B

It is acknowledged that the above data sit without context and yet the data suggest that individuals strategically draw on instances such as an informal conversation to legitimate social action as was the case with a further participant;

> *After delivery (giving birth), this (pointing to the breast) was painful and even bigger. The nurse at the (name) hospital said "hurry, go to the hospital, I will help you" she said. And I wanted to do that but I didn't go directly. Somebody told me to go and get herbal medicine again and so I tried herbalmedicine again.* 4P_01B

One reason that women turn to input from within their social groups is to ensure harmony and to reinforce a sense of belonging to a group (Olafsdottir, 2013). In other words, underpinning women's responses to breast cancer are salient community values that women use as a basis for action.

Thus the women participants acted in ways that can be explained by cultural and social factors including, in part, a desire to conform to the normative beliefs and the values of the groups to which they belong. For Nowak, Szamrej, and Latané (1990), social influence is any influence on individual feelings, thoughts, or behaviour that is exerted by the real, implied, or imagined presence or actions of others. This view affirms that behaviour is at once individual, social and cultural. Indonesian people have traditionally embraced an extended family system and therefore every single action in everyday life, including health and illness, is interpreted and enacted upon through a collectivist frame. Hence, people behave on the basis of the expectations of others in their communities.

Although there is research on individual reasons that women with breast cancer seek alternative therapies (Azhar, Achmad, Lukman, Hilmanto, & Aryandono, 2016; Chui, Abdullah, Wong, & Taib, 2015; Han et al., 2011; Taib et al., 2007), there are few studies on the processes that underlie the decision-making of women in such situations and how decision-making evolves over time. The following section explores the decision making process and beyond.

5.2.3. Rationalising Decisions

As noted above, there are many forms of alternative or traditional healing methods in Indonesia that have been established and applied over a long period of time and have assumed a legitimacy that is not afforded to the western biomedical tradition. This was evident in the decision making process described by a women participant:

> *The doctor said, after the biopsy was finished, whether you want to or not, you have to be operated on. I said, 'yes doctor'. After that, I did not go back the doctor. Once home, I thought about it and then finally I went to get herbal medicine (again).* 5P_01B

The positioning of a medical doctor is reflected in how the participants responded to medical advice. The decisions of the women participants in response to the advice of doctors differed to those in Obeidate's (2012) study of ten Arab American women who were surgically treated for early-stage breast cancer (stages 0, 1,2, 3A) in the northeast and Midwestern United States. In Obeidate's (2012) study, the women looked to medical doctors for treatment choices and decisions which reinforces the view of Pescosolido and Olafsdottir (2010) who argue that culture is best conceptualised as fragmented and permeable. Although medical doctors were clearly viewed as authority figures in the current research this authority did not translate into an immediate adherence to medical views on treatment.

The above phenomenon may be associated with mistrust and misunderstanding between doctors and patients in terms of relationships and communications. As Claramita, Dalen, and Van Der Vleuten (2011) argued, communications between patients and doctors in Southeast Asia are more likely to emphasise medical content than socio-emotional dimensions. Furthermore, the doctor-patient relationship is by nature strongly paternalistic in its consultation style where doctors may be more direct in addressing their agenda than engaging with patients (Bylund & Makoul, 2002; Eide et al., 2004). A contributing and related factor may be that western medicine and its proponents are inclined to dismiss traditional or folk therapies as soley symbolic rather than promote integration of different therapeutic approaches (A. I. Ross, 2012). Certainly the research participants perceived choice of treatment as one between the discreet areas of traditional and western medicines rather than a combination of both. As reported by one participant; *I was treated, everywhere by traditional medicine.* 3P_02B and as another said; *I did everything that people said; the variety of herbs, the many kinds of herbal therapies.* 4P_02B

Surgery had certain embedded connotations and yet ultimately the women returned to the medical system because of worsening conditions that traditional therapy had been ineffectual in addressing. In other words, surgery was positioned as a choice on the exhaustion of other options. A hierarchy of choices is reflected in the following two excerpts:

> *I was afraid to have the operation, I wanted to do it but I felt afraid...., but as time passed by, it was getting bigger and bigger. My body was not feeling good anymore and I was suffering. So finally I had the operation. I surrendered. I just forced myself to be operated upon* 6P_01B
>
> *It was not good anymore. It failed again. But I still did not want to go to a doctor. I only had to go to a doctor because I was so very sick.* 2P_11B

The above data resonates with a sense of powerlessness experienced by the women who were forced to follow a treatment trajectory not of their choice. This situation reflects cultural concerns and social meanings attached to hospitals, western medicine and to traditional therapies.

5.3. Collectivity

The spectrum of individualism to collectivism, according to Van Hoorn (2015), is a fundamental cultural syndrome. Individualist and collective cultures are distinguished by the relationship that an individual has to the broader collective. Characteristic of non-collectivist cultures, which exist predominantly in Western European and North American countries, is a focus on the needs of the individual and individual action and accountability as the desired norm (G. H. Hofstede, 2001). Most Asian cultures can be described as more collectivist than individualist and typically strongly integrated where individuals exhibit “behaviours based on concern for the broader social group and adhere to tradition and values” (Shiraev & Levy, 2010, p. 12). The conceptualisation of a collectivist culture is pertinent to decision-making around breast cancer in Indonesia where actions are at once individual and social.

Indeed, the social roles of individuals are interrelated to the rights and obligations of belonging to a family as a daughter, wife and mother, each of which is associated with particular commitments and expectations. Hence, there is a strong expectation that individuals will fulfil role-specific, relation-oriented, responsibility (Tsai, 2001). This phenomena corresponds with cultural mapping where the family systems in Indonesia embrace collectivism and thus the Indonesian family system exists as an extended social group. Even though the participants were manifestly individually competent to make choices on treatment, social roles were critical to decisions. Adherence to social and family values and norms was expected so that decisions took account of the interests of all (individual, family and the community). Although conflict may arise in regard to fulfilment of role expectations with families or significant others, if something disadvantageous occurs, or there is an unexpected outcome, then all (such as family members) will be responsible for that occurrence. In this sense, individuals are bound to cultural considerations in every single action in their lives.

As noted, the collectivist culture in Indonesia is strong and is said to distinctively reside in “the sense of a shared communal life, as a sense of oneness, togetherness and harmony” (Rahardjo, 1994, p. 495). There are some historical metaphors that reflect the importance of togetherness. One metaphor is reflected in the term of “gotong-royong” which means mutual assistance between people in the community to attain a shared goal such as building bridges or improving roads (Bowen, 1986). A further example are the words ’mangan ora mangan kumpul’ which similarly mean being together either for eating or not eating. Furthermore, it is not uncommon that visitors to homes bring healers or information regarding treatment or therapy for a disease. Some may be grounded in scientific evidence but most are not (Torri, 2013). In turn, all of these factors will contribute to the shaping of women’s actions such as consulting traditional healers. The following participant was confident that many had benefitted from alternative treatments:

> *There are some people distributing alternative medicine brochures and there are plenty who have had success with herbal medicine. So I thought I would like to try.* 7P_01B

There was much encouragement from families and friends for the participant women to consult traditional healers. This was at a time when the psychological state of the women and their families was fragile; there were conflicting feelings and thoughts. So, where there was readily available customary therapy for cancer treatment it was perceived to have benefits. In developing countries across the world, women exchange information about the accessibility of health services and about the quality of those services, and they assess their families' and peers' approval or disapproval of the use of health services, all within their social networks (Edmonds, Hruschka, Bernard, & Sibley, 2012). In the decision-making of the women, as has been eluded to above, were the potential benefits, both clinically and economically, of traditional medicinal theory.

Hence, the explanations of cultural mapping and ethnomedicine contribute to the intricacy of reasons why the women participants were reluctant to seek western treatment. The decisions were guided by what was considered appropriate for and by those with whom they were closely and less closely engaged. This corresponds with the interactionist assumption that individuals act in a manner that accords with those around them and the norms and beliefs of the group to which they belong (Gayen & Raeside, 2007).

The concept of temporality is also integral to an undrstanding of what was laten in the process of choice and decision making in this research. As argued by Toombs (1990, p.228):

> experience is not as a succession of discrete, isolatable, now-points along a given time-line but rather as a continuum – a continuum which at once incorporates not only the present now-point but those now-points which are just-past, as well as anticipations of future now-points.

The historical antecedents were integral to the ways in which the women participants encountered the reality of a 'mastectomy'" which appeared as present time. In other words, the women faced a sense of experience of having breast surgery which came from the past and was retained in the present consciousness. Thus in encountering breast surgery and anticipating a future situation a response to the present action unfolded temporally.

The concept of illness as a temporal object resonates with the work of Sartre (1956) and particularly in terms of illness as disease. For Satre, illness represents an objective disease which is known to the sick person by means of concepts acquired from others. The illness experience influences not only the individual but is also shaped by others (people) who confirm the sick person as sick. It appears that the influence of others in this state of being sick removes the subjectivity of the experience of illness as it becomes a disease. This process of conceptualising illness and disease converges with the experience of decision-making around the treatment of choice for women diagnosed with breast cancer. The situation of the women participants was synergetic with the Indonesian culture and the collectivist tradition which it embraces. As such, at any one point where bodily changes are noticed, where a diagnosis is confirmed and where treatment advised, it cannot be predicted that women will adopt treatment that is scientifically grounded or the more obviously beneficial trajectory.

Traditional medicinal approaches to illness had a critical role in relation to breast cancer in the research context. There thus appeared a disjuncture between the expectations of the women and health professionals regarding illness and its treatment. Indeed, patients and doctors are separated by a fundamental and decisive gap in understanding illness and in turn how to address that illness. These relations are mediated by geographical, social and organisational processes (Sinding et al., 2010). In Indonesia, the education of health professionals is grounded in the western biomedical model and there is much less emphasis on the local context within which the people for whom they care reside. Yet illness as experienced as disease is fundamentally influenced by the concepts of lay people and other people in the community (Quinlan, 2011). Thus tradition, social roles, economics and culture all interrelate in shaping decision-making. A further and critical mediating factor in this research was religious belief.

5.3.1. Fate and Bargaining

The meanings surrounding breasts are constructed as representational systems of gender, ethnicity and religion that may be mutually reinforcing or conflicting. Certainly, different people in different places will produce different perceptions and representations of cancer. Thus the way women perceive and interpret living with breast cancer will be at once a subjective and social, cultural, and religious experience (Taleghani et al., 2006).

The relationship between breast cancer and faith or belief is underpinned by a range of essential issues that shape the process of decision making on treatment. The dominant religion in Indonesia is Islam and a prevailing belief drawn from this perspective is that cancer is a test of one’s faith and that the orientation of treatment should be focused on spiritual healing. Where people regard breast cancer as life threatening and hold strong religious beliefs there may, therefore, be a fatalistic acceptance. Thus when people are confronted with life threatening conditions these are perceived to have been designed by God. This was a dominant framing of the experience by the women participants as reflected in this quote;

> *So maybe it was His (God) decision to choose me (and) well, I was really thankful. This showed me that I was..., what is it, why not another family member, why me? I just thought that*. 2P_20 A

> *I think that I have been given a second chance and I don't want to waste it. I have become more patient and also stronger because I am convinced that everything has been neatly arranged by Allah and so we just need to pray…* A3 193P

The interpretation of fatalism is still open to debate and misconceptions do exist. As a component of an ethnographic study, Hamdy (2006) spoke to a number of renal transplant surgeons in Egypt who asserted that they would personally reject renal transplantation, if indicated, on the grounds of religion because "our body belongs to God". Yet Hamdy (2006) argues that this fatalism discourse is but one of a number of competing discourses that actively construct reasoning that is compatible with religious beliefs. The fatalism discourse that manifested in the current research appeared as passive acceptance of a fate as one participant said:

> *... I think, Allah has set my destiny like this, I have to be grateful. Many people are worse than I am. So don't look up, something like that, look down* 5P_02B

And a further participant declared;

> *I think that is an unforgettable experience, but I accept it totally. I surrender everything to Allah and that was the result. I think it is not a coincidence. I believe that there is no such thing as coincidence in the world* 1P_04A
>
> *It was not easy for me but I was convinced that it was a form of Allah's love for me. If He wants to, everything can happen, this might be Allah's love expressed to all of us, the love that is expressed in different ways*. 2 P_04A

The women participants above interpreted breast cancer as a creation of Allah and as destiny rather than punishment. Indeed, women expressed gratitude for having been chosen to have breast cancer. Thus and on the one hand acceptance of an illness represented a total submission to God. Nonetheless and on the other hand, acceptance of divine will was not necessarily passive and could be actively cultivated as Hamdy (2009) argued and hence not contrary to acting in the world. Hamdy (2009, p. 174) makes the point that:

> Whether and when to ultimately cultivate such a disposition is necessarily contingent upon how much control patients feel they have in the face of illness and other trials, and on whether they have any options that would really provide an appropriate “solution” that could be lived with medically, socially, and spiritually.

The sense of an active rather than submissive process if is reflected in the following participant comment;

> *... so I thought this was a disease from God, nothing else. God gives us illness, there has to be a cure, that’s what I thought. Then I thought, it is better for me to go to alternative medicine.* 3P_04B

In the process of the sense making in the above a fatalistic comment is posed alongside a statement about the use of alternative medicine. This suggests, as Keeley, Wright, and Condit (2009) also argue, that fatalism sits alongside other beliefs or perceptions that may or may not be compatible but function as a resource in negotiating responses to breast cancer. Swidler (2001) refers to a cultural toolkit where individuals draw on different strands of a cultural repertoire as the need arises.

An example of the above point is the research by Obeidat, Lally, and Dickerson (2012, p. 309), which found that Arab American women used religion as collaborative coping and while the women believed that the ultimate outcome of an illness was in the hands of God “they still work with God to manage their illness by using adaptive coping strategies such as actively seeking treatment”. The fatalistic orientation, therefore, does not necessarily dissuade people from actively engaging with the processes surrounding an illness such as breast cancer (Flórez et al., 2009; Harandy et al., 2009).

Fate in these terms corresponds with the Islamic thought that encourages people to do something that can solve problems actively. Islamic writings state that a person’s body is a gift received in trust from the higher power and that this gift should not be misused (Rajaram & Rashidi, 1999). In this study, there were synergies between a surrender to Allah's will and seeking help from professional persons (medical or others). This is reflected in the following participant's words:

> *I just put it in Allah's hands. I asked Him to make it easier for us to get the money, the sustenance, everything and also for people around me to make things easier so I was calmer. I never thought about the end result of the treatment.* 1P_01A

Hence, the responses of the women to breast cancer and treatment were not as simplistic to imply a fate that was a global and unified reaction of all women in this study. Rather, the ways in which fatalism and other responses functioned indicated access to various understandings and interpretations. Thus the responses of the women were a reflection of a dynamic process and not a single action.

The process of understanding is not linear but reflects the hermeneutic circle as a dynamic movement between the parts and the whole of text in the process of interpretation in order to reveal the conditions of understanding. Hence, the way women responded and acted was a process of movement back and forth, and thus one of ongoing change. Religious beliefs shaped in various ways how the participants made sense of the experience of breast cancer and beyond simply coping. There was a dynamic process whereby the participants encountered situations that disrupted their identities as women. Tradition, past experience, present experience and the future were all antecedents to the ways in which the women struggled and then transformed their future lives. In contrast to fatalism, a further dimension of the experience of the women was an association of breast cancer with punishment for wrong doing.

Decision making was a complex process, which involved not only the women as individuals but also the family system and society that embraced the beliefs and faith of the community, the perceptions of illness and interpretations of risk. All interplayed to reflect a collectivity of decision making about treatment. The context, importantly, also rested on the socio-economic resources of the participants and the community more generally.

5.3.2. Accessing Resources

Low income countries face the broad spectrum of problems in relation to health care; greater mortality and morbidity and limited resources. Cancer is often not a stated priority in such countries because infectious diseases typically dominate health care systems. As a result early access to effective health care treatment remains a potential obstacle for women with breast cancer. Economic status is purported to be a common denominator (Sharma, Costas, Shulman, & Meara, 2012) in the delay of diagnosis and treatment of breast cancer . As reported by one participant:

> *I wish I known earlier and had gone for treatment immediately. It would not be like this. It is a waste…we would seek treatment straight away if we had money and for any illness that we experienced.* 4P_04B

Breast cancer therapy is expensive. The Indonesian government is committed to providing universal health insurance through a mandatory public health insurance scheme called the Health Insurance for the Poor Population that was introduced in 2004 as the initial phase of universal coverage (Ministry of Health Republic of Indonesia, 2008). Nonetheless and while the government provided health insurance designed to cover all health problems including cancer treatment (surgery, chemotherapy, radiation) there were significant collateral expenses such as non-medical, out of pocket factors (DiFazio & Vessey, 2011; Langa et al., 2004). This form of expenditure, the so-call hidden costs (Rozario & Samuel, 2010), refers to financial outlay directly attributed to the patient’s and family's health care needs that are necessary to sustain family life including transportation, temporary accommodation, personal care, reduced income from parental employment, and unexpected expenses (DiFazio & Vessey, 2011). Hence, women participants had to consider whether such expenditure would place an unjustifiable burden on the family. One woman explained the complexity of decision making around treatment as it related to her role in the family;

> *I was supposed to come to be checked. The minimum treatment was radiation, the most important thing was the radiation, for 30 days. Radiation was for 30 days. I had to have some money, a minimum of 50 thousand per day, for transport, back and forth and some meals. My husband is not working. And it's better for my children to go to school...It's twenty thousand a day for my children. I decided not to go...* 5P_04B

Another woman recounted a neigbour's predicament where a local hospital refused treatment for a recurrence of breast cancer;

> *My neighbour lives in Garut (a district in West Java) and was operated on in the local hospital. But she said when the lump re-appeared and so after the second time she went back to the hospital but the hospital would not take her in.* 8P_01B

Where resources are constrained decisions will be prioritised within health care and based on expectations of outcomes of treatment. The socio-economic structure existed as a further layer of complexity for women diagnosed with breast cancer to negotiate.

5.4. Summary

This chapter explored two interpretations of decision-making with which the research participants engaged. The first was a decision to engage with traditional medicinal therapy from the outset of the breast cancer process and the second was the point at which Western medicine became the treatment of last resort as other options were exhausted. Thus the participants accessed traditional healers not as complementary but as primary therapies. As others have pointed out, there exist a variety of reasons including misconceptions such as fear that surgery will disturb the cancer and cause it to grow larger (Leong et al., 2009), in adequate medical facilities in the primary health system, poor infrastructure, and information systems (Pai, 2002) and lack of financial resources (Al-Adawi, 1993; Pai, 2002; Tovey, Chatwin, & Ahmad, 2005). All have been posed as barriers to medical intervention and conversely as underpinning preferences for traditional therapy. Where a system of traditional medicinal therapies endures the ways in which an illness is managed have been passed down from generation to generation. While often not scientifically grounded, such treatments are readily accepted in communities because they are embedded in people's lives and converge with the social and cultural context.

Women experience particular challenges at every period of their cancer journey. Changes occur over time, from the point of diagnosis, through treatment and in life after treatment. Delays related to breast cancer occur not only in diagnosis but also in decisions on treatment. There is tension between the self and the values and norms of the family and society. From a socio-cultural perspective, the identities of the women in this study were inextricably tied to their families and society decisions on diagnosis and treatment therefore, women not only decide by themselves, because making decisions about breast surgery in this context closely corresponds to the society and culture in which the women are situated. Women have to reconcile their own expectations with hose of the social group in which they live. Religious and cultural beliefs are critical in the formation of a social identity which, in turn, bonds people to a system of beliefs and practices. Decision making in the case of breast cancer treatment thus reflected, in this research, a complexity of social, cultural and religious dimensions that existed together in shaping the responses of the women participants. The following chapter moves on to explore in greater the positioning of the women participants in the milieu described above. The chapter brings to the discussion a temporal perspective where understanding is situated within a historical awareness pertinent to the current research. This is not to suggest a writing of history but a broad articulation of context which informs understanding.

Chapter 6: Social Positioning of Women

> *There was a woman beside me, during chemo, she had mastectomy, I heard her talking to she talked to her husband " I am sorry dear… I only have one breast now. He said " that's ok, do not think too much about that… there many women with two breasts out there". That was ridiculous* 11P_18B

6.1. Introduction

Social position can be defined as the place occupied by an individual in a particular society and culture and by a broad range of factors that collectively determine that place in a social environment and social organisation. This given position comprises categories, such as occupation, profession, place within a social network, community and class (Suddaby, Viale, & Gendron, 2016). Hence, social positioning shapes social status and the social role of an individual, which ultimately underpins a system of social class and hierarchy.

The status of women within this process of positioning is complex and also influenced by socio-economic, geographical, and cultural settings. This chapter addresses the social positioning of women in the Indonesian research context. In so doing, the chapter begins with the understanding that women in Indonesia do not constitute a homogeneous group, and that gender relations across this nation are not universal in appearance (Jacubowski, 2008; K. Robinson, 2008). Yet, there are some overarching features of gender relations evident in the research analysis that are a legacy of first, what K. Robinson (2008) refers to as the homogenising imperative of the Suharto New Order ideology and regime in Indonesia in the 1965 to 1998 period and second, a global resurgence of Islam in the 1980s and onwards. As such, the following discussion is organised around two contextual concepts that reflect a further tentative interpretation of the impact on the lives of Indonesian women of a diagnosis of breast cancer: *women and patriarchy* and *shifting cultural values*.

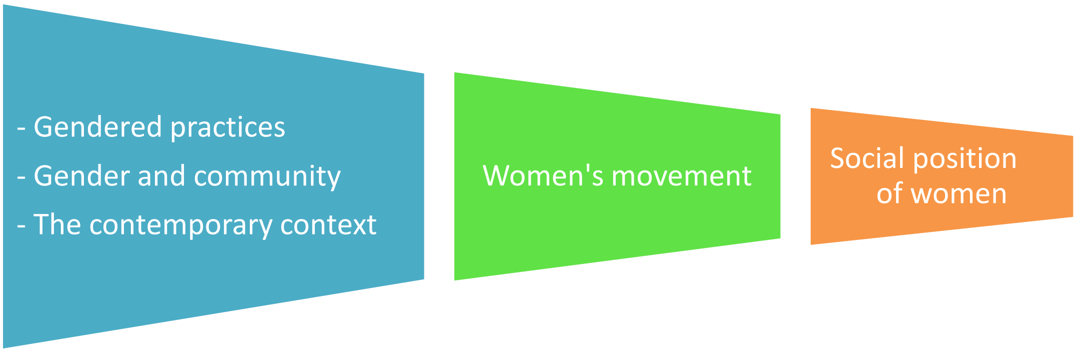

Figure 6.1. Second analytical finding

6.2. Women’s Movements

An engagement with the background of the women’s movements in Indonesia provides greater insight into the evolution of gender issues and specifically the positioning of women on patriarchy in Indonesia which has been far from united in approach. The process of a shift from object discrimination to a fairer situation for women varies across social and political contexts and nations. As such, activist Indonesian women assumed positions that transversed the entire political spectrum, from those who supported the development of an Islamic state and strict adherence to shari’a (Islamic law) to women who worked towards a secular state that would incorporate women’s rights, equality, and resistance to subordination to men. In relation to the latter, Islam was perceived as a primarily spiritual rather than political matter.

In Indonesia, the women's rights movement initially appeared as an entity in 1928 at the first Women's Congress in this nation and at the following congress in 1929 the Federation of Women's Congresses was formed (Bessel, 2004). Women activists, both feminist and conservative Islamic, have since been represented at United Nations conferences on women. The integration of Indonesian women into the global women's movement also gave rise to influential non-government organisations (NGOs) in Indonesia (Brenner, 2006; K. Robinson, 2008). These have included the Centre for Electoral Reform, the International NGO Forum on Indonesian Development, the Urban Poor Consortium and the Environmental Forum (Bessell, 2004) all of which have been headed by women and have pursued women's rights. Hence and particularly since the 1990s, women's NGO networks, both secular and religious, have been active in Indonesia and the terms "gender equality" and (for some groups) "feminism" have become part of the discourse of expanding activist groups of women (Rinaldo, 2010).

The divergence in views on women's rights had an obvious political context. Up until 1945 and independence, the political activity of Indonesian women strongly converged with the anti-colonial (Dutch rule) nationalist cause. Following independence and with less of a shared cause divisions between moderate and Islamic feminists became much sharper (Rinaldo, 2010; Brenner, 2011). Hence, women activists, progressive and conservative, have not worked synergistically to achieve better status for women, as the goals of these two broad groups differ in important ways. For radical Islamic feminists, as noted above, the goal was an idealised Islamic state. For moderate Islamic feminists, the stated goal was to improve the lives of Indonesian Muslim women through reinterpretations of Islamic text that were more compatible with the concept of gender equality (Brenner, 2005).

The objective of the progressive feminists was to ensure a continuation of a secular state and to secure women's liberation and freedom from patriarchal religious ideology. Debates around women's roles in public life and in the family, therefore, have, been ongoing (Robinson, 2008).

While the work of the NGOs in the 1990s eroded some resistance to gender equality (Brenner, 2005), this period coincided with a worldwide Islamic resurgence fueled by the Islamic revolution in Iran and a subsequent concerted campaign by Muslim conservatives against the pursuit of women's issues. The persistence of patriarchal institutionalism in Indonesia was evident in the research although, as in the following excerpt, women did not present as passive players in the face of patriarchy;

> *I asked my husband for his permission and whether he would allow me to ask for help from my friends. I did this because he is my husband and I didn't want him to lose his dignity.* 3P_04A

Relevant to the above is the concept of bargaining with patriarchy which, as argued by Kandiyoti (1988), refers to strategies that women employ to maximise benefits within an existing set of rules that reproduce a patriarchal system. Kandiyoti (1998) revisited the concept ten years on to point out that an alternative gender ideology does not enter a level playing field but one where certain discourses are dominant and others marginalized or obscured. This appears pertinent to the following description by a participant of her treatment decision experience;

> *No one told me not even the doctor. The medical team told my family that the pathology result was (the tumour) malignant and gave the consent form to them. My Husband, my older brother and my parents, all of them agreed to a radical mastectomy.* 1P_08B

The above suggests that resistance is culturally sanctioned and hence that a challenge to patriarchy will always be circumscribed already existing constraints and that resistance itself is a construct of those constraints. Bessell, (2004), Brenner (2005) and Rhoads (2012) all argue, if in different ways, that while Indonesian women have long played a critical role both symbolically and materially in nation building and in progressing the rights of women, a shift to a more public political position by women has not readily translated into the more liberal advance of women's issues. One explanation is the gender stereotypes that re-emerged along with the cultural conservatism of the resurgence of Islam. The result has been that women with more liberal ideas remain marginalized as political participants within a strongly male-dominated sphere (Blackburn, 2008; Rhoads, 2012).

Women and patriarchy

From the above it is clear that the factors which currently shape the ways in which Indonesian women live and how they are perceived cannot be separated from their historical, religious, social-cultural, and political origins. Indeed, it is widely accepted that the contemporary role of women in Indonesia has evolved from a combination of Islamic religious views, the historical legacy of patriarchal norms and industrialisation (Adamson, 2007).

Patriarchy is "the presumed centeredness, domination, control, and power of men which entails the oppression, subordination, and submission of women" (Elboubekri, 2015, p. 27). Traditionally, the concept of patriarchy has referred to and been reinforced by a biological determinist position where biological differences not only define a binary gender system of a man and a woman but their respective social and cultural roles. Sexual differentiation in these terms is accompanied by other and significant implications such as the question of equal rights between the genders where women are defined by biological motherhood as the natural state of that gender (Jauhola, 2010). The emphasis on the biological, as reflected in the following participant data, serves the function of objectifying women so that they are non-participants in decision-making about their own bodies and health care;

> *The next thing doctor X said to my husband was: "I don't have to ask your wife whether she is ready or not to accept the treatment because she wants to recover. But I want to know about you. Are you ready if the worst happens and we have to take her breast, the pride of any woman... and something beautiful of your wife that you also admire .....*
> 2P_01A

It should be noted that, when placed in context, the participant went on to state that; *My husband replied that he would stand by me whatever happened because I was the best thing that had ever happened to him (* 15P 001). Nonetheless, the gendered hierarchy of authority is reflected in the exclusion of the above participant from the conversation.

Patriarchy refers to a role recognisable across the globe whereby the appropriate place of men is in a position of authority in a family and beyond and for women in a role largely constrained to domestic responsibilities (Daulay, 2007). The formation of gender relations in Indonesia has occurred within a patriarchal frame that is embedded in Islamic doctrine. Thus in Indonesia, the positioning of women is dominated by norms and values that have been produced and reproduced through religious and institutional power. In the past, this has meant that women were expected to largely remain in the domestic, or the significant informal economic setting, rather than seek waged employment elsewhere. During the period of the New Order, however, the emphasis turned to industrial development which was heavily dependent upon the participation of women in employment outside the home and on higher education for women (Brenner, 2005). The imposition of a new economic order was also accompanied by a shift in political focus towards state control over the definition of gender roles within families (Rhoads, 2012). The objective of the state was to engender a normative view, posed as a unifying strategy in a geographically and culturally disparate nation, of the woman as wife and mother. Thus when the women were diagnosed with breast cancer, decision-making around treatment was shaped by a patriarchal authority that gave primacy to the views of husbands and family members.

6.2.1. Gendered Practices

The above discussion indicates that the development of the discourses around the role of Indonesian women was closely connected to religion and culture and in turn to economic development. In relation to the latter, the period of rapid economic growth, both during and following the Suharto regime, extensively changed the lives of Indonesian women. Industrialisation, urbanisation and modernisation saw raised standards of living and higher levels of education for women. The demographics in the current study reflect such progress where 43% of participants had achieved university level qualifications. Importantly, however, political changes elsewhere also underpinned a revival of Islam and religious practices in Indonesia from the 1980s onwards. Tensions between economic development and the Islamic resurgence were multilayered, complex and reflected the diversity in views on the position of women. Brenner (2005) points to, for example, the paradox evident in Indonesia and other Muslim countries where social transformation that led to higher education, greater employment opportunities and increased mobility for women also saw greater participation by women in Islamic organisations that favoured constraints on those developments. As Islam is the belief system embraced by the majority of Indonesian people any discussion of gender issues in Indonesia cannot be disconnected from the resurgent influence of Islamic teaching.

While the socially prevailing positions on woman's rights, as discussed above, were diverse they were grounded in the Qur'anic values and thus a commitment to Islam. Even where gender issues were pre-eminent, therefore, such as in early 20th century women's movements, religion had been important in constructing the discourses underpinning women's roles in Indonesia (Brenner, 2011). Hence, an articulation of women's issues, or women's self-representations, in this research did not sit far from prevailing views. While women may have had the potential to participate equally in Indonesian society this was not on equal terms (Koning, Nolten, Rodenburg, & Saptari, 2013). The position of women continued to be;

> …based on the widely held assumption that in Islam a woman is considered secondary and inferior or subordinate to men and therefore men are charged with the religious responsibility of protecting and taking care of her in every way-her basic needs, her life, morality and chastity (Othman, 2006, p. 344).

The teachings of Islam do not schematically distinguish between men and women but rather present the genders as part of a whole. As indicated above, biologically and socio-culturally it is determined that each requires the other. Qur'an Verse An-Nahl 97 (Ministry of Religion Republic of Indonesia, 2006c): states that: "Whoso acts aright, male or female, and is a believer, we will quicken with a goodly life; and we will recompense them with their hire for the best deeds they have done" Thus Quranic verse asserts that there is no difference between men and women, that both genders have potential and that men and women are human beings that need each other (Attamimi, 2012). In religious terms, this suggests that there is no discrimination and as long as each acts according to this guidance a reward will come from Allah. Nonetheless, how deeply entrenched were the normative views of the social role of women, whether prior to the New Order or following, is reflected in the words of one participant who stated:

> *I was already ill, and as a wife I felt guilty because I could not function as a good wife, a good mother… I also thought that I had used family money, all our savings were used. We used the children’s education savings, we sold the car, everything was sold, the house was sold. I felt that I had created trouble. I had become a burden and that very thought became a further burden to me.* 4P_04A

The dominant culture in Java, the site of this research, has arguably provided little space for equality between men and women (Handayani & Novianto, 2004) where the success of a woman has continued to be judged on the basis of her husband’s achievements. For example ’konco wingking‘, in the Javanese language, literally means that the wife is a friend who must always sit behind. The translation of ’swarga nunut, neraka katut‘ is that wherever a husband is going, either heaven or hell, the wife will be there. Furthermore, Muslim women were expected to be obedient and not commit acts that challenge the authority of husbands (Nurmila, 2013). In terms of inheritance this translated into women receiving half of what a man has a legal right to claim in any family.

There continued to be complex areas where men and women are overtly treated unequally and purportedly in the name of Islam. An example is polygamy which, according to Islamic text, is condoned by Islamic law if it meets the criteria of fairness to a seriously ill wife and permission is gained from the wife. The issue of polygyny was raised by women participants when talking about their experiences with breast cancer. There appeared a sense of vulnerability that associated breast cancer with the possibility of a change in marital status. This vulnerability was expressed in a number of different ways. One participant noted that:

> *It is degrading for women when men want to engage with polygyny with no clear reason. Indeed, our sickness can be used as a reason to marry again.* 1P_07B

Yet others assumed a self-sacrificing, or pious, stance:

> *I felt that I had not fulfilled my role as his wife for nine months, and finally I said to my husband: "Dear... I think you need someone to take care of you".* 3P_01A

> *He almost married (again) and then I said just do it if it will make you happier. I don't mind because I am not perfect anymore.* 1P_06 B

The law considered polygyny as a possibility for men where there was a failure on the part of the wife to fulfil a husband's sexual needs and desire (Nurmila, 2013). This religious construction of gender is grounded in the Qur'an: Verse An-Nisa 34:

> Men are leaders of women, because Allah has given some of them (men) superiority than the other (women), and because they (men) support them from their means. Therefore the righteous women are devoutly obedient, and guard in (the husband's) absence what Allah would have them guard. As to those women on whose part you fear disloyalty and ill-conduct (*Nusyuz*), admonish them (first), (next), refuse to share their beds, (and last) beat them; but if they return to obedience, seek not against them means (of annoyance) (Nurmila, 2013, p. 63).

The law did not in any way address circumstances where a husband became disabled, infertile or could not fulfill his marital obligations. As such, a sanctioning of polygyny rested solely upon the inadequacies of women (Qibtiyah, 2009; Syamsiyatun & Qibtiyah, 2006). Indeed, as Blackburn (2008) argues, the pietistic face of the Islamic revival of the 1980s onwards had much that might be important to women including certainty of doctrine and of support and protection by men for women of any family.

The interpretation of the Qur’an Verse involves language and context (time and place) that have certainly influenced the meanings attributed to gender roles from the perspective of Islam. A further argument is that it is difficult to assert that patriarchy is predominantly about religion because patriarchy occurs to a greater or lesser degree across all societies. As Elboubekri (2015, p.27) states, where patriarchal values position women as disadvantaged this is “largely connected to ideological and materialist interpretations rather than any religious basis where the position of women is preordained and natural”. Indeed the view of Islamic feminists is that women live in societies wherein men execute a power endorsed by control of class, law, nation, and language (Elboubekri, 2015, p.27). Thus the materialist interpretation argues that patriarchal views are not inherent to the Muslim identity. Rather the points of argument above contend that patriarchal beliefs are fundamentally structural and have little to do with the Muslim identity (Alexander & Welzel, 2011).

Despite the persuasiveness of the above arguments, religion is and continues to be used to legitimate patriarchal practices (Ray, 2006). Even where economic structures and political institutions are considered influential in shaping patriarchy, this is strengthened and justified through religion (Alexander & Welzel, 2011; M. L. Ross, 2008). As Priyatna (2013) points out, a normative reading of the Qur’an gives primacy to the status of men in assuming responsibility for protecting the rights of women to fulfill their roles.

Thus while Indonesian women assume greater responsibility for looking after family members, those women have limited autonomy and less power (Jejeebhoy, 2001; Adamson, 2007; Stoler, 1977). Most decisions and actions must be approved and permitted by the husband. Hence, where a woman is advised to have breast surgery she has to address, not only her emotional response related to the disease, but the acceptance or otherwise of her husband for treatment of that disease. There is a risk that the experience of a mastectomy may precipitate abandonment by partners (Peek, Sayad, & Markwardt, 2008). For the women, there can be no independent decisions or at times even shared decision-making. As one participant said in reference to a friend who had undergone surgery for breast cancer:

> *She was not told that the breast was going to be removed, but after the medical check-up it was found to be malignant and with her husband's permission, it was removed. She didn't know that it was to be removed. After surgery it (the breast) was gone and then she was down, very stressed, and resentful.* 6 P_02B

A further participant expressed similar distress described a similar situation and the associated distress;

> *When I became alert after surgery… and then touched the breast area and it felt deflated… I screamed and screamed. I did not know…. the doctor didn't explain what was going to happen. The decision to remove the breast was based on the consent of my husband and my family.* 2P_08B

The above data suggest that the rights of the women held little authority in health care decision-making. There appeared sparse systemic consideration for the one to whom the body (breast) belonged. This is not to suggest that family were acting in any way other than expected. While the women may have been unhappy about being excluded from the decision-making processes there was a sense of expectation and acceptance of this outcome.

Indeed, in Indonesia, legally informed consent is provided by the husband, or family members for a woman who is not married, so that it appears as a shared responsibility. It is also associated with the family system which includes the extended family and where all family members are involved in all decision making. Hence, the women were treated as subordinate not only to their husbands but to all older family members (Kandiyoti, 1998). This norm is reinforced through both prevailing social views and marriage laws.

The discussion above on the social and political subordination of women is not to impose a passivity on those women who participated in the research. Indonesian women have engaged actively in movements dedicated to change and reform throughout Indonesia’s history. Yet a combination of historical legacy, the New Order patriarchal ideology and a revival of Islam (Bessell, 2004) have all posed as constraints on the pursuit of a share of power and rights for Indonesian women.

6.2.2. Gender and Community

As noted above, male domination is legitimated in various sectors of both public and private lives. In patriarchal cultures, therefore, control over women is practiced not only at the household level but also in the public and institutional domains. In addition and under the guise of the interrelated conditions of culture, religion and law non-acceptance of existing gender/power relations is difficult. Due to gender stereotypes a challenge to the authority of men would have been disruptive for the women participants and hence there was a tendency to ‘accept’ the role of dependent. Social acceptance in collectivist societies requires conformity to group norms more so than where individualism is the dominant orientation. Indeed, interdependence is considered necessary for sustaining an ongoing level of harmony (Jetten, Postmes, & McAuliffe, 2002). A potential threat to harmony has long been the women’s movements in Indonesia.

In the 1930s and the early period of the women's movement in Indonesia votes for women around issues such as polygyny, consent and child marriage were consistently on the women's political agenda (Bessell, 2004). Furthermore, during the national revolution of the 1950s, the women's movement was absolutely vibrant and active. During this time and in response to a demand for people to fight for the revolution there were many opportunities for women to participate openly in the political domestic sphere. This role is not recognised or acknowledged in most analyses of women's movements nor in historical works on the Indonesian national struggle (Martyn, 2004). The invisibility of the role of women in the revolution, in the struggle for national independence and in movements since the colonial era, is a reflection of a patriarchal culture.

The barriers faced by the feminist movements have therefore been historial, many and varied and have been entrenched at both the macro and micro social levels in Indonesia. During the Suharto era, women generally, whether earning wages or not, were expected to be economically productive and as such to carry out a double role that was not expected of men. The contradiction here is that throughout the Indonesian archipelago, women have traditionally engaged in economic endeavours such as farming and trade and other livelihoods (Brenner, 2005) that were external to domestic activities and were not demarcated from the work of men. The concern of the government was not, however, long standing practices but the threat of the appeal of Western freedoms for women. The construction of relationships between women and men was focused on strengthening and reproducing culture and tradition and was not women friendly. Indeed, the New Order regime effectively discredited and decimated the women's movement by disallowing women to join any movement. Any tradition, either religious or otherwise, that gave support to women assuming influential public roles was also deliberately excluded from official discourse (Bessel, 2004).

Thus, during the period of the New Order, the focus was on sustaining traditional gender roles. For example, programs were instituted based on gender stereotypes, such as distributing sewing machines and running cooking competitions for women (Qibtiyah, 2010). This agenda was tied to the civil service where an association for civil servant’s wives was established (Jones, 2010). Women were obliged to be members and to attend meetings that focused on “the virtues of housewifery, cooking, interior decorating, dress, and beauty…” (Jones, 2010, p. 275) all in the interest of contributing to a developing nation. A failure to participate would pose risks for a civil servant husband.

The government, as such, propagated the ideal of women as devoted wives and self-sacrificing mothers (Brenner, 2011). Education played an important role in this process by giving shape to the ideal of the public-oriented male subject and the modern domestic-oriented female subject. Education of women was promoted “in the context of this new ideal configuration of gender roles, not for their own individualistic achievements” (Hapke, 2013, p. 16). These expected roles and images of women appeared more of a burden than a right. Women were invariably required to fulfil various obligations but did not have the right to be acknowledged in the public domain. In the present period, gender relations and patriarchal norms in the state are shaped by three sets of social, economic, and cultural factors, or events that converged in historical developments (Hapke, 2013).

6.2.3. The Contemporary Context

It is significant that even while the participant women assumed less powerful social positions than men they were not passive actors on a social stage but worked actively to negotiate effective outcomes for themselves and for those significant others. In so doing, the women negotiated a complex interplay between tradition and change. In decision-making women asked for the approval of their husbands and yet the women were also overtly critical of their own positioning and sought to influence major decisions. It is assumed that the women's roles can be restructured through higher levels of education. This may lead, in return, to work that attracts better remuneration. As seen in this research , women participants were overtly conscious of change;

> *I see that there is change. As a general point, a husband and wife in a household must have their own roles. And for this generation, a wife cannot just depend on her husband's earnings. She also has to work. Women go to school to ensure their own existence. A woman can say to herself, "I am useful, I exist". I think this is where our society is heading.* 3P_20B

> *Now, women are becoming more participative. She became a wife and also participated in household life.* 4P_20B

Hence, social norms have shifted in Indonesia. Women are challenging dominant social expectations regarding attitudes towards women when they become ill. As noted in the previous chapter, in relation to social and cultural networking, social norms are central to every phase of illness, as one feature of a collectivist society. However, in some contexts traditional practices are no longer rigorously upheld and implemented. The following participants questioned, implicitly or explicitly, the traditions of family and society:

> *That is why for some working mothers, if somebody asks why do women look for jobs? To be honest, they might have everything that they need from their husbands. It appears that we are being fulfilled because we are needed by our husbands. But as an individual, I also need to feel appreciated. It is something that cannot come from my husband.* 5P_20B

> *Existence is outside family life. Take my example. As a lecturer I feel that I have succeeded in becoming an intelligent woman. It gives me a sense of self-satisfaction. I look for satisfaction that cannot be gained from my family.* 6P_20B

> *Because I am working, then I feel that I am not too dependent on my husband* 1P_15B

Bargaining with patriarchy involves “not timeless or immutable entities, but is susceptible to historical transformations of the relations that open up new areas of struggle and renegotiation of the relations between genders” (Kandiyoti, 1988, p. 275). Patriarchal bargaining is compatible with Gadamer’s (2004) concept of temporality. The awareness of temporality is the centre of situating and developing understanding and occurs during the fusion of horizon where the whole of understanding is realised in terms of its temporal parts in a unity of past, present and the future. The women in this research were aware that their positions and roles were governed by tradition, society and culture. Yet, from the point of a diagnosis of breast cancer, the experiences of the women progressively shifted. Just as their earlier experiences shaped their understandings of the present and beliefs about the future so the experience of the present and thoughts of the future allowed for reflection on the past.

The ways in which the women participants conceived of their social roles was changing. The women had reached a point at which they demanded greater recognition and self-fulfillment. In other words, women’s self-perceptions were shifting and this gave rise to questions about a long embedded status quo. As one participant noted:

> *…in my opinion, religion is good. Religion says that a woman has to comply with her husband and that is good. But how much should one be compliant? Sometimes the concept of compliance to the husband is expected without question. Even if the husband is bad, the wife is supposed to accept this. In other words, the wife should comply. I am sure this is not how it is written in the Qur'an.* 7P_20B

As articulated above, some women in Indonesia have long argued for legal freedom from patriarchal authority. Other and more conservative Islam feminists contend that the translation of the Qur'an Verse should be contextually re-interpreted and in a more gender sensitive way rather than accepting a literal translation that reinforces patriarchy (Rinaldo, 2010). In the current research, women experienced discrimination in the workplace as a direct result of their illness. Women had to resist any suggestion that they should not work while having treatment (chemotherapy):

> *While I was having chemotherapy, I was called to the office of my boss. He said 'what if you are in chemo and I'm holding a position in a branch office, as the head of a taskforce. The burden will not be easy. While you need to have it we both know how painful chemo is. So if you feel you are not ready or that you are not able to do the job that is alright'. He meant during chemo and just to finish the treatment first. Maybe I could not work or something else, or be transferred to another division.* _2P_15B

The participant went on to state;

> *At that time I said I am ready. I can do it. I can make decisions about my own strengths. I think I can. That was what I said. So, for the time being, let me be until I feel that I am not strong enough, then I will say so. So maybe I am ambitious and I have a strong will. Yes, I think that I have to be strong.* 3P_15B

The economic growth from the late 1980s in Indonesia was reflected in a rise in the middle class with the capacity to engage with global discourses through educational institutions, civil society, and through the media (Rinaldo, 2011). The fact that the younger generation of women has had more opportunities in education and employment reflected a generational change in views on gender roles and responsibilities (Hapke, 2013). Developments in social media had also transformed communication about change whereby it was internationalised. Yet global feminism had come to co-exist with a wave of international Islamic resurgence which reinforced competing visions of the future trajectory for Indonesian women.

The various women's movements thus continued to struggle for what each group considers the priorities of women's rights. Much has been achieved in areas such as domestic violence and women's education and gains have been not as fulfilled in areas such as marriage law. According to Brenner (2011, p. 484) in the post New Order period, gender activists have had to face new challenges as the coincidence of the newfound freedoms of this period and the "dynamics of global Islam" have given space to a new conservatism for which the issue of gender is central. Conservative Islamic scholars argue that the Qur'an, as the highest source of guidance for Muslims, incorporates no provision for the dominance of one sex over another but simply endorses a gendered division of labour. Contemporary Islam feminists have sought to shift the emphasis to the contextual meanings of the Qur'an in arguing that its meaning must be contextualised in time and space (Arimbi, 2009, p. 66).

The complexities of the historical context of the women participants, as depicted above, resonate with Gadamer's concepts of historical awareness and tradition. As Gadamer (2004, pp. 323-324) argued; "Historical knowledge can be gained only by seeing the past in its continuity with the present…" and furthermore, historical understanding can only ever be partial because history is always in the making. In the same way, understanding can only be achieved (if partial) through a connection with tradition because tradition constructs the frame for interpretation. In other words, we cannot stand outside tradition in understanding the experiences of the women in this research because the women belong to tradition. Thus, the complex layers that underpin the experiences of women with breast cancer in Indonesia are constituent of culture, tradition and belief systems and most prominently Islam.

6.3. Summary

The starting point of this chapter was the social positioning of the women participants and how this positioning shaped their experiences and decision-making in relation to breast cancer. The two components, women and patriarchy and shifting cultural values, framed an exploration that was broadened to contextualise tentative interpretations in terms of cultural, social and political frames. Of particular relevance to this understanding was the concept of temporality which gave focus to the intersection (the fusion of horizons) of the encounter with the past or tradition, the present and future expectations. What we see is not a linear transition from a time passed to the present and indeed future, but rather a constant iterative process where elements of all appeared. Thus what was constructed was an understanding that is both historical and interpretative. The account is an interpretation of the social positioning of the Indonesian women diagnosed with breast cancer.

In the Indonesian context, processes that constructed the role of the women were complex and involved the interplay of a range of factors including religion, culture and state regulation. The context was important because the women were actively involved in redefining their roles at the social and the household levels and yet struggled with the more problematic and contextual aspects of gender issues. Although Indonesian women have been politically active throughout Indonesia’s history, their activities have not impacted greatly on the numbers of women involved publically in the political realm. While gender issues were given high priority in the interests of the nationalist cause it appeared that those interests were not to be served by gender equality.

It can be proposed from the analytical findings of this chapter that two key components shaped situations of the women; the given and the created. Culture, tradition and beliefs were posed as given categories that could not expect to change as a reflex response to external developments. The created situation refers to law, policy and rule which could act as facilitators of change in improving the conditions for women. A critical tension existed between law and religion as the appropriate framework for social development and there was a blurring of the two regulatory frames. This gave rise to tensions evident in the history of women's movements and ways in which women experienced and articulated their social realities.

The combination of Islamic religious views and a patriarchy that was embedded in religion and law constituted the ideology of traditional gender roles in Indonesia. It should be noted, however, that the situation is more complex as the manifestation of gender ideology is entrenched local cultures and there is need to explore how gender ideology shapes the lives of women in various ways beyond the context of this research. Indonesia is an archipelago country of great diversity and gender considerations may not be readily applied across local cultures of diverse ethnic groups without taking into consideration the factors that render the features of the construct of each ethnic group. The following chapter moves on to explore two further interpretive elements of the experience of Indonesian women who were diagnosed with breast cancer that focus on a *changing identity* experienced by the women conceptualised as shifts in *gender identity* and *community identity.*

Chapter 7: Changing Identity

> *So many women in the end blame themselves over and over and yet they don't want to say … they don't want to say that they have complaints and they don't want to say that they have cancer.* 15P_04A

7.1. Introduction

The mediating factors (culture, religion and government) that produced and reproduced the role of women in this research also shaped the ways in which the women negotiated the experience of breast cancer. Breast cancer is a life-threatening illness that has the potential to alter a person's core identity, and to replace primary identities with those related to the illness (Deimling, Bowman, & Wagner, 2007). A salient means by which breast cancer influences the core elements of the self is through gender identity. Broadly defined, identity is a "set of meanings that define who one is when one is an occupant of a particular role in society, a member of a particular group, or claim particular characteristics that identify him or her as a unique person" (Burke & Stets, 2009, p. 3). Identity is also dynamic and subject to change in adapting to particular situations (Burke, 2006). As such, identity formation is not a static process but develops over-time. In emphasising the temporality of identity, Leary and Tangney (2011, p. 69) argued that the focus of identity includes a time frame that is "the past – what used to be true of one, the present – what is true of one now, or the future – the person one feels obligated to try to become, or the person one fears one may become". Just as importantly, identity is shared and forms the basis of interactions with others, and ultimately of social structures (Stets & Burke, 2003).

For women diagnosed with breast cancer, the self as identity and its temporal nature are important issues where women experience changes in their appearance and their bodies. Once a diagnosis is confirmed, women may start to notice their altered bodies with which they begin to identify. Body and self are not separable but are a unity and hence bodily change as a result of any disease impacts on the self. Self is also connected to identity and so people will experience not only an altered body but an altered self and identity change. Changes occur from the point of a breast cancer diagnosis, through the treatment period and onwards through life in response to the long-term effects of treatment and cancer itself. In the words of (Tritter, 2009, p. 164), such changes result in "…a series of transformed identities based on particular understandings of cancer and what it is to be a cancer patient".

Thus, the purpose of this chapter is to explore the process of changing identity in the event of a breast cancer experience for Indonesian women. The chapter is organised around two areas which reflect further tentative interpretations of change in the women's lives in response to a diagnosis of breast cancer; *changing gender identity* and *changing community identity*.

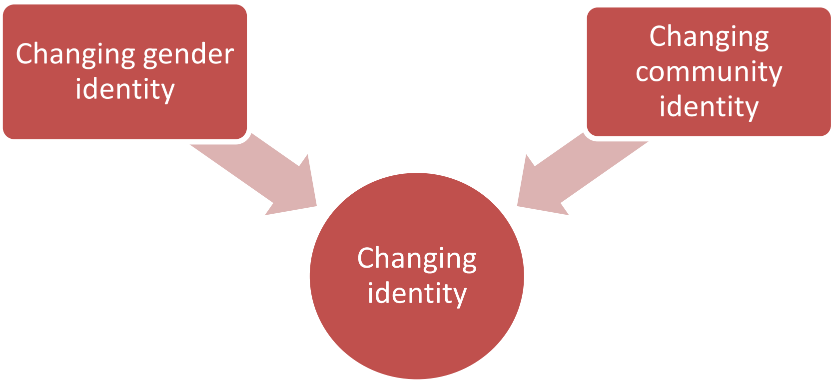

Figure 7.1. Third Analytical Finding

7.2. Changing Gender Identity

7.2.1. Normalcy

Integral to the breast cancer journey are significant challenges to gender identity encountered by women. Breast cancer is perceived a severe and threatening disease and as such, with significant implications, both personal and social. The diagnosis and treatment of breast cancer can thus disrupt the elements that constitute a coherent self – identity such as femininity, body image, and body integrity (Thomas-MacLean, 2004).

Maintaining a sense of normalcy was important for the women participants in establishing order and a focus on the future. Yet, in terms of identity, ensuring some order or control meant that the women defined themselves on the basis of what was considered socially relevant and appropriate at that time and place. Reflection on the self is fundamentally a social phenomenon where group membership (religion, ethnicity, or gender), family roles and physical appearance, among other factors, will matter more or less depending on what is valued in one's culture and in one's place within the social hierarchy (Leary & Tangney, 2011). In this research, a disruption of normalcy was fore mostly framed in gender terms. One participant referred to the values that shaped the breast cancer experience and that were external to medical treatment;

> *I just want to emphasise that cancer management and especially for breast cancer. Why breast cancer? Because the disease carries values in the family and in the community. There is an image of a woman's perfection. These things sit outside medical factors.* 5P_04A

And as reported by another woman:

> *Sometimes I am not self-confident. I don't have one of my breasts. Sometimes people like to, or try to, look. The truth is I don't want to be looked at (Her voice weakened and her eyes became teary).* 04P_01

Cultural notions of the nature of the body and illness as they relate to every day life present as an internal logic for understanding an illness. Even where there are obvious biological manifestations of an illness, social and cultural meanings are attached to those changes. For example, the interrelationship between Javanese cultural identity and herbal and other traditional medicines is considered profound (Torri, 2013). Hence, jamu has been extensively used in Indonesia and is very easy to access in Java in particular (Torri, 2013). Such medicines are perceived as beneficial and safe to the extent that they do not disrupt the essence of lives because their origins are local plants and roots. On the contrary, however, when the participants were compelled to follow bio-medical advice, which involved systemic and/or local therapy, life and identity disruption was intense. The women participants encountered what they perceived was greater ill health and dislocation of self and body caused following surgery and treatment.

> *Well, it was the saddest situation... the doctor said, "you probably should cut your hair..." ... I had never had short hair. I always had long hair, this long. So, when I was having chemotherapy, I cut my hair short. When I was out in the sun, around here,, just in front of the house, there was the wind blowing, and it just took my hair away even my eyebrows. It just flew away with the wind, all of it......* 11P_03B

It has been argued elsewhere that women with cancer are generally expected to resume their usual obligations with no visible mark of their loss and no concession to the fact that the world has been irrevocably changed (Wilkinson, 2001). As Broom (2001, p.254) remarked, when reflecting upon her experience with breast cancer, the definition of health has become a form of "social duty" where society is obsessed with "'productivity"' and discredits individuals who are very sick. During the period of breast cancer treatment, many participants remained at work. This was explained as sustaining some form of self-esteem and presenting the self as strong rather than vulnerable. The women challenged themselves to demonstrate to the world that the disease would not consume them and that they would retain control of their lives rather than allowing the disease to take control. One participant recounted a situation where the disease of cancer appeared to define her;

> *When I came to the hospital to start my regime of chemotherapy, a nurse asked "Who is the patient?". Then the nurse turned to look at me and she continued asking "Is it you?" This implied (to me) that a cancer patient who is having chemotherapy could not use make up and look attractive.* 1P_08A

The above reveals the interaction between social and cultural issues that determine a person's identity and hence, how women acted and responded to their encounter with breast cancer. The women were also vulnerable and considered the potential to be dismissed from employment as a result of the illness. One participant described the ordeal of performing a test/examination for a head of a school position while undergoing chemotherapy:

> *I undertook a test, a test to become a principal, a head of school in the district. Alhamdulillah (thank God), I passed... well, oh my God, can I even write? I was still in this condition, shaking all over. But I could do it, because I was really motivated.* 1P_03B

The compulsion to appear normal for women who have undergone treatment and in particular surgery for breast cancer is strongly embedded in gendered social structures. The concept of beauty is embedded in all cultures where symmetry and wholeness are emphasised and disability assumes a function in reinforcing what is perceived as beautiful, healthy and normal (Thomas-MacLean, 2004). A cancer illness thus becomes, as a disability, an identity category for a woman that she can enter into at any time in her life (Garland-Thomson, 2002). The construct of disability, in turn, reveals the dynamism in one's identity that undermines the cultural belief that women’s bodies can be an “unchanging anchor of identity” (Garland-Thomson, 2002, p.20). In terms of determining breast cancer treatment, adaptation to a rapidly changing identity amid the challenge of illness had become a problem for the women participants.

As such, in this research women participants experiencing physical disabilities, restricted in arms movement and pain. These physical disability are similar with the literautres reported, such as disability related pain and limited in arm movement (Little, 2017; Karki, 2005; Jones , 2015; Shelley, 1985; Hayes, 2010). However, in this reseaarch women also experiencing psychologic disability, as they felt not normal as a women after breast surgery or mastectomy. As such, not many reseacrher reported about this particular experience. Seems that the terms of disability is very tight with the culture and can be defined in the particular context. As Garland-Thomson (2006, p. 259) argues that, “disbility - like gender - is a concept that pervades all aspects of culture: its structuring institutions, social identities, cultural practices, political positions, historical communities, and the shared human experience of embodiment”. In particular, women who had had mastectomy repotrted their experiencing as a disabled and other also called them as a disabled person. This is similar with Manderson (1990, p. 390), he contend that disability is realated to “how women perceived themselves and how others perceived them, particularly (but not only) as sexually desirable. ... and women who have had a mastectomy must redefined themself as both gendered and sexual despite the absence of a breast”.

The symbol of femininity

Women with breast cancer experience multiple and competing agendas that are all embedded in their specific social contexts (Thorne & Murray, 2000). For the participants in this research, those agendas were framed around, as noted in Chapter 5, biomedical and traditional discourses. Further and conflicting agendas related to expectations that the women would maintain the status of the families and manage the consequences of a changing identity. From a feminist view it is argued that "having multiple conflicting attitudes that are all embedded in structures of institutional power, makes it hard for women with breast cancer to make sense of their experiences and to decide how to respond" (Collie & Long, 2005, p. 580). There is a strong connection between the existence of the breast and femininity and the values which the breast carries are important and for women extend beyond the physiological and psychological to a broader social function. In the context of Indonesia, women who were diagnosed with breast cancer also confronted the symbolism of the breast (Afiyanti & Milanti, 2013) and felt deeply about a loss of femininity and body image.

> *It was the change in myself and my body. I felt that I was not normal because originally I had two breasts.* 9P_01B

In Indonesian society (as in many societies) the breast is equated with a woman's identity and carries biological, psychological, psychosexual and psychosocial values (Hawari, 2004). The breast is an organ symbolic of womanhood and when affected by cancer will, in turn, influence that identity. Where the role of a woman is as a wife and mother a disease such as breast cancer fundamentally threatens identity (Hisham & Yip, 2003). As reported by one participant;

> *When making the decision to have a radical mastectomy we have to think not only whether the surgery will run smoothly or not but also what happens after that, when the woman has only one breast*. 1P_05A

A further participant referred to the objectification of the perfect woman;

> *Not all (women with breast cancer) receive good support. She has to be whole and of physical perfection. So the woman has to fight her cancer and she has to fight the values around her including those of her family.* A3P_051

Indeed, breasts are connected with the status of women not just in terms of appearance and physical and physiological functioning, but more broadly in relation to their social function. For example, body image will impact an identity as reported by a woman below:

> *There were some worries in the beginning. I felt, what is it, disabled. I did not feel whole* 3P_06B

Another woman stated that:

> *…well it's difficult to make it disappear, because, maybe a woman's perfection is reflected in her hair, breast and the shape of her body. It is not only beauty, but if all these aspects are perfect then it is called beautiful. That is the ideal of becoming a woman.* 2P_05A

A mastectomy is thus not simply an operation but carries social and cultural implications for normalcy, identity and status. Hence and although the development of breast cancer treatment has brought benefits, the side effects of breast cancer therapy, both physical and psychological, may be profound.

Women's attitudes towards breast cancer are oriented to the integrity of the body. Losing one or both breasts was meaningful for the women participants because the breast was connected with femininity and beauty and was symbolic of a normal female or the woman who looks normal regardless of health issues. Women who have undergone a mastectomy and experience the absence of a breast or breasts may engage in processes of redefining themselves in terms of gendered identities.

Body is also connected with the self and mind. The social and cultural messages around breast cancer that were absorbed by the women in the research culminated in the belief that surgery would result in disability and as a result stigma as reflected in the following:

> *Are you ready to be operated on? They said to me can you stand the risk of an operation?" What is the risk? Maybe because..., oh maybe it was because I would have to live abnormally.* 11P_01B

It is common for women undergoing breast cancer to be considered disabled due to norms and values that underpin the social construction of the status of women. Thus the risk of appearing disabled and what that would mean in the social worlds of the women participants was a salient factor in the expression of fear of breast surgery. Hence, the sense of what constitutes normality is deeply intertwined with cultural and social norms. In the words of Garland-Thomson (2005, p. 4), disability is"… a pervasive, often unarticulated, ideology informing our cultural notions of self and others".

Disability or ability system that creates subjects by distinguish and mark off bodies (Garland-Thomson, 2006). Since, the concept of disabilty is linked with the normality concept. Because, "we live in a world of norms. Each of us endevours to be normal" (Davis, 2006, p. 3). As Garland-Thomson (2006, p. 259) argues, "disbility - like gender - is a concept that pervades all aspects of culture: its structuring institutions, social identities, cultural practices, political positions, historical communities, and the shared human experience of embodiment". This is mean that disability not simply about physically, but also include the socio-psychologically. As some shcolars argued that the term of disabilities can be categories as physically (e.g., pain, reduced range of motion, lymphedema) and psychologically (e.g., body image, feminine role) in which can be impacted on all aspects of life during their illness period or survival (Garland-Thomson, 2006;

Ginsburg et al., 2017; Montazeri, 2008; Ness, Wall, Oakes, Robison, & Gurney, 2006). From the lens of feminist disability theory, "disability has social, experiential and biological components, present and recognized in diff erent measures for diff erent people" (Wendell, 1996, p. 244).

The women participants were disturbed about how they would be perceived by others and such views affected determination of choice of therapy:

> *To be honest, in my opinion, it is expected that people will consider that I am a disabled person because originally I had two breasts and now I have only one*. P_20B

> *It can be said that I am disabled or abnormal now that one side is gone.* 4P_01A

A disruption to identity was also associated with guilt in the participant experience and most obviously as it related to a woman's roles as wife and mother. As noted in the previous chapter, Indonesian women are obligated through religion and law to care for children and to ensure the stability of the household. If a woman is ill, this may affect the stability of the family. A source of anxiety was therefore uncertainty over who would manage the household and all that related to the survival of the family. This situation is reflected in the following comment;

> *It is a double burden for an Indonesian woman when she is diagnosed as having cancer. The woman has to fight her cancer and she has to fight the values around her, including those of her family and society*. B1_07P_05I

Following illness, individuals seek to re-establish their former relationship with their own bodies, where "self and body are in harmony" (Manderson, 1999, p. 390). Harmony of the self and body was the result of the interrelationship between the bodily experience and the specific cultural and social context and associated expectations.

> *After the operation I was not appealing to my husband in every way. When my hair had not yet grown back my niece bought me a wig. I wanted to be different in the way that I looked. When my husband was about to come home, I dressed up, put my make up on and my wig. I stood on the veranda but facing the back. I felt that by doing all of this I would be different. I wanted to be different.* 3P_11B

Even where the women perceived that they were disabled or abnormal, they sought to present their physiological selves as normal and to demonstrate that the altered body would not mean that they could not participate fully in the social world.

> *For me it is not big deal. I don't know if I am too naïve, or if I am too indifferent. I always believe that people will not only see me physically. That means it is not important what people see. The most important thing is the inside (the inner or soul).* 15P_06B

The women evaluated, reflected upon and reconstructed their identities. A participant described the evolution of this process of rationalisation;

> *... actually I am not like that (damaged). I also don't want to be like that. Why should I become like that? We see other people who are physically disabled and they appear alright with their situations. Some of them do not have arms and legs. So for me? It is just a breast. That is how I think of it. I still can use my arms and legs. It is nothing compared to them.* P_20B

Yet community values extended to a perceived stigmatisation of those who did undergo surgery for breast cancer. In the above excerpt, the participant challenges salient social meaning that associates a loss of a breast with disability. Such a challenge indicates the existence of social perceptions of women who have undergone mastectomies as disabled. It was very important to reclaim a normalcy which involved reasserting an engendered and social self.

What people think about us and how they see us may not be the same as our self-expectations. Nonetheless, the very disjuncture between a dominant social meaning and self- perception can create a disintegration and feeling of disharmony in relation to a woman’s identity. Hence, when the women encountered the experience of breast cancer treatment they attempted, in the words of Charmaz (1987, p. 286), to “attain, maintain or create a valued identity after an episode of chronic illness”. This experience becomes “crucially significant to ill people who become acutely aware of hardships in doing so” (Charmaz, 1987, p. 286). Regaining a valued identity was thus an important act in order to restore the self.

7.3. Changing Community Identity

A salient identity for women following a diagnosis of breast cancer is that of the sick role. Although the sick role may be acceptable at times, a shift in identity is inevitable. The new identity must and will change the direction of women’s lives and activities in the future. Hence, adjustment to the perceived limitations of the present altered body will be required because inappropriate adjustment may result in tensions around roles and activities, including work, family and relationships (Deimling et al., 2007).

Identity is always attached to meaning and it operates based on the role that one holds (Stryker, 1968). What is meant here is that “identity provides meaning to life and allows individuals to label themselves based on the different social roles that they played” (Bagger, Li, & Gutek, 2008, p. 189). Examples are being a woman, a mother, a teacher, and a wife.

Hence, a further dimension attached to identity is the expectations of an identity. The expectations associated with “a particular identity that lead one to behave in a manner which is consistent with the identity when it is invoked in a situation” (Burke, 2003, p. 4). An example in this research was the initial post diagnosis period when women turned to traditional therapies rather than Western medicine. As argued above, this can be explained in terms of deeply embedded traditional beliefs and social norms. Meaning and the expectation are thus inherent parts of a general culture. When a person holds a particular identity it is automatically accompanied by the meanings and expectations surrounding that identity and meanings and expectations cannot then be seen or treated separately.

Yet, identity change does occur and how this manifests depends upon context. A woman may assume either a “me” or “us” perspective that reflects sense making on the basis of ethnicity/nationality or gender. A ‘me’ perspective accords more obviously with the ideology of individualism that underpins Western societies while an “us” perspective reflects the environment of collectivist communities. Thus ,women have limited options within their respective social worlds (Willig, 2011) and this means that a disruption of identity as a result of breast cancer demands that individuals manage their new identities in ways that are socially coherent and compatible.

In similar terms, as human beings, people cannot be detached from others, and indeed, interact and maintain relationships with others. Each individual’s action always refers to the actions of others. An analogy is the key and the lock, which are always paired. In terms of identity, there are both individual and collective identities, both of which inform an individual’s identity. The collective identity, as Mead (1934) suggested, is where we and others can simultaneously see ourselves, and thus, social identity and individual identity are ultimately the same (Jenkins, 2004). As such, identity is shaped through the process of social interaction and also through how individuals see themselves as viewed by others (Jenkins, 2004). This means that individual and collective identity always come together and an understanding of collective activity is imperative in order to understand, in turn, individual identity.

An important dimension for women with breast cancer is not only the reconstruction of an identity but the confrontation by women with intersecting social and cultural discourses surrounding diagnosis, as well as issues of femininity, masculinity, ethnicity, sexuality, agency, and age (Thorne & Murray, 2000). The stigmatisation of breast removal following cancer is related to all of those factors.

7.3.1. Disclosing or Concealing

There is considerable variation in the expectation of disclosure of illness across cultures and countries. In Western societies, disclosure of cancer is considered the norm (Hoff, Tidefelt, Thaning, & Hermerén, 2007; W. A. Wood, McCabe, & Goldberg, 2009). In the US, for example, a majority of people with cancer report that they will disclose their cancer status and concerns to significant others (Henderson, Davison, Pennebaker, Gatchel, & Baum, 2002). This is not the case in many Asian countries where cancer sufferers are more reluctant to disclose their illness status (Tsuchiya, Horn, & Ingham, 2015).

Regardless of the different practices around disclosure noted above there are some consequences of diagnosis and treatment of breast cancer that are largely shared. Following treatment for breast cancer, concealment of distress, anxiety and fear of others becomes part of the breast cancer experience. Women are often expected to avoid talking about cancer and to conceal any ‘unseemly’ evidence of the illness or its effects (D. Broom, 2001, p. 270). The following participants referred to the practice of concealment of illness;

> *We become very good at managing ourselves, especially as women. We’re good at hiding what we feel and putting on a brave face for everybody else.* 4P_11B

> *I shared it with my friends, that I am a cancer patient. I told them everything. They were surprised. They said, "how can you talk about it?" I said that I wanted to share it because may be people can learn from my experience, particularly for people who are not aware of their own condition. And after I shared my story, I heard that several friends in my group had also suffered from cancer. But they just kept quiet, did not want to meet other people, and they also worried about themselves.* 8P_20B

The all-pervasive discourse of concealment, supported by the practices of vast medical and fashion industries, ensures that this remains the case. In the West, the sense of becoming partial is addressed through the commodification of the reconstruction of the woman following alterations to the body related to breast cancer. The claim of one such program that originated in the US was titled 'Looking Good Feel Better' (LGFB) and offered women a way to regain a sense of self and normality, not by recreating the self prior to diagnosis but by creating a self that reflects the normative social definition of femininity (Kendrick, 2008, p. 264). The overarching message of the LGFB program was that the social stigma of 'looking sick' is so strong and a feminine and abled body is so central to a positive self-definition that even women who did not define themselves in terms of femininity prior to cancer can find a path back to 'normality' through appearance.

The commodification of the female body was not as evident in this research. Expectations of breast reconstruction in the West, where reconstruction assumes a role in the re-construction of identity (Ucok, 2005), were not mirrored in the participant views although there was some ambiguity as the following reflections suggest;

> *I try to believe that a woman is a human being and it is not only the breast. Well, I still feel like a woman as a whole. From my heart, from my thoughts, I did think of breast reconstruction. That option was always there in the beginning. But after all this time I don't think that I could manage if*

> *anything was done to my breast. Once is enough. And also I don't need it, I don't think I need it.* P 06B

> *I bought a special bra. I was measured for it and the shape was also measured. So I am confident now to be a person. Indeed, for those who don't know thing will be usual. It increased my confidence and I am able to dress normally.* P 02B

Thus at the centre of this concealment is the routine assumption that after breast surgery, a woman will be fitted for a prosthesis (or undergo breast reconstruction) so that her outward appearance to the world is unchanged and 'no-one will know' she has had breast cancer (Prior, 1987).

As feminists have long argued, "silence and invisibility go hand in hand with powerlessness" (Smith-Rosenberg, Lerner, & Dubois, 1980, p. vii) and unless and until women with breast cancer can freely reveal their experience, it will remain a solitary ordeal, rather than an issue to be owned and addressed by the community at large.

The symbolism extended to around sexuality issues related to breast cancer treatments that included sexual intimacy and connectedness to others. The notion of sexuality needs to be viewed on a broad spectrum where sexual intimacy involves social rather than simply individual aspects. The discussion, therefore, brings emphasis to the social dimensions of sexuality, bodily appearance and connectedness to or interaction with others. Indeed, in this research women struggled with issues beyond the loss of a body part in terms of relationships and interactions. This resonates with Goffman's work (1963) on how the nonconforming body implicates social interaction. The current research extends Goffman (1963, 1959) concepts of "self-presentation," "stigma" and "interaction order" to include issues of bodily appearance and self in surviving breast cancer, a context in which intimate interaction is emphasised as well as public interaction. As a participant comment reflects:

> *When I meet a friend and we hug, another friend will say: "don't hold too her tightly, just in case her breast moves to the back (pointing her left breast)".* 5P_01A

It may be perceived that Muslim women who have undergone breast removal have an advantage of concealing their asymmetrical torso, since Muslim women cover most parts of their body, and specifically, the breast area. Yet, this implies that the woman participants did not engage in intimacy. Indeed, in terms of personal relationships, the women expressed concerns around intimacy and relationship issues. One woman noted that:

> *There is a little feeling, what is it? There is something missing...sometimes I am ashamed to show my husband.* 2P_05A

And another revealed:

> *I only had one problem. I am still not confident if I have to sleep with my husband. I would rather do the laundry for seven days in a row than sleep with my husband. I am really ashamed.* 6P_04B

Thus patterns of interaction with husbands were impacted due to body appearance. Culturally, both husband and wife are obligated to be sexually intimate with each other. When women experience a bodily change, such as a mastectomy, this directly influences sexual intimacy. The women participants substituted a role as wife with other roles (such as doing laundry) as a metaphor for guilt and shame. As suggested by Merleau-Ponty (1976, p. 5):

> All human experience comes out of our body position, and emphasizes body experience as the source of selfhood. Rather than being just an object in the world, it is through our bodies that we come to know the world and our relationship to it.

Hence, women with breast cancer who experience profound alterations to the body will change the way they perceive themselves and also the way they interact with others and the world.

Disclosure of identity is thus not easy for women diagnosed with breast cancer. As Charmaz (2006, p. 159) suggested, it represents a subjective form of telling which brings “one’s experiencing, feeling self into the foreground”. Following breast cancer diagnosis and treatment, women encounter body and self-disruption. As a consequence, feelings of disfigurement and disappointment cannot be avoided. Shame was a common term articulated by the women in the research. Women expressed difficulty in disclosing their cancer identity both during and after treatment. Discomfort was particularly apparent when women felt that disclosing their condition would change their identity.

Removal of reproductive organs will engender some concern about the consequences for sexual relationships but appears to have only minimal effect on the sense of femininity as defined in terms of explicit relations with others as well as in terms of physical appearance (Sekse et al., 2010). By contrast, removal of a breast is perceived as a greater threat to femininity because of the visibility of the removal of a breast which sets in play cultural values around appearance (Hofmann, 2004).

From the above it appears that the women participants deemed it important to regain a sense of self and normality, not necessarily by recreating the self that existed prior to diagnosis but by recreating a self that reflects the normative social definition of femininity (Kendrick, 2008, p. 264). Turner (1992, p. 15) words in this respect still resonate; “Women are clearly responding to the belief that social life depends on the successful presenting, monitoring and interpreting of bodies”.

Nonetheless, the experiences varied and some women were less concerned about bodily changes. There may have been alteration to the body but this was perceived as positive at times. The Western cultural imperative to “think positively” (Ehrenreich, 2009; Willig, 2011) when experiencing cancer, however, was not a pervasive feature of the research. A desire to share experiences with others may also have been a response that evolved over a period of time. The breast cancer experience is a long journey, not only in terms of the effects and consequences of the treatment, but also post-surgery and the struggle with the nature of survivorship (Thomas-MacLean, 2004). Two women participants reflected on the ways in which disclosure helped others and themselves;

> *By disclosing the breast cancer identity, I can help other women to care about their health especially to prevent breast cancer.* 1P_02A

> *I was very keen to inspire people. Even though I had cancer I could still excel in my work. Cancer is not the end of the world. I want to share my experience and hopefully it is useful for others not only to encourage myself. So, it has been helpful yes, mentally helpful.* P 02 A

Others have similarly argued that breast cancer disclosure functions as a means to ensure that women obtain information and advice from others (Petersson, Wennman-Larsen, Nilsson, Olsson, & Alexanderson, 2011) and better understand their experiences (Dagan et al., 2014). Yet, to disclose breast cancer status is challenging as moving from concealment is one dimension of stigma. In other words, concealment of cancer identity may prevent stigma. The following discussion addresses two concepts associated with cancer, stigma and metaphors, as issues related to a changing community identity.

7.3.2. Being stigmatised

Breast cancer is seen variously as a challenge, a warning, and a punishment the extent and nature of which depends upon meaning making and culture and history (Thorne & Murray, 2000). Accompanying the biomedical construction of breast cancer is the notion of stigma, initially formulated by Goffman (1963), as an attribute that converges with prevailing social norms to discredit a person and to allow that person to be denigrated. Thus stigma can be viewed as a process of social construction or a “special kind of relationship between an attribute and a stereotype” and one embedded in a “language of relationships” (Goffman, 1963, p. 4). Further, stigma manifests as a discrepancy between ‘‘virtual social identity’’ (how a person is characterised by society) and ‘‘actual social” identity (how a person is in actual fact) (Goffman, 1963, p.2).

The process of stigmatisation reflects the co-occurrence of its components: labelling, stereotyping, separation, status loss, and discrimination (Link & Phelan, 2001) which reflects Goffman’s (1963) theorising around blemishes of character as a stigma factor. When associated with cancer the implication is that there is something morally malignant about the individual. Willig (2011, p. 902) refers to the “relentless and unforgiving individualism” which positions those diagnosed with cancer as those responsible for the disease in the first instance and subsequently recovery or otherwise. Such views, Willig (2011) points out, reflect Western values. Women in the current study also engaged in a process of self-denigration because of a belief that they were being subjected to punishment by a higher being as is depicted in this comment:

> *I was sad and scared and asked why has this happened to me? Where did I go wrong, there were so many questions. Why did this happen to me, why me?*. 2P_02A

There was also reflection on individual behaviour that implied a moral responsibility;

> *We are already punished by having cancer and that is not an easy thing and then we are also punished by the community when they say that it was our fault because we do not eat well and so we are also punished by accusations about our behaviours. They also add that the disease will erase sins, so your sins will be erased, all of them.* 7P_04A

In the above, breast cancer was perceived as discrediting which reflected a process of stigmatisation that risked disrupting the social identity of the women. This disruption was reinforced by the association of breast cancer with individual lifestyles. Cancer could then be constructed as punishment and in turn, suffering as redemption as the following participants described:

> *I felt that I had created trouble, become a burden and that thought became another burden to me.* B1_08P_06I
>
> *I was afraid that the doctor would sentence me with cancer. When I heard "cancer", I was so afraid. It was just like a scourge.*11P
>
> *I was very sad the night before the operation, my family held prays for me at my house. It seemed to me that they were not sure that I would be fine with the operation.* 8P
>
> *I like to do exercise. The first time I did that again after the operation, there was one person that was fussy. She asked me, "well.., can you do exercise?", Alhamdulillah (thank God), I am healthy now, I said. She wanted me to show her the scar and suddenly she touched this (breast). Then I told my husband about her. My husband was very angry.* 11P_29B

Social stigma remains a feature of breast cancer if in different ways within different cultures. In Western countries a decrease in stigmatisation is suggested by the level of the commercialisation of the "pink" campaign. Nonetheless, stigma in connection with mastectomy persists and hence the social stigma of 'looking sick' is strong while a feminine and abled body is central to a positive self-definition. Even in contexts where women may not have defined themselves in terms of feminine appearance prior to cancer they may perceive that the path back to 'normality' is through appearance (Ucok, 2002). The appearance of health, however, could not obscure the positioning of the women as cancer sufferers. As one women explained;

> *I did do some make up work in a reception venue. At the point of time the bride and groom were seated, people did not realise that I was the one who had done the make-up. They then started to whisper, "oh, she was the one responsible for the bride and groom make up! She is fine now". They all came to me and asked, "are you alright?" They imagined that I would be different after the operation.* 6P_11B

This participant continued on to say;

> *People think that I am going to die and maybe I will not do make up anymore. I am afraid that there is a rumour that I quit my job. I am still good at my job, but maybe people think that I have quit. So I just watch TV and do nothing. I just daydream.* 5P_11B

The above excerpts indicate that stigma is a feature of the experience of breast cancer. The disease of breast cancer, for the participant above, was the way in which she was defined by others regardless of her capacity to resume her former life. While the effects of cancer were disruptive, the woman perceived that her role could continue within the community. Yet, the perceptions of others resulted in reduced work. A similar experience was described the women participant in the below:

> *I did not work in the bank anymore. The competition in my work was very strong and then with my condition like this (women with breast cancer). I was very weak, fatigue of course. It seems that the word cancer (people with cancer) means I deserve to be kicked out. Yes I felt like they wanted to kick me out.* 8P_25A

The impact of stigmatisation challenged the women both physically and mentally in imposing a label of abnormality. One participant reported that: *at my* *work, there was a change. I was called a disabled person. I felt as though I was disabled* (C_22 P_04). The sense of stigma associated with breast cancer also led some women and their families to conceal the disease. The strength of interdependent values meant that if the identity of one individual changed then the identity of the immediate social group would change and give rise to the risk of stigmatisation. One participant, a medical practitioner, who had been diagnosed and treated for breast cancer, made the following observation about her experience with patients diagnosed with cancer:

> *I have had several patients who felt embarrassed when they had to say that they had cancer and also ah … the family did not really like us to visit and talk about it because of that embarrassment.* 8P_04A

> *I didn't want anyone to know. I was not comfortable with it. So, I was really comfortable if I was on my own. If there were people around, what is it called.. When it was only me I was in a positive state. I did not have to be a strange person.* 7P_06B

Hence, for women with breast cancer, breast surgery can be a stigmatising corporal sign perceived as a disfigurement and considered a strong deviation from the feminine norm (Else-Quest & Jackson, 2014). Viewed through a male lens breasts are highly sexualised (Ward, Merriwether, & Caruthers, 2006) and the surgical removal of the breast may thus lead a woman or others to perceive herself as nonsexual or less feminine (Datan, 1989).

Through engagement within the community and interacting with others, women transformed their perceptions of disappointment and disfigurement through new ways of perceiving their worlds and through the creation of new identities. This is reminiscent of the work of Freedman (1994) who argued that women who encounter chronic illness work actively to reformulate themselves within the context of their illness.

Cancer-related stigma continues to be widely explored by researchers. This research has shown that women worked as active social agents to reject socially imposed stigma and this process appeared as a medium of change for the women. The women actively rejected stigmatisation and moved forward to reclaim their identities.

7.3.3. Metaphors and Cancer

Sontag (1977) argued that meanings (or metaphors) around illness are profound, that they change over time and that few would respond to diseases that dominated in 19th century as they would in the 20th century (Sontag, 1977). An example is that having tuberculosis in earlier times was seen as the "implacable theft of a life" (Sontag, 1977, p. 5) until the disease was able to be cured. Cancer has assumed the mantel of tuberculosis, according to Sontag (1977, p. 6), where contact with someone with a disease "regarded as a mysterious malevolency inevitably feels like a trespass; worse, like the violation of a taboo".

The cancer experience is complex and metaphors are often used to conceptualise those complexities that constitute cancer experiences (Gibbs Jr & Franks, 2002). The power of metaphor lies in the language used and a metaphor can function to reframe complex issues and to provide meaning. A metaphor is not only the communication of words, but also represents the very concept of an argument (Gibbs Jr & Franks, 2002).

The metaphor offers a plan for personal transformation in coping with illness and brings a contribution to the intellectual and linguistic tools for communication about senseless sufferings (Guinjoan & Ross, 1999; Jenny & Logan, 1996; Mallinson, Kielhofner, & Mattingly, 1996). The metaphor comprises both a representational and determinative function for individuals through reflecting on past experience and serves as a filter to regulate how people view their present experiences and project their futures (Siegelman, 1990). As such, metaphors are not simply a figure of speech, but function to redescribe a reality in ways that bear traces of the culture in which the metaphor is constructed. Cancer, for example, provokes responses of dread and fear that other illnesses do not invite (Altmann, 2008).

> *When we hear about cancer, suddenly we think of it as a deadly disease. Well death is not a crime, isn't it?*. 10P_20B

Military terms are the most prominent of oncology metaphors. "Cancer is war" was most frequently used in a comprehensive analysis of the use of metaphor in popularisations in scientific articles on cancer (Camus, 2009). From this stance, it is understood that the intent of the words "cancer is war" is to induce a positive motivation to fight against cancer. This metaphor informs the actions to be taken in order to overcome changes in the body due to breast cancer. The metaphor indicates that cancer is something that must be fought for where " if the patient shows enough determination to win and fights hard enough they can win the war" (Willig, 2011, p. 899). The military metaphor thus produces and reproduces the crucial message that patients must have a fighting spirit, soldierly bravery, and stoic acceptance, together with an optimistic attitude and a belief in one's ability to "win the battle" (Gibbs Jr & Franks, 2002). The military discourse was evident in the current study, where the relationship between the patient and doctor was posed in military terms:

> *I am very grateful that I met Doctor X who can convince and explain in detail the disease and what we can do together. He always says that we are a team, we have to believe together, and we cannot go anywhere if we are not working*

> *as a team. I used to say to Doctor X that he was the war commander and my husband and I were the ones who prepare what should be prepared.* 9P_04A

The desirability of positive thinking is implied by the construction of cancer as war, as it is assumed that the fight against cancer is a test of an individual's emotional strength or will to win. "Winning the battle", and "not giving up" are more highly valued than any other stance within the cancer context (Willig, 2011). One participant shared her understanding of breast cancer:

> *Well, I am learning, I am searching to find the cure for cancer. Cancer is the devil... it is true, cancer is the devil. I just want to ask the doctors to find the potent medicine to cure and kill the disease. Cancer is really a devil. I am horrified if I see cancer. Do not let other people experience it, it is enough that I had it.* 3P_03B

The above excerpt invokes a conceptualisation of cancer as evil, as a monster and something not even to be named. The women participants also applied metaphors to describe their re-conceptualisations of preparation for their future lives. An example is the use of the metaphor of traffic lights, as this woman explained;

> *Now my life can be described as already in the 'red zone, while other people are still in green zone'. I must do my best in my religious life, not for my life here in on earth, but more for my life hereafter. It does not mean that I become a pessimist. Rather, I am more positive thinking. Every step I take I always think about the usefulness of my actions because I do not want to waste my life by being sinful. I must think more of any risks associated with my actions. So, I have to be more careful in everything. I must be good to other people, good in choosing food, and good in others. 'If I am a car, I have an excellent brake'.* 6P_01A

Another woman said:

> *After the procedure was done so (I considered) there is always rainbow after the rain. I didn't make any judgement. This is part of life that I had to go through, that's it.* 8P_06B

As Altmann (2008) argues, metaphors matter because they provide a way to interpret and experience the world. They also shape the way that cancer is experienced with both positive and negative implications. For the above women, the metaphors acted as tools that, when applied, reflected meaning making processes. Metaphors are cultural and social constructs but are also interrelated to salient identities that inform the writing and function of metaphors in any particular context.

7.3.4. A Changing Identity

Salient identity refers to "the probability, for a given person, of a given identity being invoked in a variety of situations" (Stryker, 1968, p. 560). Of course, what is important to one can be different to that which is important to another. Gender identity, for example, might be most important for one individual, while social identity (as a member of a particular community) might be the most salient for another. Different identities assert priority and identities are hierarchically ordered into a structure of salience, defined as the possibility of activating a specific identity in any of a variation of situations (Stryker, 1987). Identities close to the top of the hierarchy are more able to be activated in a specific condition; and hence, are more self-defining than those close to the bottom (McLeish & Oxoby, 2007). Moreover, the salience hierarchy is reflected in the subjective importance of each identity and the varied rank of resources one is ready to commit to these identities (Bagger et al., 2008).

Ideally, people are expected to act or behave in ways that support their salient identity (Honeycutt & Rosen, 1997). In so doing, people seek to diminish the gap between personal identity salience and what people expect of them. However, in some situations, people resist changing their self to fit with the meaning and the expectation that certain social identification expectations hold (Burke, 2003). For instance, when women are diagnosed with breast cancer, it is unavoidable that a new identity will be added; the “sick” and “woman with breast cancer”. As such, the woman has not previously experienced this identity. This means that women have to shift their identities in terms of emergent meanings and expectations associated with being a woman with breast cancer. An example in this research is where women were viewed as inadequate and vulnerable in the workplace. This implicitly indicates that a woman diagnosed with a disease should not participate in the public sphere. Any manifestations of disease should be confined to the private realm.

Yet, in the domestic sphere women with breast cancer are also treated as sick and people who are limited in the responsibilities they can undertake. These situations largely relate to social structure and the social expectations attributed to women with breast cancer, and the extent and form of their embeddedness. However, this argument is also linked with the patriarchal tradition, where women are readily viewed as the weaker gender and often inappropriate for a specific job or prestigious position. In turn, this situation also impacts on women’s roles, limiting opportunities to sustain and maintain their activities and ultimately their identity.

It appears that a tension between what people expect and what women want to do is not uncommon. In an individualist tradition, the winner might be the individual, but in a collectivist culture, group thinking is more important. The concept of identity salience can be applied in the situation where people determine and make decisions that are congruent with a salient identity (Honeycutt & Rosen, 1997). Where the salient identity is collective the hierarchy within a group forms judgement on salience. Hence people will make choices and act in ways in any given situation that are self-fulfilling. While an individual decision is foremost in the context of social identity theory people are expected to not only behave based on their self-consideration but to consider the social, group, and community norms. Individual and social roles are thus perceived as congruent to the norms and values of the social and the values of the individual (Honeycutt & Rosen, 1997). Furthermore, identities are the traits and characteristics, social relations, roles, and social group memberships that define who one is. Previous research indicated that these identities could be noticeable predictably in which each of these identities give strong impact towards behaviour (Akerlof & Kranton, 2002).

Moreover, the salient identity will become problematised when people encounter a critical situation, such as breast cancer. As stated by Kiecolt (1994), the examination of life events will bring about an interruption of salient role identities. Hence, when women are diagnosed with breast cancer their worlds will be irrevocably changed. In turn, these experiences make fluid values, beliefs, and self-perceptions in relation to the world. As found in this research , in terms of decisions around treatment options the more salient identities, religion, gender, wife and mother, were not immediately obvious as discreet but appeared to converge to shape decisions. More importantly, however, salient identities repositioned as the women negotiated the diagnosis process, decided on traditional healers for treatment and subsequently reverted to biomedical treatment as a result of disease progression. As such the identity processes were not linear. The women participants did not act from one position of identity prominence or salience, or on the basis of a given hierarchy of identities, but rather shifted back and forth from one identity to another. The temporal frame within which the women acted, as explored in the final chapter, offers an explanation for the non-linear positioning of the women participants in relation to the breast cancer experience.

7.4. Summary

The intent of this chapter was to explore the third analytical finding of this research: *changing identity*. Maintaining, attaining, or recreating a valued identity after an episode of chronic illness is considered crucially significant. Women diagnosed with breast cancer encounter socially constructed norms related to femininity which are caused by mastectomies or bodily changes. Breast cancer disrupts the structure of daily life, and treatment induces not only changes in physical appearance but also in a person's sense of self-identity. In other words, a breast cancer diagnosis and the impact of treatment cumulatively disrupt an existing self-identity. Breast cancer also has the potential to threaten all aspects of women's life including how to perceive and to think about their bodies as gendered selves (Ogle & Ullstrup, 2006).

Two key dimensions of the concept of changing identity generated in this research were expanded upon. The first was changing gender identity that incorporated normality and the disclosure of self-identity. Hence, these concepts are perceived as mechanisms by which the women participants worked to reformulate and re-claim their identities in response to a critical change in their lives.

The second concept was changing community identity and its constituent parts of the stigma and metaphors related to breast cancer. The metaphors that manifested in the research were consistent with metaphors identified in other research on cancer. However, there is an interesting concept related to stigma that was generated in this research. The stigmatisation of women with breast cancer assumed a particular form within the Indonesian context. The overt gendered roles of women in Indonesia and the implications of living in a strictly patriarchal society may have rendered the women as subservient and passive social actors. By contrast, the participants responded to stigma by reconceptualising their bodies, roles, and futures. Kandyoti (1998) argued some decades ago that the patriarchal bargain is not an immutable entity, but can be transformed as historical conditions open up space for renegotiating relations between genders. Women thus redefined themselves beyond the definition that the diagnosis had imposed which was not to dismiss the past but to construct an identity that simultaneously would look to a new future.

The final chapter returns to Gadamer and the construct of temporality as it manifested in the research. The chapter explores the importance of considering temporal frames in understanding the experience of having breast cancer as a woman. The chapter then moves on to addresses some implications of the research and potential limitations.

Chapter 8: The Temporal Experience of Breast Cancer: Remaking the Past, Present and Future

Time present and time past
Are both perhaps present in time future,
And time future contained in time past.
If all time is eternally present
All time is unredeemable. (TS Eliot)

8.1. Introduction

On being diagnosed with breast cancer the women participants in this research experienced significant and irreversible change. Breast cancer disrupted time and lives (Rasmussen, 2010) and the perception of the past was an intrinsic part of individual and self-understanding that influenced how the women perceived their life positions for the future. In other words, the past was defined as coming forth in memory through its relationship with an emergent future.

For Gadamer (2004), embeddedness in culture, history and tradition is a necessary condition for interpretation and understanding. The research reported upon in this thesis thus built on the assumption that participant interpretations were dependent upon the historical conditions in which they were articulated and on the context in which the interpretations took place. It was on the basis of this understanding that the research sought to construct a hermeneutical understanding of being an Indonesian woman diagnosed with breast cancer. A dominant body of work on breast cancer has emphasised the biomedical aspects of the disease and focused on early detection of breast cancer and ways to reduce symptomatology (McCann, Illingworth, Wengström, Hubbard, & Kearney, 2010). There is less emphasis on the experiences of women with breast cancer beyond the physical and psychological body of biomedicine and little known about the experience of breast cancer within the Indonesian context.

The purpose of a hermeneutic interpretation is to enquire into what is not obvious in research data. Hence, the task of hermeneutic analysis is to “seek to express meanings and to transform them so the unknown becomes something that can be understood by other than the researcher” (Gadamer, 2004, p. 281). The analysis in the current study engaged with the temporal processes central to hermeneutics. Indeed, Gadamer’s (2004, p. 60) view of life’s practice is that “every experience is taken out of the continuity of life and at the same time related to the whole of one’s life”. Hence, an awareness of temporality is at the centre of situating and developing understanding where the whole of understanding is realised in terms of its temporal parts, or the unity of a past, present, and imagined future (Gadamer, 2004). In other words, the notion of temporality suggests that the experiences of women with breast cancer, the focus of this study, are bound by time as the essential product of culture and history.

The findings of the study reflected the ways in which the participants were perceived and how they acted in response to potentially life-threatening situations. The analytical findings of the research were generated from two levels of interpretation. The initial level of analysis produced tentative interpretations around three key conceptual findings. The first interpretation was that collective decision-making shapes the challenges faced by Indonesian women diagnosed with breast cancer. Here, a tension existed between the conceptualisation of self and the values and norms of family and society. The women participants belonged to their families, communities, and the broader society. As a result, in terms of determining treatment, the decisions of the women were overtly social and political rather than individual. Decision-making around breast cancer treatment thus strongly corresponded with the social and cultural frame within which the women were situated.

The second conceptual interpretation refers to the ways in which the participants engaged in a process of negotiation whereby the women began to question their rights and obligations as women. While the patriarchal tradition could not simply be put aside, women sought to renegotiate their roles within the emergent context. This was reflected in the experience, or rather the coming to terms with, the present situation. Changing identity was the third key analytical interpretation. This concept depicted how the women redefined their identities as a response to the experience of breast cancer. Women transformed identities to fit with a ’new life‘, one that differed significantly from the past and was purpose driven with a view to the future.

Following on from the above interpretations, an additional and more abstract level of analysis was undertaken that produced the overarching interpretation of temporality. Temporality refers to time as perceived and in the analysis as a remaking of the past, present, and future of Indonesian women diagnosed with breast cancer. The conceptualisation of temporality incorporated collective decision-making, the social positioning of women, and changing identity, all of which were embedded in history, society, and culture. More specifically, the understanding of culture referred to the elements of beliefs, norms and values, and also to culture as a process that was dynamic and ever-changing. A detailed exploration of temporality and related concepts is presented below.

8.2. The Concept of Temporality

8.2.1. Time

Time is one of the most important structures of human existence. Time plays a vital role in our daily life as we perform routines, activities, rituals, and rationalities (Biesenthal, Sankaran, Pitsis, & Clegg, 2015). Hence, understanding through interpretation cannot be achieved unless the interpretation is grounded in some consideration of time. As Sato, Hidaka, and Fukuda (2009, p. 218) argued, "the study of a life course cannot exist without the notion of time". The concept of time, however, carries a range of definitions which depend upon the particular foci of interest and which indicate that "time in all its forms is socially constructed" (Biesenthal et al., 2015, p. 45).

Although understood as socially constructed, time presents largely as a dichotomy in much of the social sciences, where it is conceived of as either an objective or subjective phenomenon (Adam, 2013a; Orlikowski & Yates, 2002). Time as objective is embedded in the metaphor of the atomic clock as neutral and quantitative. From this viewpoint, time is articulated as a sequential occurrence of events presented in chronological order (Brockmeier, 2000). Here, time is perceived through a linear lens where it is understood that the past is never repeated and thus always differs from the future (Crossan, Cunha, Vera, & Cunha, 2005). Clock time, in this sense, is associated with an emphasis on time commodification, work discipline, and machine time in industrial organisations (Adam, 1994, 2013b). Blyton, Hassard, Hill, and Starkey (1989, p. 42) referred to the predominance of the use of objective time in social science studies of organisations, whether synchronic or diachronic, where time is treated as "quantitative time- continuous, homogeneous, and therefore measurable because equal parts are equivalent". Time, as objective, is hence ever present and taken-for-granted and yet time is also invisible.

Application of objective time within contexts such as nursing is ubiquitous due to an overriding emphasis on time management (Waterworth, 2003). For example, how much time (duration) a nurse should spend with a patient, the speed (tempo) at which the nurse carries out her work and the timing (synchronisation) of the nurse's work with other nurses or other members of the health care team form the temporal reference frameworks that underwrite the strategies and actions that the registered nurse adopts. In relation to health and illness and nursing care, Purkis and Bjornsdottir (2006) challenge the modernist temporality that is directed only and always to the future.

In contrast to objective time, a subjective understanding is where experiences of time are shaped by history, context, and expectations (Dawson, 2014). Hence, subjective time is considered a product of the norms, beliefs, and customs that cannot be de-contextualised (Dawson, 2014; Orlikowski & Yates, 2002) and is thus understood as socially and culturally embedded. The pattern of subjective time is, therefore, more dynamic simply because it varies according to conventions, norms and context (Orlikowski & Yates, 2002).

The adoption of one side or the other in coceptualising time was inadequate to construct a hermeneutical understanding of the experience of breast cancer in this research which gave emphasis to illness as an "assemblage" (N. J. Fox, 2011) of cultural and social representations and expectations. More appropriate was a conceptualisation of time as socially and culturally shared and as a temporal structure that regulates and cordinates the ways in which people carry out their activities in communities and in a particular historical period (Orlikowski & Yates, 2002). This is not to situate time in the minds of individual participnats in this research but to emphasise the connections, relationships and interactions between the women as social actors and their situations. As such, the experiences of women with breast cancer were understood through a contextual interpretive process and, in the terms of Ricoeur (1988), an interpretation of context that occurred within three time dimensions; interpreting the present as it is, interrelated to how we understand the past, and also how we view the future. In keeping with Gadamer (2004), the whole of understanding is then realised in terms of temporal parts, in the unity of past, present, and imagining the future. In this research, therefore, time was perceived as in a frame, the past, present, and the future, collectively called temporality.

8.2.2. Temporality

The human sciences offer an alternative to the natural sciences and it is a grounding that allows us access to human life and to even render it intelligible. Similarly, temporality offers an alternative conceptualisation in breast cancer research.

Temporality is the integration of one’s past and future in a way that has meaning for the present (Haugan & Innstrand, 2012). Temporality refers to consciousness of time through the experience of being in time, and as such, a person is temporally located in the world (Heidegger, 1962) and allows past, present, and future to be experienced as a unity (Mackey, 2005). In other words, understanding temporality means the past can never be seen as an object in the past with an absolute separation from the present and the future (R. Palmer, 1969).

Temporality also refers to ongoing relationships between the past, present, and future and is relevant when people in particular situations make claims about who they are or who they are becoming in time and place (Schultz & Hernes, 2013). For example, experiencing an illness is a temporal entity that is lived through, which means that illness is not only a spatial entity located in a particular part of the body (Toombs, 1998). This means that the experience of breast cancer in an early phase may be constituted as a sensory phenomenon and not as a disease. The participants spoke of feeling a growth in the breast and it was only when diagnosed by a doctor as breast cancer that the condition became a disease. In other words, breast cancer as a disease was constituted by medical doctors. The disease as an objective entity exists as a physiological disease state that is chronological and future oriented. This temporal view differed for the women participants who experienced breast cancer as something far more than a chronological narrative of a biological process. Thus understanding the experience of breast cancer for the women participants was to view the illness in temporal terms where the meaning of the illness did not exist as a point in time but rather as a collectivity (Toombs, 1998) of past, present and future meanings. Understanding, therefore, cannot be achieved where interpretation does not account for temporality (Heidegger, 1962). This means that interpretation must sit within the historical and traditional context in which the past and present are not separate but are united (Gadamer, 2004).

In Denzin's (1989) terms, a sequence of events within a time period is recounted as a temporal production, and therefore all events deal with a temporal order of events; some come after or before other events, or can be simultaneous with other events. As such, and as Denzin (1989) pointed out, in interpretive approaches to life stories, lived time is not linear, it is circular and interactional. Reading the text is in now time (present) and it is about the past (because it was constructed before the reading), and while reading, judgments on predicting the future will be made, which in turn produces new understanding. All of these processes occur within the same timeframe that brings the past and the future to the present. As R. Palmer (1969) pointed out, people simultaneously understand in three modes of temporality: past, present, and future. This means that time is seen as non-linear, where the past and the future have come into the present, and are placed and examined in the same time.

Importantly, the concept of temporality is always accompanied by the notion of space (situated or location). Hence, the notion of being in the world is always about time and space, where everything (phenomena) in the world belongs (is situated) somewhere. For example, talking about temporality means talking about temporal spaces related to tradition and the past, temporal spaces related to the present and temporal spaces related to future expectations. As such, while experience are understood to be embedded in historical cultural, and social meaning, to construct an understanding of the experience of women in this research, a further layer was required; temporality. It was not only historical but also contemporary factors, or the present, that shaped the women's experiences. History and the present do not appear on a linear spectrum but simultaneously at work. Tension between the present and past is central to hermeneutics, where understanding resides somewhere between the past and present, or between the strangeness of the old and familiarity of the known in the present (Fry, 2002).

As such, through a temporal lens, time in this research was not perceived as a temporal location where the "now is most real as an isolated and separate event, unrelated to either the past or future, except perhaps in something like memory or bodily movement" (J. Robinson, 2006, p. 99). On the contrary, the temporal experience of Indonesian women with breast cancer could not be treated separately from either the past, present, and future; the temporal dimensions were to be seen as juxtaposed or as a shifting whole. This view rejects the notion that "the future is not yet and the past is no more, so now seems to be the only true time" (J. Robinson, 2006, p. 99).

The analysis in this research interpreted treatment of choice as a central issue where decisions about treatment were infiltrated with past and future. Women were very much influenced by prevailing views around traditional medicine and yet ultimately moved towards Western medicine. While Western medical treatment appeared as a last resort it cannot be assumed that the delay was the result of a lack of information or knowledge related to breast cancer treatment. This is so because on experiencing symptoms and bodily changes the women accessed medical facilities in order to determine a diagnosis. Yet, in considering treatment options the women brought to the decision-making process social, cultural, and historical discourses These discourses constituted a language through which norms, values, and traditions were produced and reproduced and through which human understanding and action took place.

As noted in Chapter 3, culture is a dynamic, ever changing whole and hence while the individual women participants had the capacity to make choices about the breast cancer trajectory how those choices unfolded for the women was complex and mediated through language and narrative. The understandings imparted by culture came to the forefront as the women were confronted with a serious illness. It was as though the decisions that the women made about treatment were part of processes that were protracted narratives "tied in one way or another to the models handed down by tradition" (Ricoeur, 1991, p. 25). In Western societies those narratives, while also complex, appear to converge to a greater extent around treatment from a biomedical approach.

Furthermore and at the point of the impact of a diagnosis of breast cancer, everyday taken for granted lives came to be experienced differently and variously and in ways not previously encountered. The encounter between tradition and an extraordinary experience reconstructed prior understandings. Importantly, this is not to presume that the women came to understand their situations better as this would assume a linear movement where the past is discarded and a truth prevails. Rather, the women came to understand their situations differently. From the above, it is concluded that the women reached understanding that was the result of, not only this moment (present), but an integration of past and future. The women were operating in the temporal space between tradition and the past and the present and the future which, in Gadamer's non-linear conceptualisation of time, occurred simultaneously.

Thus, the lens of temporality allowed the experiences of the women participants to be understood in new ways. For example, when participants considered breast surgery as treatment (the present), the women incorporated their past (history, culture and social, and traditions) and also anticipated the future; the future was a condition of decision-making. Thus, the future also came to the present where the women imagined what futures would result from their decisions. Interrelated with these processes were cultural and social practices and expectations around health and illness and decision-making where gender relations were both private and political. From this temporal view, the past and present played an important role where time was seen as a recurring pattern from which predictions of the future can evolve (Biesenthal et al., 2015).

The key interpretation of this research was generated from all processes that constituted the hermeneutic interpretation of women diagnosed with breast cancer:

remaking the past, present, and future of women with breast cancer. Diagram 8.1, as appears below, demonstrates the temporal whole of this research as dynamic.

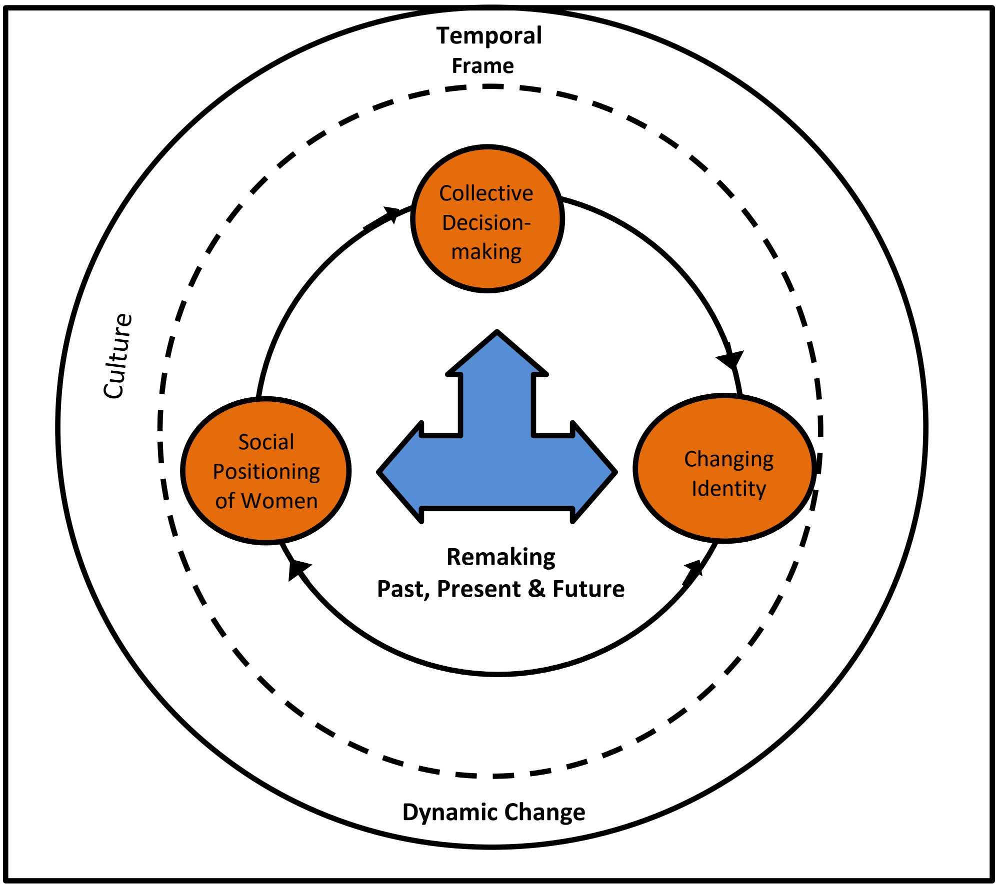

Figure 8.1. Remaking the past, present and future of breast cancer women

8.2.3. A Dynamic Process

The human being is an open system and can be understood as dynamic, fluid, contextual, and relational (Jardine, 1990). Hence, this research on the human experience of breast cancer is understood as a dynamic process where the research process took place within the context of time (history) and the society and culture of Indonesian women. Moreover, the research process was constructed in a fluid manner where the subject was not perceived as a discrete individual but one constantly in interaction with the environment through ongoing dialogue.

The responses of the participants to the realisation of having breast cancer were also dynamic and not characterised by an immediate and enduring acceptance of the condition as “God’s will.” It appeared that the women worked actively to make sense of their condition and they rationalised the illness in different ways at different times. The sense making constantly shifted where the women turned at times to religion, at other times to friends and families and further to perceptions of self. The women referred to a universal belief in Islam that if one acts appropriately and accepts what God has given then rewards will be reaped. Conversely, if people suffer and reject that which God has given punishment will follow. The participants were at once fatalistic and wanting to assume control. Thus the women were not passive, as fatalism may imply, but responded to the breast cancer and its symptoms in different ways as they drew on different sources of knowledge and discourses. This was a reflection of a dynamic process whereby the women did not assume just one view of the world but a complexity of views derived from their experiences. The experience accords with the Dallmayr (2009, p. 224) definition of culture as “internally diversified and unfinished, that is, always evolving and changing on the move”.

In keeping with culture as a dynamic, ever changing process (Dallmayr, 2009), the women did not always follow the roles of their parents even though there appeared to be deeply entrenched and gendered expectations of the society in which the women were situated. Yet, the long history of the struggle for women’s rights in Indonesia and the ongoing tension between conservative Islam and the women’s movements reflects a shifting landscape within in which the women found ways to adjust that at times challenged prevailing social norms. The result may have been a coming together of elements of the past and the present where ultimately the women needed to let go some of the past and as such part of their identity that was embedded in traditional beliefs and practices.

8.2.4. Summary

As Zebrack (2000, p. 238) stated; "cancer is not just a single event with a certain end but an enduring condition characterised by ongoing uncertainty, potentially delayed or late effects of the disease or treatment, and concurrent psychosocial issues". A cancer diagnosis, in the above sense, deconstructs a previously experienced normality and in turn one's self-identity (Ferris & Stein, 2002). When a woman is diagnosed with breast cancer her identity becomes 'woman with cancer'. The new identity is accompanied by various responses that further reconstruct the woman. Such responses exist within temporal frames that are contextual, non-linear and subjective.

Hence and in keeping with Gadamerian hermeneutics, the above findings depicted an experience that was made up of its constituent social, cultural, and historical processes. An exploration, drawing on the Gadamerian hermeneutic concept of temporality was undertaken in order to fulfil the research purpose; to construct an understanding of being an Indonesian woman diagnosed with breast cancer. The temporal lens considered the ways in which the past, present, and imagined future existed as a juxtaposed, non-linear time representation of how the women responded to and acted as a result of their illnesses.

It is significant that temporality in this research meant a constant and dynamic enactment of the past in the present and a horizon of expectation that was associated with the future. Hence, when a woman was diagnosed with breast cancer this meant that the present was altered and in turn the past was revised. In other words, for these women, the temporal experience of breast cancer was also about remaking the past, present, and ultimately the future. The women viewed the past and the future quite differently as a result of their experience of breast cancer. As Gadamer (1973, p. 83) wrote; “we become aware of time - beyond what is expected of it or in it - when we encounter negative or borderline experiences”.

Thus and in conclusion, the purpose of this chapter was to explore a conceptualisation of temporality that draws on the work of Gadamer and that underpinned an overarching interpretation of the women participant experiences of breast cancer in Indonesia. The chapter (and indeed the thesis as a whole) draws attention to the importance of moving away from the linearity of a bio-medical approach to illness to consider how illness (and indeed health) are situated beyond the biological body and within a complex network of relations. The temporal analysis incorporated the analytical findings (collective decision-making, women’s social position, and changed identity) and the resultant remaking of the past, present, and future as core interpretations of the experience of Indonesian women diagnosed with breast cancer. What follows is consideration of some implications of the outcomes of the current research and proposed limitations.

8.3. Recommendations

8.3.1. Recommendations for Health Care Practice

The research findings make clear that decision-making around treatment selection for breast cancer is far from straight forward. On the contrary, such decision making is multilayered and various dimensions of social influences. Indeed, the choice of breast cancer treatment in Indonesia (and no doubt elsewhere) is the result of a significant interplay between social, cultural, and traditional elements. A delay in time to diagnosis or treatment may impact on survival (Khatri, Whiteley, Gullick, & Wildbore, 2012). In the current research, most women participants had delayed Western medical treatment a phenomenon supported by national (Indonesia) data and known to be characteristic of developing countries. While resources are important, the delay for the women participants was mediated by a co-mingling of past, present and future (Riessman, 2015). Decisions around Western medical treatment also appeared to be dependent upon discussion and agreement with an individual woman's family members or those who were close to her and the people most instrumental in the choice of treatment was the husband followed by older siblings. This reflects the collectivist nature of Indonesian society. A prominent issue for Indonesian women lies in negotiating the patriarchal tradition which can be an obstacle in seeking treatment for breast cancer.

It is acknowledged that an appeal to 'education' as an implication of research is somewhat simplistic. This is certainly the case in the context of this research where complexity characterised phenomenon and associated processes that were explored. Nonetheless, a hermeneutical understanding may point to the possibilities of change. The following recommendations are posed in recognition of a need to consider deeply whether and why such change matters (Moules, et. al.,2015).

Two key areas that may be explored in relation to recommendations for health care practice are as follows:

1. The provision of timely, relevant and comprehensive health care information is a crucial issue. Where decisions are strongly shaped by an external context and others within that context there is the potential, if comprehensive health information is not provided, that a lack of knowledge may inform an outcome not anticipated nor sought. Hence, health information about breast cancer awareness and treatment options should be

broadly and consistently communicated through a public health education program to the Indonesian community as a whole. The symbolic sensitivity around the breast as a focus may be addressed, as has been the case in Western countries, where widespread health promotion becomes the normative accepted practice. A nationwide breast cancer health awareness program should be developed at a national health policy level along with a strategies devised to ensure consistent targeted roll out of the program.

At a local level, health professionals might be educated and encouraged to to consider a broader approach that incorporates both well established evidence based treatment guidelines and discussion about the benefits of traditional healing medicine.

2. The analytical findings support an approach that more strongly integrates and institutionalises traditional and bio-medical therapies and information. This implies greater regulation of the health care system, particularly in relation to traditional healers. As noted in this thesis, traditional healers hold an important spiritual and therapeutic position in Indonesian society and provide legitimated services. Yet, without proper regulation there is the potential that traditional therapies may be applied in an uninformed way where alternative treatment is urgently indicated. One strategy to support regulation is to maintain a public register of practicing traditional healers. A public campaign raising breast cancer awareness could also include reference to the public register of practicing traditional healers. Traditional healers are integral to Indonesian culture and for many families have an important economic function so they should not be marginalised or dismissed but brought into a more formal national breast cancer health

awareness program where Western and traditional therapies are both included.

3. In recognition that Indonesia is a largely patriarchal society it would be approriate to explore strategies to address a broader gendered perspective. As the thesis noted, women’s movements have a strong legacy in Indonesia and have been significant in articulating shifts in positioning of women. Organisations that are considered legitimate representatives of women’s issue might be encouraged to particpate in programs that encourage the involvement of both woman and men and demonstrate the wider impact that breast cancer has on families, communities and society as a whole.

8.3.2. Nursing Research

The research findings indicate that breast cancer care is complex and manifests as an assemblage of many factors including social, cultural and other normative belief systems, education, economics and gender. No one factor appeared dominant in this research as an explanation for the experience of the participant women. Many interrelated influences resulted in delayed treatment. The women also faced decisions about philosophically distinct approaches on treatment of choice; traditional medicine and western medicine. Furthermore, the women lacked the authority to make decisions about their own health care. As evident in the research, the positioning of the women was significant where any decision-making was dependent upon the authority of their husbands. This was evident, for example, where decisions were made by husbands and family members on procedures such as a mastectomy symbolically removed ownership of breasts from the women. Most notably and as is appropriate in hermeneutic inquiry the reseach posed, rather than answered, questions. Three identified and important strategic areas that could be the subject of further research in the area are as follows.

1) First, a discreet biomedical perspective is arguably not adequate to improve health outcomes and ultimately result in an improved high quality of life for women with breast cancer in Indonesia. Far more research on the layers of complexities of the experiences of women with breast cancer in Indonesia is needed so that the research outcomes can underpin understandings of women who are diagnosed with breast cancer (ie. traditional healing and contemporary evidence based medicine).
2) Second, the current health care system in Indonesia does not as yet have the infrastructure to distribute and transmit the relevant information and knowledge to promote breast health practices. There is no national policy nor program on the importance of early breast cancer detection as noted previously. Research that explores the possibilities around national programs in health care and reaches the attention of relevant government authorities is required to bring focus to the importance of breast cancer prevention and early detection.
3) The third area of suggested research is around the economic and social costs of breast cancer to Indonesian society. Such research would involve both quantitative and qualitative methods and suggests an interdisciplinary approach. Governments are responsive to evidence that policies and programs will reduce health care spending. While nursing research is in the developing phase, the nursing profession is well positioned to participate in such research.

8.4. Potential Research Limitations

There are a number of potential limitations to this research. The first is that the sample of women was drawn from one city, Bandung, in Indonesia. Indonesia is a very diverse nation and recommendations for nationwide breast cancer prevention and early detection programs would be better informed by research across the diversity of the country.

A second and related limitation is that difficulty with recruitment undermined the capacity for theoretical sampling. Analysis driven sampling may have expanded the range of analytical ideas to be pursued in the research.

Third and in relation to the above points, it is important to note that while the large majority of participants identified as Muslim during the interviews there appeared to be a small number who self-identified as Christian. Although not evident in the research there may have been differences around issues such as polygyny between Christian and Muslim participants. Indeed, as noted earlier, the 1974 Marriage Law was strongly contested by different religious groups and the outcomes made polygyny more difficult. There have been historical shifts on this issue among Muslims (Nurmila, 2009) and there continue to be differences. It is also the case, as Nurmila (2009) argues, that in Java both genders generally view polygyny negatively and it is therefore a relatively rare practice.

A fourth and potentially more important factor is social class which has not been overtly addressed in the thesis and may suggest that the breadth of analytical propositions generated in the research was limited. Social class in Indonesia situates women in differing positions that may impact on autonomy in all facets of life. This is a contentious issue because, as this thesis has argued, Indonesian and specifically Javanese women hold subordinate positions within a cultural hierarchy regardless of economic status. Nonetheless, the concept of culture incorporates a broad range of social practices and social processes all of which deserve fuller exploration.

Putting the above points aside, a strength of this research is the theoretical thread of Gadamerian hermeneutics that ensured a methodological continuity and coherence.

8.5. Conclusion

In the words of Riessman (2015, p. 1066); “Temporality is ambiguous: beginnings, middles and ends bleed into each other just as past, present and future do; clear divisions erase the continuing, durative nature of a chronic illness and a life”. Reismann’s words reflect the essence of the experiences of the women participants. There was no linear narrative to be revealed in the lives of the women. The experience of breast cancer for the Indonesian women appeared as an indiscriminate group of actions and events that had no clear beginning, middle and end. The temporal frames through which the women interpreted their worlds and acted, if not entirely arbitrary, were always shifting and did not exist as a coherent whole.

It was as though there were layer upon layer of mediators that interacted in diffferent ways at different points of time. The identity of women as wives and mothers within their families and the role of religion in informing people’s lives were critical temporal frames through which change was negotiated in the present. Responsibility for family, however conflicted with a temporal frame that saw many women delay treatment for lengthy periods. This was not the simply result of a unquestioning faith in traditional therapies. Rather, it was a period whereby women engaged with the assemblage (N. J. Fox, 2011) of relationships and connectivities that were historically embedded and of which the biological reality of breast cancer was only part. Thus far from being irrational the experience of the women in this study demonstrated not a passivity but an active engagement with the complex worlds within which they were located.

The tension between present and past is central to hermeneutics whereby understanding resides somewhere between the past and present, between the strangeness of the old and familiarity of the known in the present. Typical methodological approaches could not capture the salience of history and tradition and the present and future in the women's experiences of breast cancer. The lens of the interpretive hermeneutics of Gadamer (1900-2002) facilitated an exploration of the layers of the experience which were never fixed but were particular historical configurations that both shaped and were shaped by the experience of breast cancer. As such, the research moved from tentative interpretations to conceptualise identity as fluid and assuming a variety of forms some of which were enduring and others disrupted. Where identity forms were enduring, such as gender identity, this highlighted the interconnectedness of past, present and future. Other identity claims associated with, for example, education and professional work, were emergent and focused on the future. Understanding identity endurance or reconstruction gave insight into the different temporal lens by which the women encountered the breast cancer experience. This insight, in turn, emphasised the significance of social and cultural influences on the temporal frames of the breast cancer experience. The essential outcome of this research is a level of understanding of the research phenomenon that poses more questions and the need for further in-depth exploration. The value of hermeneutics is in developing our capacity for an extension of understanding; a process that is never closed.

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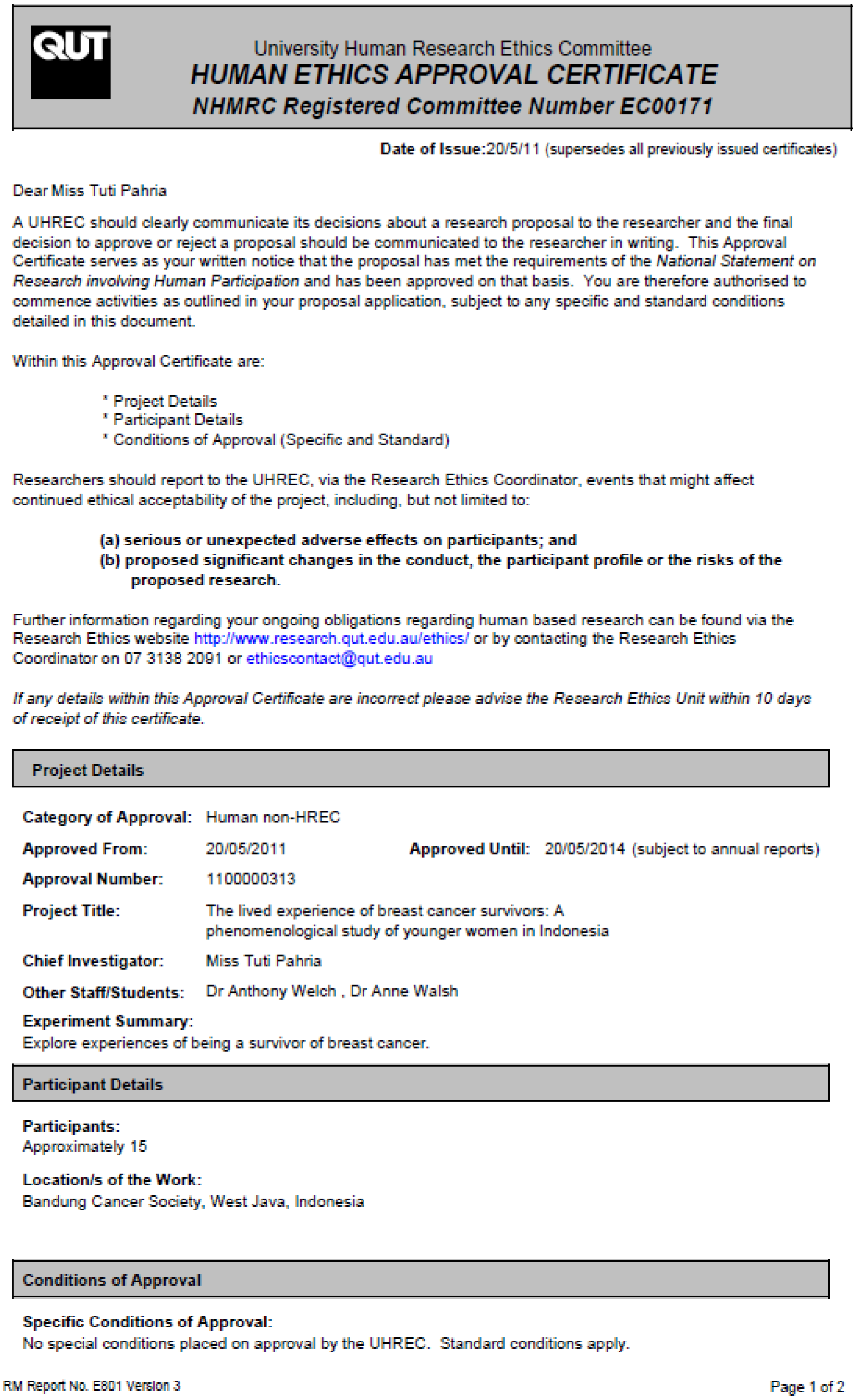
Appendices

Appendix A: Ethical Approval



University Human Research Ethics Committee

HUMAN ETHICS APPROVAL CERTIFICATE

NHMRC Registered Committee Number EC00171

Date of Issue:20/5/11 (supersedes all previously issued certificates)

Dear Miss Tuti Pahria

A UHREC should clearly communicate its decisions about a research proposal to the researcher and the final decision to approve or reject a proposal should be communicated to the researcher in writing. This Approval Certificate serves as your written notice that the proposal has met the requirements of the *National Statement on Research involving Human Participation* and has been approved on that basis. You are therefore authorised to commence activities as outlined in your proposal application, subject to any specific and standard conditions detailed in this document.

Within this Approval Certificate are:

* Project Details
* Participant Details
* Conditions of Approval (Specific and Standard)

Researchers should report to the UHREC, via the Research Ethics Coordinator, events that might affect continued ethical acceptability of the project, including, but not limited to:

(a) serious or unexpected adverse effects on participants; and
(b) proposed significant changes in the conduct, the participant profile or the risks of the proposed research.

Further information regarding your ongoing obligations regarding human based research can be found via the Research Ethics website http://www.research.qut.edu.au/ethics/ or by contacting the Research Ethics Coordinator on 07 3138 2091 or ethicscontact@qut.edu.au

If any details within this Approval Certificate are incorrect please advise the Research Ethics Unit within 10 days of receipt of this certificate.

Project Details

Category of Approval: Human non-HREC

Approved From: 20/05/2011 **Approved Until:** 20/05/2014 (subject to annual reports)

Approval Number: 1100000313

Project Title: The lived experience of breast cancer survivors: A phenomenological study of younger women in Indonesia

Chief Investigator: Miss Tuti Pahria

Other Staff/Students: Dr Anthony Welch , Dr Anne Walsh

Experiment Summary:
Explore experiences of being a survivor of breast cancer.

Participant Details

Participants:
Approximately 15

Location/s of the Work:
Bandung Cancer Society, West Java, Indonesia

Conditions of Approval

Specific Conditions of Approval:
No special conditions placed on approval by the UHREC. Standard conditions apply.

RM Report No. E801 Version 3

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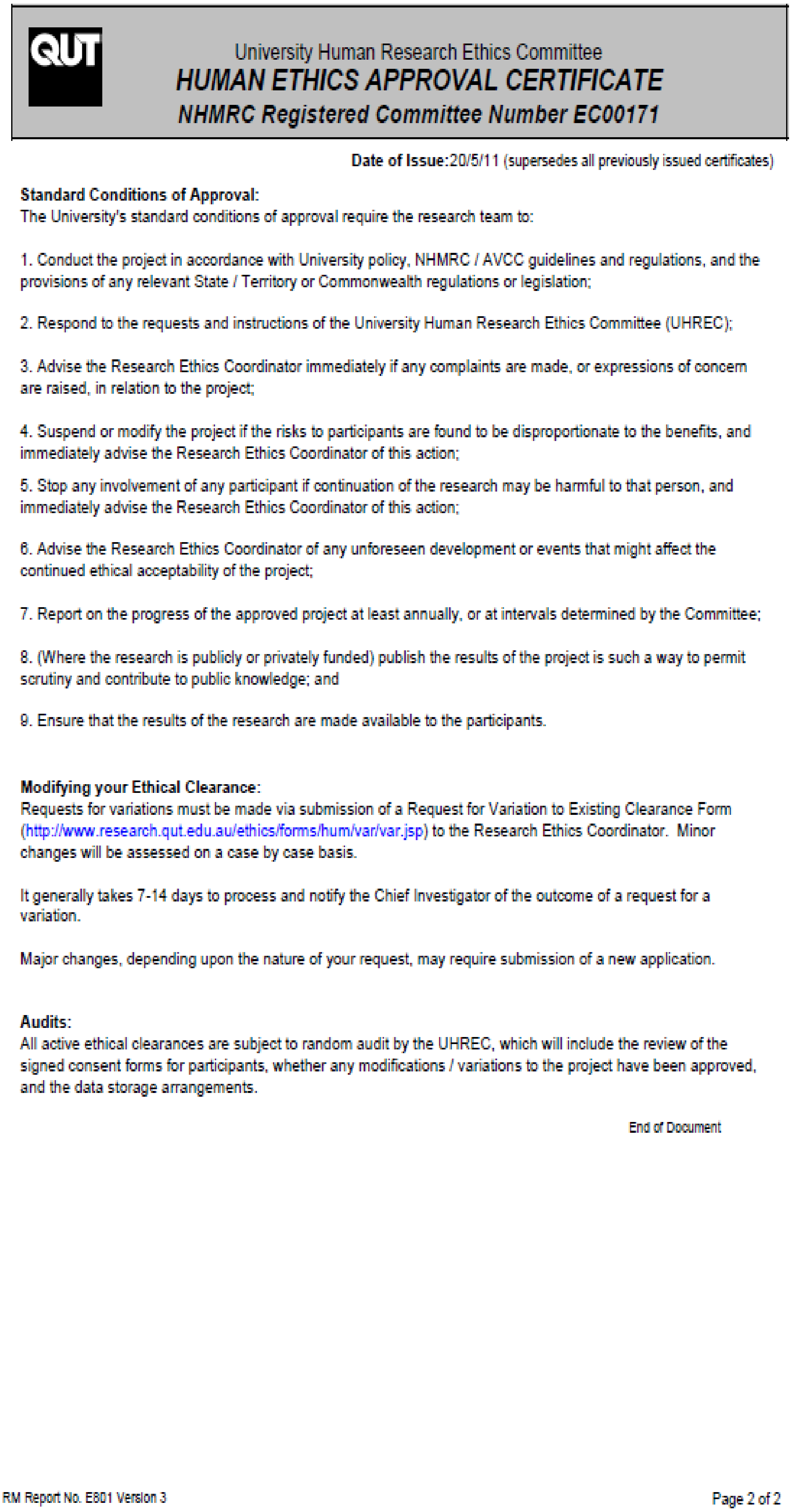

University Human Research Ethics Committee

HUMAN ETHICS APPROVAL CERTIFICATE

NHMRC Registered Committee Number EC00171

Date of Issue:20/5/11 (supersedes all previously issued certificates)

Standard Conditions of Approval:
The University's standard conditions of approval require the research team to:

1. Conduct the project in accordance with University policy, NHMRC / AVCC guidelines and regulations, and the provisions of any relevant State / Territory or Commonwealth regulations or legislation;

2. Respond to the requests and instructions of the University Human Research Ethics Committee (UHREC);

3. Advise the Research Ethics Coordinator immediately if any complaints are made, or expressions of concern are raised, in relation to the project;

4. Suspend or modify the project if the risks to participants are found to be disproportionate to the benefits, and immediately advise the Research Ethics Coordinator of this action;

5. Stop any involvement of any participant if continuation of the research may be harmful to that person, and immediately advise the Research Ethics Coordinator of this action;

6. Advise the Research Ethics Coordinator of any unforeseen development or events that might affect the continued ethical acceptability of the project;

7. Report on the progress of the approved project at least annually, or at intervals determined by the Committee;

8. (Where the research is publicly or privately funded) publish the results of the project is such a way to permit scrutiny and contribute to public knowledge; and

9. Ensure that the results of the research are made available to the participants.

Modifying your Ethical Clearance:
Requests for variations must be made via submission of a Request for Variation to Existing Clearance Form (http://www.research.qut.edu.au/ethics/forms/hum/var/var.jsp) to the Research Ethics Coordinator. Minor changes will be assessed on a case by case basis.

It generally takes 7-14 days to process and notify the Chief Investigator of the outcome of a request for a variation.

Major changes, depending upon the nature of your request, may require submission of a new application.

Audits:
All active ethical clearances are subject to random audit by the UHREC, which will include the review of the signed consent forms for participants, whether any modifications / variations to the project have been approved, and the data storage arrangements.

End of Document

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Appendix B: Consent Form (English Version)

Queensland University of Technology
Brisbane Australia

CONSENT FORM FOR QUT RESEARCH PROJECT

“The lived experience of women diagnosed with breast cancer : A Hermeneutic phenomenological study of women in Indonesia”

QUT Ethics Approval Number: 1100000313

RESEARCH TEAM CONTACTS

Tuti Pahria – PhD student
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Faculty of Health
Phone: 0422 443 299
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Dr Carol Windsor – Assoc Supervisor
School of Nursing
Faculty of Health
Phone: [+61 7 3138 3837
Email:
c.windsor@qut.edu.au.

STATEMENT OF CONSENT

By signing below, you are indicating that you:

- have read and understood the information document regarding this project
- have had any questions answered to your satisfaction
- understand that if you have any additional questions you can contact the research team
- understand that you are free to withdraw at any time, without comment or penalty
- understand that you can contact the Research Ethics Unit on +61 7 3138 5123 or email ethicscontact@qut.edu.au if you have concerns about the ethical conduct of the project
- Understand that the project will include audio-recording
- agree to participate in the project

Name ....

Signature ....

Date ....

Please return this sheet to the investigator.

Appendix C: Participant Information (English Version)

Queensland University of Technology
Brisbane Australia

PARTICIPANT INFORMATION FOR QUT RESEARCH PROJECT

“The lived experience of women diagnosed with breast cancer : A Hermeneutic phenomenological study of women in Indonesia”

QUT Ethics Approval Number: 1100000313

RESEARCH TEAM

Principal Researcher :	Tuti Pahria, School of Nursing , Faculty of Health, PhD Student
Principal Supervisor:	Dr Anne Walsh, School of Nursing , Faculty of Health
Associate Supervisor:	Dr Carol Windsor , School of Nursing , Faculty of Health

DESCRIPTION

This project is being undertaken as part of a PhD research project conducted by Tuti Pahria. The purpose of this project is to explore your experiences of being a survivor of breast cancer. Your participation will provide new insights and understandings of the lived experience of being a breast cancer survivor.

PARTICIPATION

Your participation in this project is voluntary. If you do agree to participate, you can withdraw from participation at any time during the project without comment or penalty. Your decision to participate will in no way impact upon your current or future relationship with QUT or Bandung Cancer Society.

Your participation will involve an audio-recorded interview at an agreed location that will take approximately 60 minutes of your time. The purpose of the interview is for you to describe your experiences of being a breast cancer survivor. Questions will include:

- How do you describe your experience of having breast cancer?
- How do you deal with the impact of breast cancer?

Please note it is not possible to participate in the project without being audio-recorded. The audio-recording is to ensure the accuracy of the data collected.

EXPECTED BENEFITS

It is expected that this project will not benefit you directly. However, the findings of this study have the potential to provide new insights and understandings of the lived experience of being a breast cancer survivor. Hence, the results of this study may be valuable for health professionals and nursing educators who are involved in either the care of patients with breast cancer or preparing nurses to work in this specialist area of practice.

RISKS

If you experience any sense of discomfort at recalling any unpleasant experiences, the interview will be stopped immediately. You may withdraw from participation at any time during the project without comment or penalty. If you experience discomfort or distress as a result of participation in the study a counselling service is available through ‘Bandung Cancer Society’ or ‘Hasan Sadikin Hospital’ Bandung.

CONFIDENTIALITY

All comments and responses will be treated confidentially and will be made anonymous when transcribed. The names of individual persons are not required in any of the responses.

You will have the opportunity to verify your comments and responses prior to final inclusion in the project. The information provided by you will only be used for the purpose of this study.

Any data collected as part of this project will be stored securely with access restricted to research team members. The audio-recording will be destroyed at the end of the project.

CONSENT TO PARTICIPATE

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to participate.

QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT

If you require further information about the project please contact one of the research team members below:

Tuti Pahria – PhD student
School of Nursing
Faculty of Health
Phone: 0422 443 299
Email:
tuti.pahria@student.qut.edu.au

Dr Anne Walsh – Principal Supervisor
School of Nursing
Faculty of Health
Phone: +61 7 3138 3905
Email:
am.walsh@qut.edu.au

Dr Carol Windsor – Assoc Supervisor
School of Nursing
Faculty of Health
Phone: +61 7 31383837
Email:
c.windsor@qut.edu.au

CONCERNS / COMPLAINTS REGARDING THE CONDUCT OF THE PROJECT

QUT is committed to research integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Unit on +61 7 3138 5123 or email ethicscontact@qut.edu.au. The QUT Research Ethics Unit is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

Thank you for helping with this research project. Please keep this sheet for your information.

Appendix D: Consent Form (Indonesian Version)

Queensland University of Technology
Brisbane Australia

SURAT KESEDIAAN MENGIKUTI PENELITIAN UNTUK PENELITIAN QUT

Judul penelitian:

The lived experience of women diagnosed with breast cancer: A hermeneutic phenomenological study of Indonesian women

TIM RISET YANG DAPAT DIHUBUNGI

Tuti Pahria : Student/ Peneliti School of Nursing and Midwifery, Faculty of Health Phone: 0422443299/+62222039871 Email: tuti.pahria@student.qut.edu au	Dr Anne Walsh: Supervisor Utama School of Nursing and Midwifery, Faculty of Health Phone: + 6173183905 Email: am.walsh@qut.edu.au	Dr Carol Windsor: Supervisor Kedua School of Nursing and Midwifery, Faculty of Health Phone: +61731383837 Email: c.windsor@qut.edu.au

PERNYATAAN KESEDIAAN

Dengan menandatangani surat ini saya menyatakan bahwa saya:

- Telah membaca dan mengerti tentang penelitian ini
- Telah menerima jawaban yang memuaskan tentang yang saya tanyakan
- Mengerti bahwa jika ada pertanyaan saya bisa mengontak peneliti
- Mengeri bahwa saya bisa membatalkan diri untuk terlibat dalam penelitian ini tanpa hukuman
- Mengerti bahwa saya bisa mengontak kantor Riset Etik di [+61 7] 3138 5123 or email ethicscontact@qut.edu.au jika ada sesuatu yang saya perlukan
- Bersedia berpartisipasi pada penelitian ini
- Mengerti bahwa informasi yang saya berikan akan direkam
- Saya mengijinkan informasi yang saya berikan direkam

Nama ....

Tanda tangan ....

Tanggal .... / .... / ....

Appendix E: Participant Information (Indonesian Version)

Queensland University of Technology
Brisbane Australia

INFORMASI UNTUK PARTISIPAN PADA PENELITIAN QUT

Judul penelitian:
The lived experience of women diagnosed with breast cancer: A hermeneutic phenomenological study of Indonesian women .
QUT Ethics Approval Number: 1100000313

TIM RISET YANG DAPAT DIHUBUNGI

Tuti Pahria : peneliti utama School of Nursing and Midwifery, Faculty of Health Phone: 0422443299 / + 62 022-2037891 Email: tuti.pahria@hdr.qut.edu au	Dr Anne Walsh: Supervisor Utama School of Nursing and Midwifery, Faculty of Health Phone: + 6173183905 Email: am.walsh@qut.edu.au Dr Carol Windsor: Supervisor kedua School of Nursing and Midwifery, Faculty of Health Phone: +61731383837 Email: c.windsor@qut.edu.au

GAMBARAN PENELITIAN

Penelitian ini dilakukan oleh Tuti Pahria, mahasiswa PhD (Doctoral) di Queensland University of Technology (QUT) Brisbane, Australia. Tujuan penelitian ini adalah untuk mengetahui pengalaman hidup sebagai penderita kanker payudara yang sudah tuntas menjalani pengobatan.

Tim penelitian meminta batuan anda karena anda memilki pengalaman itu dan kami yakin pengalaman dan kesediaan anda dapat membantu untuk memahami fenomena tersebut.

PARTISIPASI

Partisipasi anda pada penelitian ini adalah sukarela. Keputusan anda untuk berpartisipasi tidak akan berpengaruh terhadap hubungan anda saat ini maupun dimasa datang dengan Bandung Cancer Society maupun QUT. Anda dapat mengundurkan diri dari penelitian ini kapan saja tanpa pemberitahuan atau hukuman. Proses wawancara akan akan di rekam dengan seijin anda.

Anda diminta untuk berpartisipasi dalam 2 (dua) kali wawancara. Wawancara pertama akan berlangsung kurang lebih satu jam, dan wawan cara kedua sekitar 10 -20 menit. Anda diminta untuk menggambarkan atau bercerita tentang pengalaman hidup anda sebagai wanita yang didiagnosa kanker payudara sudah menjalani pengobatan secara tuntas. Sedangkan wawancara kedua adalah untuk memberikan kesempatan pada anda untuk memberikan komentar pada transkrip wawancara atau menghapus jika anda kurang setuju dengan trnaskrip tersebut. Wawancara akan dilaksanakan

Selama wawancara anda akan diberi pertanyaan sebagai berikut:

- Bagaimana anda menggambarkan pengalaman anda sebagai orang yang didiagnosa kanker payudara

- Bagaimana anda mengatasi masalah-masalah yang ditimbulkan sebagai akibat dari kanker payudara

MANFAAT

Hasil penelitian ini akan dapat meningkatkan wawasan dan pemahaman tentang pengalaman hidup penderita kanker payudara. Selanjutnya hasil penelitian juga sangat berguna bagi petugas kesehatan dan pendidikan keperawatan dimana mereka terlibat dalam pelayanan dan juga perencanaan asuhan keperawatan pasien dengan kanker payudara.

RISIKO

Tidak ada resiko yang luar biasa terkait dengan partisipasi anda dalam penelitian ini.

Namun demikian, apa bila anda mengalami ketidaknyamanan, maka wawancara akan dihentikan segera. Jika anda ingin wawancara tidak dilanjutkan , keputusan anda kami hargai. Jika anda memerlukan bantuan lebih lanjut, kami akan merujuk ke pelayan konseling yang akan kami siapkan sebelum penelitian ini

KERAHASIAAN

Seluruh jawaban dan komentar anda bersifat sngat rahasia dan nama anda tidak akan dimunculkan di laporan penelitian.. Informasi yang anda berikan akan direkam dan hanya akan dipergunakan untuk tujuan penelitian ini saja. Informasi yang anda berikan akan disimpan secara aman sesuai dengan manajemen dan peraturan QUT.

KESEDIAAN BERPARTISIPASI

Kami meminta anda untuk menandatangani surat persetujuan untuk memastikan bahwa anda bersedia berpartisipasi pada penelitin ini.

PERTANYAAN / INFORMASI LEBIH LANJUT TENTANG PENELITIAN

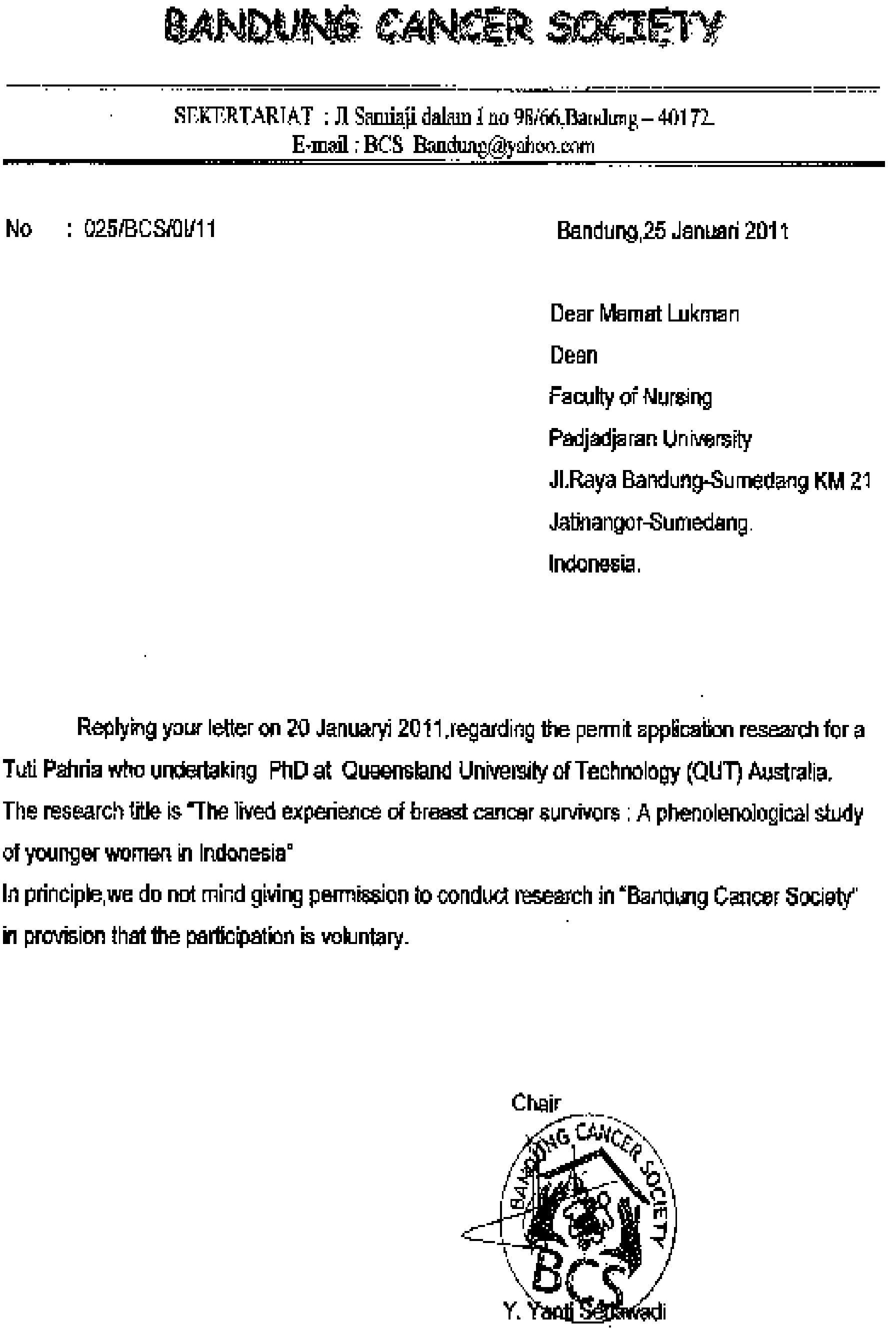
Apa bila anda ada keluhan (komplain) tentang penelitian, anda dapat menghubungi salah satu anggota tim riset diatas.

KOMPLAIN TENTANG PENELITIAN

QUT berkomitmen terhadap integritas peneliti dan pelaksanaan etik pada penelitian ini. Akan tetapi jika anda ingin menyampaikan sesuatu atau ingin complain, anda bias menghubungi kantor Riset Etik QUT di [+61 7] 3138 5123 or email ethicscontact@qut.edu.au. Kantor Riset Etik QUT tidak ada hubungan dengan peneliti sehingga bias memfasilitasi untuk menyelesaikan permasalahan yang anda sampaikan.

Terimakasih atas bantuan anda pada penelitian ini.

Appendix F: Letter of Support from Bandung Cancer Society



BANDUNG CANCER SOCIETY

SEKERTARIAT : Jl Samiaji dalam I no 98/66.Bandung – 40172
E-mail : BCS Bandung@yahoo.com

No : 025/BCS/01/11

Bandung,25 Januari 2011

Dear Mamat Lukman
Dean
Faculty of Nursing
Padjadjaran University
Jl.Raya Bandung-Sumedang KM 21
Jatinangor-Sumedang.
Indonesia.

Replying your letter on 20 Januaryi 2011,regarding the permit application research for a Tuti Pahria who undertaking PhD at Queensland University of Technology (QUT) Australia. The research title is "The lived experience of breast cancer survivors : A phenolenological study of younger women in Indonesia"
In principle,we do not mind giving permission to conduct research in "Bandung Cancer Society" in provision that the participation is voluntary.

Chair

BCS

Y. Yanti Setiawadi