

# **Mothers, breast cancer survivorship and physical activity promotion**

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# Table of contents

<b>Table of contents</b> .....	<b>3</b>
<b>Tables and figures</b> .....	<b>8</b>
<b>Summary</b> .....	<b>9</b>
<b>Declaration</b> .....	<b>11</b>
<b>Acknowledgements</b> .....	<b>12</b>
<b>Chapter 1: Introduction</b> .....	<b>15</b>
<b>Thesis aims</b> .....	<b>15</b>
<b>Why this study?</b> .....	<b>15</b>
<b>Research questions and scope</b> .....	<b>19</b>
<b>Key concepts used in this thesis</b> .....	<b>20</b>
Meanings of survival, survivorship and survivor .....	20
Breast cancer as a journey .....	22
Everyday/everynight lives .....	22
<b>Thesis structure</b> .....	<b>23</b>
<b>Chapter 2: Literature Review</b> .....	<b>27</b>
<b>Introduction</b> .....	<b>27</b>
<b>Public health significance of this study</b> .....	<b>27</b>
Breast cancer in Australia .....	27
<i>Incidence and survivorship</i> .....	27
<i>Socioeconomic and social demographic influences on breast cancer incidence and mortality</i> .....	28
Physical activity participation in Australia .....	30
<i>Participation in physical activity of women with breast cancer</i> .....	32
<i>Motherhood and physical activity</i> .....	34
Breast cancer survivorship and physical activity participation .....	35
<i>Breast cancer treatments and physical activity participation</i> .....	36
<i>Recurrence, survival and physical activity participation</i> .....	38
Exercise intervention studies with women who have/had breast cancer ...	39
Women's accounts of breast cancer survivorship and physical activity ...	41
<b>Theoretical frameworks for exploring women's accounts of breast cancer and physical activity</b> .....	<b>44</b>
Public health and health promotion .....	45
The new public health .....	46
Models of health promotion .....	49

<i>Breast cancer prevention</i> .....	49
<i>Breast cancer screening</i> .....	50
Risk and choice - from public health to private lifestyle.....	52
<i>Heightened risk awareness after breast cancer as a teachable moment?</i> .....	53
<i>Criticisms of risk promotion</i> .....	55
Feminist theories and public health.....	58
<i>Feminist critiques of medicalisation</i> .....	58
<i>Feminist theorising of ideologies of motherhood</i> .....	60
<i>Motherhood, social support and health</i> .....	63
<i>Feminist leisure theory</i> .....	64
<i>Feminist theories of the body</i> .....	68
Theorising the body and public health .....	71
<i>Definitions of embodiment</i> .....	75
<i>Embodied expertise</i> .....	76
<b>Conclusion</b> .....	<b>78</b>
<b>Chapter 3: Methodology</b> .....	<b>81</b>
<b>Introduction</b> .....	<b>81</b>
<b>Feminist research principles and methodological rigour</b> .....	<b>82</b>
Feminist research principles .....	82
Voice and feminist research ethics .....	84
Voice, lay theorising and embodied expertise.....	85
Methodological rigour and reflexivity .....	87
<b>Study Methods</b> .....	<b>88</b>
Purposive sampling method.....	90
Sample recruitment.....	92
Sample description .....	96
Ethical considerations .....	100
<b>The study process</b> .....	<b>100</b>
Small group interviews.....	100
In-depth interviews.....	103
<i>Interview method</i> .....	104
Advisory group .....	108
Health promotion sources and materials.....	108
Sample/study limitations .....	109
<b>Method of analysis</b> .....	<b>110</b>
Presentation of findings .....	112
Analysis of demographic forms .....	112
Analysis of health promotion sources and materials .....	113
Coding physical activity participation .....	114
Coding partner support .....	116
Style and language notes .....	118
<b>Conclusion</b> .....	<b>119</b>

<b>Chapter 4: Breast cancer journeys.....</b>	<b>123</b>
<b>Introduction.....</b>	<b>123</b>
<b>The journey begins.....</b>	<b>125</b>
Finding the lump .....	125
Breast cancer surgery .....	129
Reconstructive surgery and physical activity.....	139
Chemotherapy, radiotherapy and physical activity .....	147
<b>Journey into survivorship .....</b>	<b>154</b>
<b>Conclusion .....</b>	<b>161</b>
<b>Chapter 5: Responding to health promotion after breast cancer.....</b>	<b>163</b>
<b>Introduction.....</b>	<b>163</b>
<b>Knowledge about health benefits of physical activity .....</b>	<b>164</b>
<b>Key responses to health promotion messages .....</b>	<b>169</b>
<b>Theorising causation and risk.....</b>	<b>171</b>
Individualist theories of causation .....	174
<i>Was it something I ate?</i> .....	175
<i>Something in me</i> .....	177
<i>Stress</i> .....	181
<i>I want to know the cause</i> .....	184
<b>Taking health promotion with a grain of salt .....</b>	<b>184</b>
<b>Health promotion information sources .....</b>	<b>189</b>
Mainstream cancer-related organisations .....	190
Complementary and alternative cancer-related organisations .....	199
Breast cancer advocacy and action organisations .....	204
<b>Conclusion .....</b>	<b>208</b>
<b>Chapter 6: Mothers, breast cancer and physical activity participation.....</b>	<b>209</b>
<b>Introduction.....</b>	<b>209</b>
Levels of participation .....	209
<b>Factors influencing physical activity participation .....</b>	<b>210</b>
<b>Social influences .....</b>	<b>211</b>
Social support .....	211
<i>Family support</i> .....	212
<i>Partner support</i> .....	213
<i>Support groups</i> .....	226
Paid work .....	228
Gendered identity.....	229

Class .....	230
<b>Individual influences .....</b>	<b>232</b>
Stage in the breast cancer journey - pain/fatigue.....	232
Pre-breast cancer physical activity participation and “being competitive”.....	233
Knowledge of health benefits of physical activity .....	235
<b>Participation in context.....</b>	<b>235</b>
More active women.....	236
Less active women .....	246
<b>Conclusion.....</b>	<b>256</b>
<b>Chapter 7: Discussion.....</b>	<b>261</b>
<b>Introduction.....</b>	<b>261</b>
<b>Interpreting risk as cause .....</b>	<b>262</b>
Individualising risk.....	263
Self-blame.....	266
Resisting self-blame.....	270
Cause as a social and political construct .....	271
Reflections on the teachable moment.....	272
<b>Social context and participation .....</b>	<b>274</b>
Gender, class and participation.....	274
Gendered identity, care work and participation .....	277
<b>The journey, embodiment and health promotion .....</b>	<b>282</b>
The breast cancer journey and embodied expertise .....	284
Embodied decision-making.....	286
<b>Conclusion.....</b>	<b>288</b>
<b>Chapter 8: Conclusion .....</b>	<b>293</b>
<b>Introduction.....</b>	<b>293</b>
<b>Summary of thesis aims, objectives and findings.....</b>	<b>293</b>
<b>Key findings against research questions.....</b>	<b>294</b>
Responses to health promotion information.....	294
Information sources .....	296
Decision-making about health.....	296
Key influences on participation in physical activity.....	297
Enabling participation.....	298
<b>Study quality and limitations.....</b>	<b>302</b>
<b>Further research .....</b>	<b>303</b>
<b>Concluding reflections.....</b>	<b>304</b>
<b>References .....</b>	<b>305</b>

**Appendices ..... 329**

## **Tables and figures**

### **Tables**

Table 1: Purposive sample – breast cancer description.....	98
Table 2: Purposive sample demographic description .....	99
Table 3: Physical activity and potential influencing factors .....	218

### **Figures**

Figure 1: The women’s theories of causation.....	171
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## Summary

Breast cancer is the most commonly reported cancer in women in Australia, with increasingly high survival rates. Consequently, the health and wellbeing of breast cancer survivors is becoming an important field of cancer survivorship research. Research shows that regular physical activity participation improves important health outcomes for women after a breast cancer diagnosis. In Australia, rising average age of first birth means more women diagnosed with breast cancer in Australia are mothers of dependent children, but little is known about their experience. This thesis explores the experiences and views on physical activity promotion and participation of this significant but scarcely researched group of women.

This thesis adopts a critical and feminist lens to ask: how do Australian women who were mothers of dependent children at the time of their breast cancer diagnosis respond to information about health benefits of regular participation in physical activity? To answer this question, the thesis asks five sub-questions; firstly, from what sources do the women gather information about physical activity and health and how do they feel about the information? Secondly, how do they make decisions about acting to support their health in general and physical activity in particular? Thirdly, in what ways do factors such as socioeconomic status, gender or location influence their views on and participation in physical activity? Fourthly, what would it take to enable this group of women to undertake physical activity at a level that is likely to produce health benefit? And lastly, how can evidence from women who have had a breast cancer diagnosis assist in promoting physical activity to women at a broader population level?

This thesis answers these research questions principally by analysis of 36 in-depth interviews with rural and metropolitan women living in South Australia and Victoria, who were diagnosed with breast cancer while they were mothers of dependent children.

The analysis shows how the women's responses to health promotion

messages were shaped by their embodied experience of their breast cancer journeys in their social contexts. The women responded to health promotion information in ways that suggest that messages based on data from studies of population risk were unhelpful at an individual level. The women's responses to these types of health promotion messages ranged from resistance to cynicism and/or blaming themselves for their breast cancer diagnosis.

Consistent with both feminist and qualitative public health research, the women reported social, structural and individual enablers and constraints to participation in physical activity including level of intimate partner support, their own/partners' paid work, their everyday/everynight child caring responsibilities, their post-treatment pain and fatigue, their level of priority for physical activity participation, and the pleasure they derived from it. Most of the women spoke of knowing about the biological benefits of participation in physical activity for women after having breast cancer treatment (such as maintaining bone mineral density) whether or not they themselves participated.

The thesis supports a theoretical approach to health promotion after breast cancer that includes the concept of embodied expertise in breast cancer which is developed over the breast cancer journey. The thesis concludes that combining feminist and critical research principles is crucial to developing health promotion strategies that attend to gender and embodiment, to enable health promoters to support women's health after a breast cancer diagnosis.

## **Declaration**

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

Signed:

Date:

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## **Chapter 1: Introduction**

### ***Thesis aims***

This qualitative study aims to explore how Australian women who were diagnosed with breast cancer while they were mothers of dependent children respond to information about the health benefits of participation in regular physical activity. The study aims to find out from which sources this group of women gather information about physical activity participation after their breast cancer diagnoses, what their views on the information are and what decisions they make about their health in light of the information. Using a critical and feminist lens, this study aims to examine the women's accounts of their decisions about participation in physical activity to discover what factors such as gender, socio-economic status and rural or metropolitan location influence their views on and their participation in physical activity. The study aims to explore the ways in which the findings can assist health promoters to enable women who have/ had breast cancer to participate in physical activity at a level that is likely to provide health benefit. Thus, this thesis aims to contribute to breast cancer survivorship research and provide insights for health promotion practice in this important emerging area. Further, this study aims to provide insights into how the thesis findings can assist in promoting physical activity to women generally.

### ***Why this study?***

Breast cancer is the most commonly reported cancer in women in Australia and until recently the most common cause of cancer death. Nationally, over 12,000 women are diagnosed with breast cancer annually, and of these women, over 85 per cent survive at least five years from the time of their diagnosis. Thus, there is an increasing population of breast cancer survivors in Australia, with close to 114,000 women known to have survived breast cancer 20 years (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006). Breast cancer survivorship, the area of research interest of this thesis (being women who have/ had breast cancer) has therefore become an increasingly important area of research.

Survivorship research aims to achieve a better understanding of the physical, emotional, mental, spiritual and social processes of life beyond a cancer diagnosis (Schroevers, Ranchor & Sanderman, 2006; Bowman, Rose & Deimling, 2006).

While in Australia the most common age group of women to be diagnosed with breast cancer is between 50 and 70, around one quarter of women diagnosed with breast cancer are under fifty, including around six per cent diagnosed under forty (National Breast Cancer Centre, 2004a). Almost two thirds of Australian women become mothers. Those women who do have children are increasingly likely to begin having their children later, between their late twenties through to early forties (Australian Bureau of Statistics, 2008). Because Australian women are typically having children later in life, more women are likely to be mothers of dependent children when they are diagnosed with breast cancer. The application of these statistics suggests that in Australia, approximately 1500-2000 women diagnosed each year would have dependent children.

There is growing evidence that for most women, the completion of breast cancer treatment/s does not mean a simple return to their pre-cancer diagnosis everyday/everynight lives. Research shows that after a breast cancer diagnosis, women experience a higher than population level range of physical and mental health and quality of life problems such as osteoporosis and bone fractures, fatigue, depression and relationship problems (BCNA, 2009; Boyes *et al.*, 2009; Chen *et al.*, 2004; Thomas-MacLean, 2005; Wade, Nehmy & Koczwara, 2005). Moreover, research indicates that women who were diagnosed with breast cancer at a younger age (under 50) experience greater morbidity and social problems than those diagnosed when they are older, for a range of reasons including treatment induced menopause and/or infertility, body image and relationship issues (Connell, Patterson & Newman, 2006a, b; Fobair *et al.*, 2006; Gould *et al.*, 2006; Knobf, 2001).

The context of this research is that the last few decades have seen public health authorities turn their attention toward promoting “lifestyle” approaches



for preventing ill-health rather than, or in addition to, curative medicine (Baum 2008). With lifestyle approaches, there is an associated expectation of health promoters that people will be pro-active in maintaining their health after a diagnosis of cancer and for self-management of a range of chronic diseases such as cardiovascular disease, arthritis and diabetes (Lupton 1995).

As part of an overall increased emphasis of research into lifestyle and health, research into the health effects of participation in regular physical activity has received a great deal of attention in recent years. One such area of research interest is the effects of physical activity on women's health after a breast cancer diagnosis. Research shows that physical activity participation provides a range of health and quality of life benefits for breast cancer survivors. There is now strong evidence that physical activity ameliorates adverse effects of breast cancer treatments, such as fatigue and reduced bone mineral density, improves mental health of women who have/have had breast cancer, and potentially reduces lymphoedema caused by breast/lymphatic surgery or radiotherapy (Adamsen *et al.*, 2004; Courneya, 2009; Courneya, Mackey & McKenzie, 2002; Courneya *et al.*, 2007; Glaspy, 2001; Culos-Reed, Christopher & Lawrence, 2005; Jereczek-Fossa, Marsiglia & Orecchia, 2002; Lane, Worsley & McKenzie, 2005). There is also evidence that physical activity increases the length of survival post breast cancer diagnosis (Holmes *et al.*, 2005; McNeely *et al.*, 2006).

As in other wealthy nations, Australians' participation in physical activity (especially leisure-time physical activity) is influenced by class (socioeconomic status and education), ethnicity and gender (Australian Bureau of Statistics, 2007; Dempsey, 1989; McKay, 1986). Evidence from national- and state-based physical activity surveys show that people from advantaged backgrounds are significantly more likely to be sufficiently active for health benefit than people from disadvantaged backgrounds (Armstrong, Bauman & Davies, 2000; Bauman *et al.*, 2002; Gill & Taylor, 2004). In Australia, women with dependent children are one of the least active sub-groups, with the least amount of time available in which to participate in leisure time physical activity (Bauman *et al.*, 2002; Brown *et al.*, 2001b).

Because the evidence that regular physical activity participation produces health benefits for women who have/ had breast cancer, and that women diagnosed with breast cancer, if they have children, are increasingly likely to still have dependent children, it is important to understand the factors that influence physical activity participation for this significant group.

While medical literature on beneficial effects of physical activity for women with breast cancer has been expanding, research into women's accounts of their breast cancer experiences in relation to physical activity is scarce. In addition, there is little acknowledgement in the current literature of the realities of women's everyday/everynight lives as workers, mothers, wives and daughters living in gendered society, and what these features of women's lives mean in relation to their opportunities for participation in physical activity (Gould *et al.*, 2006).

Physical activity promotion, with its various historical framings, is fraught with socially constructed gendered meanings (Fullagar, 2003; Vertinsky, 1998). Research using feminist qualitative research methods can reveal the socially constructed filters through which women speak, by exploring the complexities and ambiguities inherent in what they have to say about their embodied experiences of breast cancer, in the contexts of their physical and social worlds (Thomas-MacLean, 2004b). Exploring lay knowledge is crucial to understanding how people think about health and illness generally (Backett, Davison & Mullen 1994; Popay & MacDougall 2007; Popay & Williams 1996; Popay *et al.*, 2003), and in this study, how the women in the study sample think about participation in physical activity particularly. Lay knowledge is particularly important for enabling an exploration of the structural processes embedded in individual behaviour/s (Popay & Williams, 1996 p761).

The qualitative public health literature on lay knowledge demonstrates clearly that participation in health promoting practices is largely dependent on social and environmental factors (Backett & Davison, 1995; Baum, 2008; Lawton, 2003; Popay *et al.*, 2003; Popay & Williams, 1996). Social constructions that maintain inequitable participation, and the mechanisms by which they

operate, are often invisible (Broom, 2008; Travis & Compton, 2001) and this thesis seeks to uncover such mechanisms by using feminist and critical research principles. The small amount of feminist research that does consider these complexities in relation to women who have/had breast cancer suggests that it is imperative that these women's voices be heard in order to understand the complexities of promoting the benefits of physical activity to them (Gould *et al.*, 2006).

### ***Research questions and scope***

This thesis is guided by the following research question:

How do Australian women, who had dependent children at the time of their breast cancer diagnosis, respond to information about health benefits of participation in regular physical activity?

#### *Sub questions:*

- From what sources (including mass media campaigns, doctors and other health practitioners, health promotion brochures, magazines, newspapers and conversations with friends/family and other sources identified by participants) do they gather information about physical activity and health and how do they feel about the information?
- How do they make decisions about taking action to support their health in general and physical activity in particular?
- In what ways do factors such as socioeconomic status, gender, rural or urban location influence women's views on and participation in physical activity post breast cancer diagnosis?
- What would it take to enable women with a breast cancer diagnosis to undertake physical activity at a level that is likely to produce health benefit?
- How can evidence from women who have had a breast cancer diagnosis assist in promoting physical activity to women at a broader population level?

I address the research questions principally by analysing qualitative

interviews of 36 rural and metropolitan women from South Australia and Victoria. I bring together critical and feminist perspectives and apply social health research principles that argue for the inclusion of lay theorising in developing health promotion strategies (Milburn, 1996). I utilise the women's narratives to examine ways in which dominant social structures such as class (household income and education status) and gender play out in their accounts of their breast cancer experiences, of their perspectives on physical activity promotion and participation, and of their everyday/everynight lives. Guided by the women's accounts, I analyse the sources of information to which they referred, and in this exercise I draw on Smith's (2005) Institutional Ethnography approach to mapping everyday texts to identify how structural power plays out in everyday lives.

In my endeavour to answer the research questions, I explore the intersections between women's experiences of breast cancer, their everyday/everynight (Smith, 2005) lives as mothers of dependent children, and their responses to physical activity promotion messages. While the central thesis topic is women's responses to physical activity promotion and participation, the women would tend to speak about other health promotion messages and practices with physical activity as one of many health promoting practices. Consistent with my approach to combining feminist and social health research principles, in my analysis I move beyond physical activity to place it within the broader context of health promotion in survivorship.

### ***Key concepts used in this thesis***

#### **Meanings of survival, survivorship and survivor**

The meanings of survival, survivorship and survivor are contested, particularly by people who have/ had cancer (Kaiser, 2008; Klawiter, 2004) and so therefore require clear definitions as to how I use the terms in this thesis. Medical use of the term "survival" refers to the length of time a person remains alive after a cancer diagnosis, for example "one year survival", "five year survival" and "10 year survival". In Australia, five-year survival marks the time that women no longer routinely see their breast cancer specialist/s.

“Survivorship” is referred to as the period of time from diagnosis through the remainder of a person’s life (Kaiser, 2008). Because of increased survival rates in many cancers and in recognition of evidence that for many people, life does not return to how it was prior to a diagnosis of cancer, survivorship research has become increasingly important to understanding the particular experiences of life beyond cancer (Bowman *et al.*, 2006; Schroevers *et al.*, 2006). I seek to situate this thesis within the broader survivorship research endeavour.

The term “survivor” is the most controversial of the three terms, particularly among people who have/ had cancer. Kaiser’s (2008) qualitative study with women who have/ had breast cancer, for example, found that women responded to the term in a range of ways. While some women identified with the term, others felt alienated by it. Kaiser argued that some of the women were not convinced they would survive breast cancer, some felt they did not have a severe enough diagnosis to warrant the term, some resisted the idea of being defined by their breast cancer diagnosis, whereas others felt it simply an irrelevant concept in the context of their everyday/everynight lives. For the purposes of this thesis, I use the terms “survivor” and “survival” only as they appear in the statistical and research literature relating to time since diagnosis and do not presume that a person who has had a cancer diagnosis (or a carer of someone who has/had cancer) would call themselves a “survivor”.

In the analysis chapters and beyond, where I talk about my thesis findings I avoid the terms altogether and use the longer descriptive phrases: “women who have/ had breast cancer” or “after a breast cancer diagnosis”. Here, I take Price Hendl’s (2006) lead and I do so in light of the contested nature of the term “breast cancer survivor” in the literature and in my findings. My intention in using “women who have/ had breast cancer” is that “have/ had” can mean “have had”, “have” or “had” breast cancer. This is because, again drawing on Kaiser’s (2008) findings, as well as my findings in this study, while some women speak about breast cancer in the past tense as

something they “had”, many view breast cancer as an ongoing part of their lives and therefore do not feel they can ever use the past tense with any degree of certainty.

### **Breast cancer as a journey**

As I use the term “breast cancer journey/s” throughout this thesis, it is necessary to explain my rationale for this at the outset. Early on in my analysis of the data, it became apparent that having breast cancer is a dynamic process. Several of the women in this study tended to use the word “journey” to describe their own experiences of the time since their discovery of a breast change, as well as when they would talk about other women who have/ had breast cancer.

The concept of a “journey” struck me as dynamic, which seemed appropriate for representing the women’s responses to health promotion information and decision-making about health over the passage of time. While I also use “experience/s”, these terms do not convey the explicitly temporal element that is inherent in the word “journey”.

### **Everyday/evernight lives**

Smith (2005) refers to people’s everyday lives in terms of their embodied experience of their everyday/evernight worlds as they are socially constituted. People’s worlds are intrinsically coordinated with the lives of other people through time and space; the actualities of what people know and unknown to each other are doing during the day and during the night. Smith describes the everyday/evernight world as the lived experience of people who are experts in the daily business of living their lives, using her own home life and work life as an example:

Home was organized around the particularities of my children’s bodies, faces, movements, the sounds of their voices, the smell of their hair, the arguments, the play, the evening rituals of reading, the stress of getting them off to school in the morning...an intense, preoccupying world of work that also cannot really be defined....My work at the university was quite differently articulated; the sociology I thought and taught was embedded in the texts that linked my into a discourse extending indefinitely into only very partially known

networks of others, some just names of the dead, some heroes and masters of the contemporary discipline...(Smith, 2005 p12).

Applying this idea, I use the term “everyday/everynight lives” in this thesis to describe the women’s experience of their daily lives because it is a more accurate description of embodiment as being continuous through day and night; neither the breast cancer journey nor motherhood ends with each day.

### ***Thesis structure***

The thesis is divided into eight chapters, including this introduction. In Chapter Two I review the literature that informs my research questions and frames the study methodology. The chapter is presented in two sections. In the first section I review the evidence that demonstrates the public health significance of this study, including the incidence of breast cancer in Australia, and the research on specific health effects of participation in physical activity in the context of survivorship. I also review evidence of the rates of women’s participation in physical activity in Australia, and mothers’ participation in particular. In the second section of my literature review, I outline the theoretical literature that frames the thesis, beginning with a brief historical account of public health, and different approaches to health promotion. I then negotiate contemporary theoretical debates about risk and lifestyle that are germane to women who have/ had breast cancer. I also review some of the social science theories of embodiment and finally, the feminist literature on embodiment, leisure and motherhood. Based on my theoretical review, I argue the importance of exploring social, embodied contexts in research that aims to inform the promotion of physical activity to women, and in this case, women who have/had breast cancer while being mothers of dependent children.

In Chapter Three I build on my literature review by presenting the feminist, critical and social health literature that underpins the thesis methodology, and describe the methods I use to answer my research questions. The main component of original qualitative research for this thesis involved in-depth interviews with 36 women diagnosed with breast cancer while they were

mothers of dependent children. I describe how I applied a purposive sampling strategy that sought the inclusion of women living in rural and metropolitan South Australia and Victoria, from a broad range of backgrounds. Hence, in this chapter I outline my feminist research principles, negotiate the use of voice in feminist research and attend to methodological rigour. I describe the study sample and outline the methods I used to analyse the data.

I present my analysis in Chapters Four, Five and Six. I separate my analysis of the data from the theoretical discussion, and describe my rationale for this in Chapter Three. In Chapter Four, I set up the importance of the journey as an analytic tool for health promotion after breast cancer. I describe the women's decision-making about health generally and physical activity participation particularly, in the context of their breast cancer journeys. In Chapter Five, I discuss the women's responses to health promotion campaigns and information about health benefits of regular physical activity, and go on to analyse briefly the key sources of information to which the women referred in their interviews. In Chapter Six, I describe the women's reported participation in physical activity, and explore critically the gendered, socio-economic and geographic factors which enabled and/or constrained their participation.

In Chapter Seven, I discuss the study findings that I described in the analysis chapters relative to the literature that I reviewed in Chapter Two. Based on the women's responses to information about physical activity and health, I relate my findings to established lay theory research to question the usefulness of individualist behavioural approaches to physical activity promotion and health promotion more broadly. I build an argument for the importance of a theoretical approach to health promotion after breast cancer that includes embodied expertise and the concept of the journey, and attends to gendered and socio-economic effects on women's participation in physical activity.

In Chapter Eight, the concluding chapter, I summarise my findings, outline



the contribution of my study to the public health literature and make suggestions for reframing health promotion to be more supportive to women who have/ had breast cancer. As part of this, I link my study to a broader feminist endeavour to bring gender and embodiment into public health.



## **Chapter 2: Literature Review**

### ***Introduction***

In this chapter I review the literature that frames the research questions and underpins the methodology for my study. The chapter is structured in two sections. The first section provides the public health significance of the issues addressed in this study, starting with an overview of the incidence of breast cancer in Australia. I then present an overview of national physical activity participation rates, including the small amount of available information on women's physical activity participation rates after a breast cancer diagnosis. Next, I examine published intervention studies that conclude that physical activity is extremely beneficial for women's health and quality of life after a breast cancer diagnosis. Finally, I explore the extent to which physical activity participation has featured in studies that have explored breast cancer experiences from the perspective of women diagnosed with breast cancer.

In the second section of this chapter I review several bodies of literature from the social sciences, including new public health, research using lay theory and theories of risk, embodiment and feminism, which together underpin the theoretical basis of this study. I argue the case for seeking the views of women who have/ had breast cancer as a crucial component of breast cancer survivorship research that endeavours to influence health promotion practice in this significant and growing area of public health.

### ***Public health significance of this study***

#### **Breast cancer in Australia**

##### *Incidence and survivorship*

Breast cancer is the most commonly reported cancer (besides non-melanoma skin cancer) and the second most common cause of cancer death in women in Australia. A woman's risk to age 75 of developing breast cancer is estimated to be one in eleven (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006; South Australian Cancer Registry, 2005). Breast cancer survival rates, however, have increased substantially in

recent decades. In the 1991-1998 period, the proportion of South Australian women surviving five years after a breast cancer diagnosis was 82% (The Cancer Council South Australia, 2002). In Victoria in 2004, the five-year survival of women was 87% (English *et al.*, 2007). Nationally, between 1982–1986 and 1998–2002, the one-year relative survival increased from 93% to just below 98% and five-year relative survival increased from 71% to almost 87% (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006).

The number of Australian women who have had a breast cancer diagnosis some time in their lives is substantial. According to national cancer registry records, in 2002, the number of women surviving a breast cancer diagnosis in the previous 10 years was 84,421 and the previous 20 years was 113,801 (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006).

*Socioeconomic and social demographic influences on breast cancer incidence and mortality*

The social, ethnic, economic, and rural/remote/metropolitan location status of populations of women influence the incidence of breast cancer and mortality rates associated with breast cancer in complex ways. Evidence, from Australia and internationally, demonstrates the ways in which advantage and disadvantage, as well as location, is associated with differing rates of breast cancer incidence and breast cancer mortality in women (Luke *et al.*, 2004; Spilsbury *et al.*, 2005; Hall *et al.*, 2004a; Wilkinson & Cameron, 2004).

In Australia and other wealthy countries, there is a higher incidence of breast cancer diagnosis in women from higher socioeconomic status areas or backgrounds than in women from lower socioeconomic status areas or backgrounds (Burnley, 1992; South Australian Cancer Registry, 2005; Yabroff & Gordis, 2003; Williams *et al.*, 1991). Similarly, there is a slightly higher incidence of breast cancer in metropolitan areas than in rural/remote areas (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006).

While there is evidence that women in advantaged groups are more likely to be diagnosed with breast cancer, women from disadvantaged groups are more likely to be diagnosed at a later stage of the disease and of those diagnosed, are more likely to die of the disease (Chlebowski *et al.*, 2005; Crowe *et al.*, 2005; Maloney *et al.*, 2006; McMichael *et al.*, 2000; Yabroff & Gordis, 2003). Though Indigenous Australian women are far less likely than non-Indigenous women to be diagnosed with breast cancer (Condon *et al.*, 2003), they are more likely to be diagnosed at a later stage than non-Indigenous women, and subsequently also experience lower survival rates (Condon *et al.*, 2003; Condon *et al.*, 2004; Condon *et al.*, 2005). In the Northern Territory, for example, five-year breast cancer survival rates for Indigenous women diagnosed with breast cancer between 1991-2000 were around 63% compared to non-Indigenous women at 84% (Condon *et al.*, 2005). There is also evidence in the literature that women with disabilities are more likely to be diagnosed at a later stage than able-bodied women (Roetzheim & Chirikos, 2002).

There is some evidence that different treatment, based on factors such as class, location and ethnicity, is associated with inequitable survivorship rates. Accessibility to appropriate treatments and length of survival is associated with whether women live in metropolitan, rural or remote areas and their level of social advantage, for example. However, living outside metropolitan areas does not necessarily influence mammography rates, indicating that survival is not entirely dependent on early detection (Hall *et al.*, 2004a; Hall *et al.*, 2004b; Kok *et al.*, 2006; Martin-McDonald *et al.*, 2003; Spilsbury *et al.*, 2005; Wilkinson & Cameron, 2004). Lower mammography screening rates in women from socio-economically disadvantaged groups and associated later diagnoses, therefore, only partly explains differences between groups of women in incidence and mortality.

Western Australian evidence suggests that women who receive treatment in private hospitals have better survival rates than those treated in public hospitals (whether or not they have private health insurance) and that women who live in rural areas but are treated in metropolitan hospitals have better

survival rates than women who are treated in rural areas (Hall *et al.*, 2004). Women in the same study from higher socioeconomic backgrounds had improved survival rates post-breast cancer surgery (Hall *et al.*, 2004). In Victoria and South Australia, however, there are no significant differences in survivorship rates between rural or metropolitan locations (English *et al.*, 2007; South Australian Cancer Registry, 2007).

After looking briefly at evidence about women's physical activity participation in Australian populations, I consider the evidence linking physical activity participation to improved health outcomes in survivorship.

### **Physical activity participation in Australia**

There have been two definitions of "sufficient physical activity to produce health benefit" used in national and South Australian population self-report physical activity surveys<sup>1</sup>. The first definition is: a total of 150 minutes over the past week including "walking, moderate or vigorous physical activity with vigorous activity weighted by a factor of two to account for its greater intensity" (Gill & Taylor, 2004, p30). The second definition is same as the first, plus "over at least five separate sessions a week" (Gill & Taylor, 2004, p30). These definitions do not include gardening or housework, because at the time of the surveys, there was insufficient research that had measured the energy expenditure of these activities (Armstrong, Bauman & Davies, 2000; Bauman *et al.*, 2002, p21; Gill & Taylor, 2004).

The South Australian Health Monitor survey has, however, included questions about survey participants' vigorous household chores. Women are more likely than men to report engaging in vigorous household chores, whereas men are more likely than women to report undertaking regular vigorous recreational physical activity (Gill & Taylor 2004). Similarly, the 1998

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<sup>1</sup> For a more thorough definition of precise levels of physical activity for health benefit, see Armstrong *et al.* (2000).

NSW Health Survey of housework and gardening activities suggests that women's participation in vigorous domestic activities should be counted:

These results highlight the important contribution 'vigorous domestic activities' can make to the overall prevalence levels of adults meeting the 'sufficient' physical activity criterion, particular (sic) for women. This is important, as fewer women reported 'sufficient' leisure-time physical activity compared to men, but when domestic activities were included the difference between men and women, whilst still substantial, decreased by 2.1% (Phongsavan & Merom, 2003).

There has been some debate regarding how to measure the levels of physical activity of women, and women with young children in particular (Collins, Marshall, & Miller, 2007). In this thesis, I do not include household chores as leisure time or recreational physical activity because there is no evidence that these activities provide the same benefits, particularly mental health benefits, as other activities generally considered such as walking, cycling or playing sport.

While levels of physical activity participation have been declining in all groups over the period of time in which data has been collected, there are systematic differences between populations in their physical inactivity. National, South Australian and Victorian evidence shows that people from advantaged backgrounds are significantly more likely to be sufficiently active to produce health benefit than are people from disadvantaged backgrounds. Specific sub-groups that have been identified as being more likely to be inactive include people in their 40s and 50s, people from non-English speaking backgrounds, Indigenous people, women (especially those with dependent children) and people with chronic disease or disabilities (Armstrong, Bauman & Davies, 2000; Bauman *et al.*, 2002; Gill & Taylor, 2004; Victorian Government Department of Human Services, 2004). Earlier physical activity surveys suggested that tertiary educated people were far more likely to be sufficiently active than people with the lowest levels of education. While this remains the case, subsequent surveys suggest a greater decline in tertiary educated people being sufficiently active than the decline in the least educated people and it is surmised that this is related to decreases in available leisure time (Bauman *et al.*, 2002).

Nationally, women are 20% less likely than men to report participating in sufficient leisure time physical activity (Armstrong, Bauman & Davies, 2000; Bauman *et al.*, 2002). In addition, married women are less likely to participate in sufficient leisure time physical activity than age-matched single women (Bauman *et al.*, 2002; Bell & Lee, 2005). Mothers of dependent children are one of the least active social groups (Brown *et al.*, 2001b) and I explore this evidence in more depth below. The evidence reviewed above informs the rationale for the particular sample chosen for this study within the broader population of women who have/ had breast cancer, that is, mothers of dependent children.

#### *Participation in physical activity of women with breast cancer*

Prior to commencing this study, there were very limited, although increasing, data showing that physical activity levels of Australian women with a past breast cancer diagnosis. One study which examined the “health behaviour of cancer survivors” found that there were no significant differences in levels of physical activity, across all age groups, between people who had had a past cancer diagnosis and people who had never been diagnosed with cancer (Eakin *et al.*, 2007). Exercise behaviour studies reviewed by Rogers *et al.* (2004) suggest most women with breast cancer living in the United States either do not participate in any physical activity or do not participate in sufficient activity for health benefit (Rogers *et al.*, 2004).

Two studies have investigated the levels at which Australian women who have/ had breast cancer are physically active (Milne *et al.*, 2007; Salminen *et al.*, 2004). A comparative study between Australia and Finland, which was mainly interested in dietary changes, found that 24% of the 215 Australian participants self-reported that they had increased their level of physical activity compared to before their diagnoses, while 12% reported having decreased their level (Salminen *et al.*, 2004). A Western Australian study which surveyed 558 breast cancer survivors about their quality of life and physical activity participation found that 31% were meeting national physical activity guidelines of either 60 minutes of vigorous or 150 minutes of



moderate physical activity per week (Milne *et al.*, 2007).

There has been increased research interest in Australia and internationally regarding participation in health promoting behaviours after a cancer diagnosis, generally and breast cancer specifically, since commencing this study although very little published as yet (Girgis, 2009; Harrison, Hayes & Newman, 2009). Much of this research is being directed at cancer survivors' behavioural responses to risk, and I review that literature later in the theoretical section of this review. The Australian research has found patterns of physical activity participation after a breast cancer diagnosis show that the four key factors that constrain physical activity participation in women who have had a breast cancer diagnosis are low socioeconomic status, low level of education, having a partner and having difficulty with tasks of daily living (Girgis, 2009).

One longitudinal study conducted in the United States of America (USA) (Emery *et al.*, 2009), which included an education-based intervention about health behaviour after breast cancer, investigated biopsychosocial influences on 227 women's physical activity participation following a breast cancer diagnosis. The study found that, while overall the women gradually increased their physical activity participation over the first 18 months following surgery and during chemotherapy, radiotherapy and adjuvant therapy, their participation decreased over the next 42 months. Women who did not undergo chemotherapy by contrast increased their participation over three years, but then decreased their participation over the next two. The study found, however, that there was a slower decrease in participation if the women had higher family support. While higher perceived family support was associated with higher levels of physical activity participation over the longer term, the same effects were not found resulting from perceived support from friends. The study found that in the early months, effects of treatment and depressive symptoms were predictors of physical activity participation, but over the longer term these became less influential and level of family support became the strongest predictor.

Another study conducted in the USA that recruited a subset of the same study sample as above investigated the effects of marital distress on longer-term health, including participation in physical activity, following a breast cancer diagnosis. This longitudinal study followed 100 women, 72 of whom were assessed as being in stable, non-distressed relationships and 28 who were in stable, distressed relationships. The study found that while both groups increased their participation initially, after 18 months the distressed relationships group dramatically decreased their participation levels, whereas the non-distressed relationships group increased participation over the first two years, after which time they gradually decreased their participation (Yang & Schuler, 2009). While these studies confirm the importance of my study topic, they were not published prior to my data collection. These findings are relevant to include in this review, however because they show that there are social effects on women's physical activity participation following a breast cancer diagnosis that require further investigation, and this thesis contributes to this research endeavour.

#### *Motherhood and physical activity*

In Australia, women who are mothers of young children are one of the least likely social groups to exercise and have the least free time of any social group in Australia (Armstrong *et al.*, 2000; Bell & Lee, 2005; Brown *et al.*, 2001b; Brown, 2003; Miller & Brown, 2005).

National Australian data...indicate that women of all ages are less physically active than men of the same age...Different lifestyle factors and domestic situations also mean that some groups of women have less free time for active leisure than other groups, with mothers of dependent children having the least amount of free time of any social group (Brown *et al* 2001b p132).

Brown *et al's* (2001b) study including 543 mothers of young children spells out the constraints to physical activity experienced by mothers. Their data indicate that:

- (a) More than two thirds of the mothers were inadequately active in their leisure time for health benefit;
- (b) While the vast majority of mothers expressed a desire to be more active, they were inhibited in their ability to act out their leisure

preferences by a combination of structural (e.g., lack of time, money, energy) and ideological influences (e.g., sense of commitment to others);

- (c) access to social support (such as from partners, family, and friends) was seen to place some women in a better position than others to negotiate constraints that inhibit leisure participation; and
- (d) within groups of varying socioeconomic status (SES) there was wide variation in the amount of time spent each week in active leisure (Brown *et al.*, 2001b p131).

The authors conclude that for mothers, participation in physical activity is dependent on complex social and individual influences which must be addressed if this social group is to increase participation in leisure time physical activity. They suggest that health promoters consider campaigning for social support of family and friends, and also that the more difficult issues of “unequal access to financial resources, asymmetrical divisions of domestic labor, and traditional familial ideologies” also need to change (Brown *et al.*, 2001b p142).

There have been a few intervention programs set up to mitigate barriers for women with young children, in particular, women with babies, for example, pram walking groups (Armstrong & Edwards, 2004; Currie & Develin, 2002) and physical activity promotion through child care centres promoting mothers to use the time for physical activity (Cody & Lee, 1999). The Busy Mums Wanted study found that mothers who have supportive partners were more likely to engage in leisure time physical activity than those who did not (Lewis 2001 citing Lo Cascio *et al.*, 1999). The study also found that women who were single mothers were more likely to engage in sufficient physical activity than partnered mothers (Lewis 2001). In the second part of this review, I apply feminist leisure theory to explore further the factors contributing to inequitable participation in physical activity.

### **Breast cancer survivorship and physical activity participation**

Participation in regular physical activity has been shown to assist women in

coping with the psychological and physical effects of breast cancer treatments, and potentially in surviving breast cancer longer. Research interest in the health effects of physical activity participation in women who have/ had breast cancer was sparked when McKenzie's (1998) Canadian study "Abreast in a boat" contested the prior belief that women who have had breast cancer treatment should not undertake vigorous, repetitive upper body exercise. Until McKenzie's groundbreaking study, such activities were avoided in order to prevent post-treatment complications such as lymphoedema (McKenzie, 1998; McKenzie & Kalda, 2003). A number of researchers have since investigated a wide range of benefits experienced by women who have/ had breast cancer who participate in dragon boat racing. They conclude that dragon boat paddling does not cause or increase lymphoedema and that women experience other physical, psychological and social benefits from participating in dragon boat racing (Courneya, Blanchard & Laing, 2001; Culos-Reed, Christopher & Lawrence, 2005; Harris and Niesen-Vertommen, 2000; Mitchell *et al.*, 2007; Parry, 2007). Research effort into biological and psychological effects of different types of physical activity for women who have/ had breast cancer has increased since McKenzie's study, as described below.

#### *Breast cancer treatments and physical activity participation*

There is accumulating evidence that exercise may ameliorate adverse effects of breast cancer treatments (Courneya *et al.*, 2007). Physical symptoms which physical activity has been shown to mitigate include fatigue (Stasi *et al.*, 2003), lymphoedema (Lane *et al.*, 2005; Moseley *et al.*, 2005) and bone mineral density loss (Schwartz, Winters-Stone & Gallucci, 2007).

Fatigue is a debilitating adverse effect of cancer treatments, particularly chemotherapy and radiotherapy (Mock *et al.*, 2001; Servaes *et al.*, 2007; Stasi *et al.*, 2003). A systematic review of several international studies found that physical activity reduced fatigue, improved cardio-respiratory fitness, physical functioning and quality of life for women undergoing breast cancer treatment and beyond (McNeely *et al.*, 2006).

A large number of women develop lymphoedema after breast and/or lymphatic surgery, and sometimes after radiotherapy. The actual percentage is unclear (potentially around 30%), mostly because of differing methods of measurement, including whether lymphoedema should be a subjective (whether a woman feels like her arm is swollen) or objective (circumference, fluid measurement) assessment (Hayes, Battistutta and Newman, 2005; Hayes, Cornish and Newman, 2005; Moseley & Piller, 2002; Pain & Purushotham, 2000). Whichever measurements are used, women with lymphoedema are more likely to experience other unpleasant symptoms and experience poorer quality of life than women who do not have lymphoedema resulting from breast cancer treatment (Gould *et al.*, 2006; Lane, Worsley & McKenzie, 2005; Loudon & Petrek, 2000). Over the last ten years, since McKenzie's dragon boat study cited above, evidence has shown that physical activity at least does not increase lymphoedema and at best reduces lymphoedema (Courneya *et al.*, 2007; Moseley, Piller and Carati, 2005).

Breast cancer treatments can cause early on-set of menopause or menopausal symptoms. Many post-menopausal women experience a return of menopausal symptoms, which can feel worse than their actual menopause experience (Thomas-MacLean, 2005). For a significant proportion of pre-menopausal or peri-menopausal women, chemotherapy-induced menopause is permanent (Hickey, Saunders & Stuckey, 2005). When women go into the menopause earlier than they otherwise would have done as a result of chemotherapy, or have drug therapy to reduce oestrogen levels, or undergo oophorectomy (surgery to remove ovaries), they are at increased risk of osteoporosis (Chen *et al.*, 2004; Swenson *et al.*, 2005). A Cochrane systematic review found that weight bearing and resistance exercises increase bone mineral density in the spine and that walking increases bone mineral density in the hip of postmenopausal women (Bonaiuti *et al.*, 2002). Studies with women who have had breast cancer treatment suggest that weight bearing exercises may prevent loss of bone mineral density, so such exercises are being promoted in the literature (Chen *et al.*, 2004; Hickey *et*

*al.*, 2005; Schwartz, Winters-Stone and Gallucci, 2007; Swenson *et al.*, 2005).

### *Recurrence, survival and physical activity participation*

There is some evidence that physical activity potentially reduces the risk of cancer recurrence (Milne *et al.*, 2007) and increases length of survival post-diagnosis (Friedenreich *et al.*, 2009; Holmes *et al.*, 2005; McNeely *et al.*, 2006; Mock *et al.*, 2005; Mock *et al.*, 2001). Women who have been diagnosed with breast cancer are at increased risk of future breast cancer diagnoses compared with women who are cancer-free (Alfano *et al.*, 2009). Based on the available evidence, it is very likely that regular participation in physical activity reduces the risk of developing breast cancer.

While there are several non modifiable risks for breast cancer, for example lifecycle hormonal changes such as age of menarche and age of menopause (Bernstein *et al.*, 2003), over the last ten years epidemiologists have investigated the extent to which individually modifiable lifestyle risk factors play a role. Factors investigated include diet, smoking, alcohol, body weight and physical activity. There is accumulating evidence that participation in physical activity is beneficial for women in reducing the population risk of breast cancer.

Observational epidemiological studies in the USA and Europe have investigated women's physical activity levels to see how and at what life-stages physical activity reduces breast cancer risk (Bernstein *et al.*, 2005; Friedenreich, 2001; Gerber *et al.*, 2003; Steindorf *et al.*, 2003). It has been and is still difficult to find out exactly how much and what type of physical activity is enough to make a difference to breast cancer risk, or at what time in women's lives physical activity is most protective. There are a number of reasons for this, in particular, it is difficult for observational studies to be entirely rid of confounders and different studies have used different measures of physical activity (Friedenreich, 2001). Key to the problem of measurement is that people's lives are complex. It is difficult to find out

everything about people's lives that may affect breast cancer risk. It is also difficult to measure accurately the various types of physical activity in which people engage in their daily lives. Nevertheless, despite the evidence being complex and contradictory, a growing number of epidemiologists agree that participation in regular physical activity reduces the risk of breast cancer in populations of women (Friedenreich, Bryant and Courneya, 2001; Kruk and Aboul-Enein, 2003; Mezzetti *et al.*, 1998; McTiernan *et al.*, 2003; Rockhill *et al.*, 1999; Steindorf *et al.*, 2003; Thune *et al.*, 1997; Verloop *et al.*, 2000).

On balance, the evidence I have reviewed above shows that the health and wellbeing benefits of exercise for women who have had breast cancer mean there is good reason to explore ways to maximise physical activity participation for this group. It is important to note here that the strong research emphasis on *individually* modifiable risk / protective factors as opposed to *collectively* modifiable risk/ protective factors is in part ideologically driven rather than being the result of value-free scientific endeavour. Placing research emphasis on individual risk factors ensures that individuals rather than institutions or corporations are made responsible for enacting modifications (Potts, 2001; Potts, Dixey and Nettleton, 2008; Tesh, 1988). While this thesis is not an attempt to criticise research effort into individual health behaviour activities such as physical activity *per se*, it needs to be acknowledged that research funding allocation is skewed in this direction, with political implications.

### **Exercise intervention studies with women who have/had breast cancer**

Evidence of health benefits of physical activity has led to a proliferation of intervention studies with women who have/had breast cancer. These exercise intervention studies have used behaviour change theories, for example the Theory of Planned Behaviour (Courneya, Blanchard & Laing, 2001; Courneya & Friedenreich, 1999; Jones *et al.*, 2005), the Transtheoretical model of behaviour change (Pinto *et al.*, 2005; Rabin *et al.*, 2006) and Social Cognitive Theory (Rabin *et al.*, 2006) to work out ways in which women with a breast cancer diagnosis may be exhorted to comply with exercise programs.

The Theory of Planned Behaviour presupposes that intention is the main motivator of behaviour, and that intention is influenced by a person's attitude (positive or negative assessment of the behaviour), subjective norm (perceived social pressure to either perform the behaviour or not) and perceived control (ability in terms of difficulty or ease to perform the behaviour) (Jones *et al.*, 2005).

The Transtheoretical Model of behaviour change presumes that individuals who are adopting a new behaviour, such as participation in physical activity, progress along a five stages of change: precontemplation (not considering participation in the next six months), contemplation (considering participation in the near future), preparation (irregularly participating), action (regularly active over a short time) and maintenance (regularly participating for at least six months) (Pinto *et al.*, 2005).

Social Cognitive Theory has been used to explore why women do or do not participate in exercise programs (Rabin *et al.*, 2006). This theory posits that behaviour is influenced by individual and environmental factors. Included in the individual factors are the concepts of self-efficacy (a person's confidence in their ability to perform a particular behaviour) and outcome expectations (the expected results of a particular behaviour) (Rogers *et al.*, 2004). While environment is included as a factor which influences behaviour, in the behaviouralist view, it is *individuals'* perceptions of their physical and social environments that influence their behaviour rather than *structural* (e.g. social – gendered identity) or material (e.g. financial) constraints or enablers. It does not include examining the ways in which individuals are deeply connected to their physical and social environments. Moreover, power is not identified as an environmental or social factor. As such, behaviouralist studies explore reasons why women may or may not participate in sufficient physical activity at an individual behavioural level. They do not necessarily examine the importance of how the social context of individuals' lives may influence their participation.



Above, I have shown that biomedical evidence has been and is essential in defining ways in which physical activity is helpful for women who have/ had breast cancer at a biological level. However, the limitations of this evidence are highlighted when viewed through a critical feminist lens. Biomedical and most behavioural evidence is unable to incorporate, or even fully recognise, the complexities of women's every-day/every-night lives, and so cannot on its own lead toward effectively increasing women's physical activity levels (Doyal, 2003; Fullagar, 2003; Vertinsky, 1998; Travis and Compton, 2001). Indeed, most research about physical activity participation of women who have/ had breast cancer separates the social context from individual women's lives. Where the social is included, it tends to be represented as another variable to which individuals are exhorted to adapt (Backett & Davison, 1995; Fullagar, 2003; Krieger, 1994; Tesh, 1988). Nevertheless, the more recent research in the USA that I reviewed above indicates that there is increasing recognition of the importance of social context to physical activity participation levels of women who have/ had breast cancer, particularly intimate partner and family support (Emery *et al.*, 2009; Yang & Schuler, 2009). To reiterate, the fact that studies that investigate individual lifestyle modifications receive far more funding than studies that investigate collective modifications should alert us to considering other possible ways in which women's experience of breast cancer may be improved, and indeed how breast cancer may be collectively prevented (Potts, 2004a; Potts *et al.*, 2008; Tesh, 1988).

### **Women's accounts of breast cancer survivorship and physical activity**

There have been a number of international and a few Australian qualitative studies that have explored women's experience of breast cancer and breast cancer related symptoms from women's perspectives, in the contexts of their everyday lives. Connell *et al.* (2006a; 2006b) focussed on issues of importance to young women (under 40 years old) who were diagnosed with breast cancer. Most of the women in their study had dependent children at the time of their diagnosis, and issues related to children (and also fertility) were identified as being extremely important to the women. Another study from the Hume region in Victoria explored rural women's experience of

breast cancer, including emotional issues, support and access to services (Verde, Cuss & Parkinson, 2004). Of the Australian studies, however, none that I have found have specifically sought the voices of women who had dependent children at the time of diagnosis, nor focussed on the women's views on physical activity promotion or participation.

Most studies that have focused on psychosocial impacts of breast cancer have been interested in topics such as body image, in particular breast loss. Other areas of psychosocial research include women's fear of breast cancer recurrence and the impact on the families of women diagnosed with breast cancer (Johnson & Vickberg, 2001; Lewis, Hammond & Woods, 1993; Shannon & Shaw, 2005; Verde *et al.*, 2004). Some feminists have been critical of a sexist privileging of research on psychosocial effects of breast loss over other breast cancer experiences that they have found to be of equal or greater importance to women themselves (Cromptvoets, 2006; Langellier & Sullivan, 1998; Wilkinson, 2000). When women have been asked about their experiences, other effects of treatment that have been neglected, but were found to be important to women, have included chemically induced menopause, hair loss and lymphoedema (Thomas-MacLean, 2004a). One Australian study has examined reasons behind women's decisions post-breast cancer surgery to wear prostheses or undergo surgical breast reconstruction in terms of a sexist cultural imperative (Cromptvoets, 2006).

Published feminist studies from the realms of public health, sociology and psychology that have sought women's perspectives of their experience of breast cancer have not as yet featured women's views specifically on participation in physical activity. In cases where exercise or physical activity was occasionally mentioned by women, it has been in relation to something else, for example where it incidentally related to going out in public or the type of clothing and/or breast prosthesis required for exercise (Cromptvoets, 2006; Thomas-MacLean, 2005). Studies that have focused on women's accounts of participation in physical activity while undergoing treatment and beyond are virtually non-existent, with the only exception being in the

feminist leisure literature, which I review below in the theoretical section of this chapter.

Above, I have outlined the public health importance of this study, by reviewing the evidence that supports the promotion of regular physical activity participation to women who have/ had breast cancer. At this point, I have shown that there is a clear gap in the literature regarding women's views on their participation in the context of a breast cancer diagnosis, especially those women diagnosed when they had dependent children. In the next section I review literature from the social sciences in order to develop a theoretical framework with which to answer my research questions.

## ***Theoretical frameworks for exploring women's accounts of breast cancer and physical activity***

Here I explore how the social sciences, including the new public health, sociology and feminism, provide theoretical tools for exploring women's experiences of breast cancer and physical activity promotion and participation. I begin by reviewing public health debates, including the different approaches to health promotion, to enable consideration of what approach/es are thought to work for women who have/ had breast cancer. I examine critically the tendency for a focus on individual-based risk reduction to dominate discussions of health promotion after a cancer diagnosis. I then examine the research findings of public health researchers who argue for the usefulness of incorporating lay theory into health promotion strategies. I do this to enable exploration applicability of this process to health promotion in breast cancer survivorship.

I review the critical and feminist leisure research to examine the ways in which social contexts have been shown to affect women's participation in physical activity. This body of literature is valuable for gaining insight into how social determinants such as gender, socioeconomic status and rural or urban location may influence this study sample's views on and participation in physical activity.

Feminist qualitative breast cancer researchers have used the concept of embodiment to understand women's experiences of breast cancer. I review literature that uses theories of the body to develop a framework for understanding how women respond to information about health benefits of participation in regular physical activity and potentially, why they respond as they do. I then consider how lay/embodied knowledge literature may be useful for exploring the women's responses and ultimately for assisting health promoters to develop strategies that enable women to participate in physical activity after breast cancer. The literature I review in this section thus frames my examination of the research questions and informs my methodology.

## **Public health and health promotion**

More powerful than vested interests, more subtle than science, political ideology has, in the end, the greatest influence on disease prevention policy (Tesh, 1988, p155)

Public health includes disease and injury prevention and control, health restoration following an outbreak of disease or natural or man-made disaster and health promotion (Keleher, 2007). This study focuses on health promotion as a branch of public health to find out how women respond to campaigns that encourage people to participate in regular physical activity for their health benefit. In Australia, campaign recall studies have shown that there is high public awareness of physical activity promotion campaigns (Armstrong, Bauman & Davies, 2000; Baum, 2008; Bauman *et al.*, 2002). How women who have/ had breast cancer respond to information about health benefits of participating in regular physical activity needs to be understood in the context of the types of information and strategies to which they have been exposed. In Chapter Five, I provide an analysis of the ways in which the organisations that the women drew upon for information frame physical activity promotion. Below, I outline briefly the approaches to public health that have been undertaken in Australia over recent decades in order to place health promotion in its political and social context.

### *Individualist and collectivist approaches to public health*

Historically public policy, public health, civil society and medicine have intersected to create imperatives for people, either individually or collectively, to behave in particular ways (Baum, 2008; Lupton, 1995). Consequently, societies throughout history have instigated public health practices in their attempts to contain disease through methods of control of individuals and/or discrete social groups, and/or their living environments (Baum, 2008; Lupton, 1995; Tesh, 1988). As Tesh's quote above suggests, public health policy has traditionally been dependent on whichever theory of the spread of disease was dominant and how the theory fitted the dominant political or religious ideology at any one time (Lupton, 2003). As such, the types of public health and health promotion strategies adopted over time by different countries and

by different organisations and professionals have been, and are, influenced by prevailing values and beliefs (Baum, 2008).

In Australia, public health and health promotion policy is made in the context of a tension between collectivist and individualist strategies. Baum (2008) highlights the dialectic between individualism and collectivism as being crucial to understanding how public health policies and practices are developed. Therefore, public health policy is developed by drawing on a combination of individualist and collectivist approaches, balanced one way or the other depending on how the particular issue is represented by different interest groups, the values and beliefs of those in power and the extent to which they are influenced by social and political interests.

Tobacco control is a good example of a combination of individualist and collectivist approaches that have been put in place after a long struggle between health promotion organisations such as the Cancer Council and the National Health Foundation, social movements such as BUGA UP (Billboard Utilising Graffitists Against Unhealthy Promotions) and vested interests including the tobacco and hotel industries (Baum, 2008).

### **The new public health**

The emergence of the new public health in the 1970s resulted from an international social health movement culminating in the Alma-Ata Declaration at the International Primary Health Care Conference in 1978 which defined the primary health care definition for health. The Alma-Ata Declaration definition of health is:

a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector (WHO, 1978).

The Alma-Ata Declaration listed strategies with the aim of achieving health for all by the year 2000, urging international organisations and governments to take action cooperatively to improve the social and economic conditions in

people's lives that affect their health (Baum, 2008). The World Health Organisation subsequently published the *Global Strategy for Health for All by the Year 2000* (WHO, 1981).

In Australia, two movements were occurring in the early 1970s, preceding Alma Ata: the women's health movement and the community health movement (Broderick & Laris, 1995). These movements recognised the importance of broader social and economic factors for health (Broderick & Laris, 1995; Broom, 1991). Community participation and empowerment were central tenets for both movements, with feminist principles in particular driving the women's health movement (Broom, 1991). The early 1970s through the 1980s saw the establishment of community health centres and women's health centres in most Australian states and territories, most funded by the Commonwealth Community Health Program (Broderick & Laris, 1995; Broom, 1991). Since that time, their maintenance, particularly of their founding principles of being independent advocates for the health of their communities, has been fraught with struggle (Broderick & Laris, 1995; Shuttleworth & Auer, 1995).

In the years that followed the Alma-Ata Declaration, its strategies, like those of the women's health and community health movements, were not taken up in the ways intended (Baum, 2008). Instead, selective primary health care was established, focussing on a medical model of specific disease prevention (Baum, 2008). In 1986 at the First International Health Promotion Conference, the Ottawa Charter set the blueprint for health promotion practice and has guided the new public health into the twenty-first century (Baum, 2008). The intent of both the Alma-Ata Declaration and the Ottawa Charter for Health Promotion was to improve the conditions in which people live, to include people's participation in the planning and implementation of their local and national health services. The premise is that health is not an end in itself, rather it is a means to reach one's potential to "realize aspirations" (WHO, 1986).

Proponents of the new public health argue that collective approaches should

be central to strategies aiming to improve health, and that individualist approaches will only be effective in conjunction with collective effort (Baum, 2008; CSDH, 2008). Thus, they advocate for public policy that promotes social justice, for example by the re-distribution of wealth to promote economic equity between individuals and between groups of people, by the provision of good public education for all people and the provision of equitable and accessible health services for all (Baum, 2008; Keleher & Murphy, 2004).

New public health research consistently demonstrates that social and environmental determinants must be attended to in any effort to improve people's health at a population level (Baum 1998; Rose 1985). Keleher and Murphy (2004 p5) define population health as being:

...concerned with improving the health of whole populations or specific populations, particularly to reduce inequalities, through policies, programs, research and interventions designed to protect and enhance health.

While those subscribing to the new public health accept that social determinants of health affect individual people's health (and ill-health), their main focus is on the health of populations, and what it is that determines the whole populations' and/or various population sub groups' health. In this view, the structure of society determines population health to a greater extent than individuals determine their own health. It follows then that, "equity and justice are central to the determinants approach of understanding health" (Keleher & Murphy 2004, p6). Thus, the new public health approach advocates for structural models of health promotion that follow closely the original concept of health promotion, as it was developed for the Ottawa Charter in 1986. While the Ottawa Charter includes both behavioural and structural models of health promotion, the emphasis is on structure and positions individual behaviour as responsive to structural change (Baum, 2008; CSDH).

Having established a background to the development of health promotion within the broader context of public health, I now turn to describe the models employed in the Australian context concerning breast cancer as the area of



key interest in this study.

### **Models of health promotion**

Public health models of health promotion not only reflect the different theories on which they are based, but also are influenced by broader social and political values and beliefs. There are three main approaches to health promotion with distinctively different theoretical underpinnings: medical, behavioural and socio-environmental (Baum, 2008; Keleher, 2007).

In Australia in the 1970s and 1980s, a feminist-based breast cancer movement emerged along with the women's health movement (Cromptvoets, 2006). Breast cancer has gained an enormous amount of public attention since that time, following the formation of breast cancer advocacy and support groups throughout Australia. In the early days of the breast cancer movement, activists pushed for greater public awareness of breast cancer and therefore early detection, less invasive (or rather, less mutilating) treatments, better doctor-patient communication and more funding for curative research (Broom, 1991; Cromptvoets, 2006). Breast cancer advocacy in Australia does not overtly include prevention; rather it focuses on support for women who have/ had breast cancer, early detection (often framed as prevention) and treatment research. By comparison with the breast cancer movements in the USA and the UK that question the effects of the practices and products of governments, pharmaceutical and chemical companies on women's bodies (Brown *et al.*, 2004; Brown *et al.*, 2001; Klawiter, 2000, 2004; Potts, 2001, 2004a), the feminist roots that initially critiqued socially constructed power-imbalances in Australia no longer appear strong. Later, I return to the related topic of feminist critiques of medicalisation but initially describe the mainstream approaches to breast cancer prevention (behavioural model) and early detection (medical model and behavioural model).

#### *Breast cancer prevention*

In Australia, the peak national cancer prevention organisation is the Cancer Council Australia, along with its state-based counterparts. Federal and State Governments are also involved in cancer prevention and control, but do most

of their cancer prevention work either through or in conjunction with the Cancer Councils. The Cancer Councils are non-government organisations dedicated to the control of cancer, and are major funders of cancer research, support services and prevention (The Cancer Council South Australia and the SA Department of Health, 2006). While the Cancer Councils have been instrumental in ensuring legislative change regarding tobacco control, physical activity promotion practice largely focussed on behavioural strategies (see Chapter Five).

Although state-based cancer councils frame behavioural strategies differently (see Chapter Five), they all use information about population risk and protective factors to encourage individuals to change their dietary and exercise behaviours to reduce their risk of cancer. The Cancer Councils have utilised mass media campaigns designed to get this message across to the public and have developed booklets and brochures outlining the benefits of diet and regular exercise for cancer prevention generally, and avoiding alcohol for breast cancer prevention specifically. The South Australian and Victorian Cancer Councils (the Cancer Councils germane to this thesis sample) have over the past decade used socio-environmental strategies to promote physical activity participation in conjunction with behavioural strategies, for example by working with local government at an urban planning level, as well as other organisations such as the National Health Foundation (Cancer Council SA, 2008; National Heart Foundation of Australia (Victorian Division), 2004).

### *Breast cancer screening*

There has been a great deal of debate about the usefulness of mammography screening in terms of lives saved. The most recent research suggests that mammography screening has increased the number of breast cancer tumours detected early. Thus, proponents of mammography screening attribute increased breast cancer survivorship to increased likelihood of early detection directly related to mammography (Australian Institute of Health and Welfare & National Breast Cancer Centre, 2007; Australian Institute of Health and Welfare & Australasian Association of

Cancer Registries, 2008; The Cancer Council South Australia, 2002; The Cancer Council South Australia and the SA Department of Health, 2006). The current approach to early detection in Australia is mammography screening, and the strategies used are a combination of medical and behavioural models. All Australian women, when they turn 50 years of age, are invited by letter to undergo a free mammography test to screen for breast cancer and thereafter are reminded by letter on a 2-yearly basis until they reach 70 years of age.

In addition to individual letters to women, concurrent behavioural health promotion strategies, including mass media campaigns, are used to encourage women to undergo this test two-yearly between the ages of 50 and 70. However, as cited in the previous section of this review, participation is inequitable across social groups and diagnosis at an early stage is more common in advantaged women. This has parallels with health promotion strategies where those least at risk of ill-health are also most likely to benefit from behaviour change (Baum, 2008; Rose, 1993). That is, if most women participate in mammography screening, more cancers will be detected early, but these will be weighted toward women already living in favourable conditions as they are also more likely to seek a mammogram (Baum, 2008; Siahpush & Singh, 2002). As noted above, breast cancer incidence is somewhat different from most other diseases because it is higher in affluent women, yet later diagnosis is more likely in women living in disadvantaged circumstances. Secondly, lower mammography rates do not adequately explain inequitable survivorship rates between groups of women (Chlebowski *et al.*, 2005; Luke *et al.*, 2004; McMichael *et al.*, 2000).

Mammography screening has produced heated feminist debate regarding the effects on women who are targeted by mammography screening campaigns. Qualitative research, in particular, indicates a moral dimension to mammography screening, whereby women feel an imperative to participate. Thus, there are elements of victim blaming (a concept which is explored in more detail below) where women diagnosed at a later stage who did not undergo mammography are more likely to be blamed for their potentially

poorer prognosis than those who did (Crabb, 2006; Crabb & LeCouteur, 2006; Crossley, 2002; Lupton, 1993; Ward, 1999; Willis, 1999).

In addition to mammography screening, women have been exhorted to be vigilant in detecting breast changes themselves. While in the 1980s and 1990s women were educated about how to undertake regular breast self examination (The Cancer Council South Australia, 2002), later evidence showed that this practice made little or no difference to early detection (The Cancer Council South Australia and the SA Department of Health, 2006). Thus, this campaign was dropped and has been replaced by a campaign to encourage women to “know their breasts”, that is, to notice any changes, such as discolouration, dimpling or unusual lumps (The Cancer Council South Australia and the SA Department of Health, 2006).

### **Risk and choice - from public health to private lifestyle**

Concurrently with the emergence of the new public health, western medical public health authorities, guided by evidence from medical biological research and epidemiology, have increasingly used the phenomenon of risk to advocate for particular health promoting policies and strategies (Forde, 1998; Skolbekken, 1995). Health promotion that uses population incidence of ill-health based on lifestyle risk factors to promote behaviour change to individuals has been largely unsuccessful without associated social, environmental and structural change. Rose (1985) calls this phenomenon the “prevention paradox”, whereby individuals are unlikely to benefit from small changes across a population, but that these small changes would have a significant impact on population health. His analysis of individuals is that even if they may be aware that they could change their behaviour, they would understand that they would gain little or no short or even long-term benefit, and so have little incentive to change. The distinction here is between causes of incidence in populations and causes of individual cases, where population risk factors are drawn upon as if they were able to be directly translated into individual risk. Despite an enormous amount of epidemiological evidence about population risk factors, risk factors remain an unreliable method of assessing whether or not a particular individual will

develop the disease in question (in this case, breast cancer) (Rockhill, 2001). Further, attributing the cause of an individual's ill-health based on the characteristics of population aggregates is commonly called the "ecological fallacy" because there will always be discrepancies between individual and aggregate variables (Schwartz, 1994). Population based aggregates are therefore more useful for examining social, structural causes of health or ill-health of populations than they are for examining causes of individual cases (Schwartz, 1994).

#### *Heightened risk awareness after breast cancer as a teachable moment?*

Risk is a complex domain in breast cancer research, and ways in which it is communicated need to be examined thoroughly. There is a growing literature about women's perceived risk of a number of diseases, including breast cancer, osteoporosis and heart disease. In this literature, the assumption is that if women are correctly educated, they will perceive their risk rationally and they will alter their behaviour accordingly (Hunter & Dea, 1999; Gerend *et al.*, 2004; Paul *et al.*, 1999). This assumption has extended into the concept of the teachable moment, whereby women who have had a breast cancer diagnosis may be more open to health education (Alfano *et al.*, 2009; Humpel, Magee & Jones, 2007; McBride *et al.*, 2008).

The concept of the teachable moment has been used in education for some decades and literally means turning disruptions or unexpected events into opportunities for teaching. An example could be that a child brings a frog or a beetle into the classroom and the teacher makes use of the interest it generates by teaching some aspects of biology. Lawson and Flocke (2009) in a systematic review of the use of the teachable moment in health education have identified three ways in which the teachable moment has appeared in this context. These include using the teachable moment as: 1) a particular opportunity (moment) for education that may facilitate behaviour change; 2) being timed with specific events that have, upon retrospection, led to behaviour change and thereby may be used in the future based on an estimated increased capacity for change; and 3) a theoretical tool which can tap into people's heightened perception of risk due to a particular illness to

facilitate behaviour change. In recent years the teachable moment has appeared in the cancer survivorship literature in relation to behaviour change (Demark-Wahnefried *et al.*, 2005; Lawson & Flocke, 2009; McBride *et al.*, 2008), drawing on the third category described above, where cancer worry is seen as an opportunity for intervention (McBride *et al.*, 2008).

Proponents of the teachable moment are suggesting that people who have had a cancer diagnosis may be more likely than the wider population to change some of their behaviour (Girgis, 2009; Humpel, Magee & Jones, 2007). Humpel *et al.* (2007) for example conclude that a diagnosis of cancer may be a teachable moment not only for people diagnosed with cancer, but also their friends and family. There is some evidence that among women who are deemed to have increased breast cancer risk because of having a first degree relative diagnosed with breast cancer, those who perceive their risk as high are more likely to participate in regular leisure time physical activity than those who perceive their risk as low (Audrain *et al.*, 2001; Audrain-McGovern, Hughes & Patterson, 2003; Lemon, Zapka & Clemow, 2004).

The idea of a teachable moment has parallels with Giddens's (1991) fateful moments. Fateful moments occur when unexpected events challenge a person's everyday world to the extent that they are compelled to make decisions "in terms of over-all life planning" (1991, p142). Giddens argues that people "are often stimulated to devote the time and energy necessary to generate increased mastery of the circumstances they confront" (Giddens, 1991 p143). In this view, breast cancer is an unexpected event that could potentially lead women to question their "routinised habits" (1991, p131) and to be open to new information, such as health promoting activities, that potentially lead to making personal behavioural change.

There is also evidence however, that educating women about breast cancer risk as a result of lifestyle factors may create distress, particularly in women with a family history of breast cancer who over-estimate their personal risk of breast cancer (Gerend *et al.*, 2004; Paul *et al.*, 1999). Katapodi *et al.* (2005)

warn that promoters of health behaviour change need to be careful that they do not lead women into a false sense of control over their risk of developing breast cancer. Moreover, other risks such as environmental exposure to carcinogens, are largely out of women's individual control and extremely difficult to estimate epidemiologically (Potts, Dixey & Nettleton, 2008). Indeed, there is substantial evidence that many women who have/ had breast cancer experience depression or stress (Wade, Nehmy & Koczwara, 2005). Fear of recurrence is a major source of anxiety and stress for women who have had breast cancer (Johnson Vickberg, 2001; Connell *et al.*, 2006a) so using strategies that potentially increase fear require further critique.

#### *Criticisms of risk promotion*

Since the publication of Beck's *Risk Society* (1992), along with proponents of the new public health, the social sciences have criticised the use by the powerful and wealthy of using western science's truth claims for the purpose of risk-mongering activities that place the onus to avoid risk on individuals. Risk can be seen as either a collective problem or as a problem of individuals, or a combination of both as shown above in the example of Australian tobacco control. Physical activity participation, however, is a public health issue that is not as simple to control with legislation, nor as simple to show direct health effects (Bauman *et al.*, 2002). Thus far, public health approaches to physical activity promotion have tended to rely on requiring individuals to change their physical activity behaviour in order to avoid risk with very few concurrent attempts to change social and environmental constraints to participation. Yet, as argued above, Rose's (1985) explanation of the prevention paradox explains why it is reasonable that individuals may not respond to population-based statistics.

The new public health literature is critical of approaches to health promotion which exhort people to cease risky behaviours in order to prevent a future which may include ill-health (and thus public expenditure), without concurrent attempt at structural change. This literature suggests public policy and health promotion approaches undertaken in neo-liberal, or neo-conservative, societies attempt to restrict public health policy to non-disruptive approaches.

Such approaches ask individuals to make personal lifestyle changes (commonly referred to as choices) rather than take the more difficult and disruptive path which would involve structural (institutional, redistribution of power) and economic (economic redistribution) changes (Tesh, 1988). Using examples from the USA, Tesh (1988) highlights ways in which responsibility for health risk management (e.g. occupational health and safety, use of toxic materials) is shifted from governments and corporations to individuals (Tesh, 1988). Thus, if people do not regulate their bodies in ways that health promoters and governments expect, they are blamed for any illness that they may develop, a phenomenon called blaming the victim (Howson, 2004; Tesh, 1988). In Australia there are many examples of health promotion actions which draw on a combination of health promotion models (tobacco control and mammography being just two). Besides piecemeal attempts at socio-environmental strategies, physical activity promotion by comparison, has largely relied on the behavioural model.

Australians from a range of backgrounds have consistently told researchers that there are particular cultural, social and environmental aspects that influence their intentional or actual participation (Armstrong, Bauman & Davies, 2000; Bauman *et al.*, 2002.; Brown *et al.*, 2001, 2001b; Cortis, Sawrikar and Muir, 2007; Wright *et al.*, 1996). International and Australian studies have unequivocally demonstrated that social, as well as physical environments play an extremely important part in people's participation of physical activity (Stahl *et al.*, 2001; Brown *et al.*, 2001b). Even staunch advocates of behaviour change health promotion models have conceded that mass reach campaigns have been unsuccessful in their aim to increase people's physical activity levels, in spite of increasing people's knowledge of health benefits (Sallis & Owen 1999).

Qualitative research has repeatedly shown that study participants' *awareness alone* of benefits or risks of particular activities (for example, eating more fruits and vegetables, engaging in safe sex, being regularly physically active or smoking cessation) has not necessarily translated into uptake or cessation of the relevant behaviour/s for a broad range social and



cultural everyday life, or ordinary, reasons (Backett-Milburn *et al.*, 2006; Backett, 1992b; Lawton, 2002; Popay & MacDougall, 2007). Qualitative public health researchers have been calling for a social approach to health promotion, and for the development of theoretical models that include lay knowledge, that can be applied to health promotion endeavour (Milburn, 1996).

Notwithstanding, approaches to health promotion that rely on a moral imperative to make healthy choices have largely been taken on by people in their lay *theorising* about health, but are not necessarily translated into their *daily practices* (Crossley, 2002; Backett, 1992; Lupton, 2005). Recent research shows that lay theories tend to blame victims as part of making sense of health inequities, whether or not the people who theorise as such engage in practices deemed to be healthy themselves (Popay & MacDougall, 2007; Potts, 2004b; Lupton, 2003). Qualitative research is extremely useful for exploring the complexities inherent in the ways in which people think about health promotion messages through the contexts of their everyday lives (Popay & MacDougall, 2007).

MacDougall (2003) for example, in his South Australian study that investigated how ordinary people think about physical activity and health found that study participants would initially recite benefits of physical activity purported by mainstream medicine to produce health, such as preventing osteoporosis and maintaining cardiovascular health. They would then go on to contextualise the place of physical activity in their everyday lives, for example by talking about feeling mental health benefits (e.g. reduces stress) and social health benefits (e.g. meeting people). Finally, his study found that people would continue to add complexity to their theories about physical activity and health by describing contexts in which they felt there were limits to the extent to which physical activity provided health benefits, for example because of their own physical limitations such as their age or personal health status (MacDougall, 2003).

Qualitative public health research offers guidance regarding the ways in

which people embody, in their lay theorising, the political, social, gendered and moral imperatives that are embedded in health promotion practices. Therefore, the literature assists in my endeavour to examine critically the structures embedded in women's accounts of their responses to health promotion messages about risk and protection in relation to health benefits of physical activity. Building on this theme, I now move to consider how feminist theorising can help to illuminate the subject of women's participation in physical activity.

### **Feminist theories and public health**

Feminism or feminist theory in this thesis refers to a body of literature that critiques theories and literature from a range of disciplines that were founded in a patriarchal western culture which has historically devalued women based on their sex (Beasley, 2005). The feminist concept of patriarchy was developed by radical feminists in the early 1970s. Early feminist critiques of patriarchy viewed the family as the key site of men's domination and exploitation of women (Bryson, 2003). Radical feminists were hotly criticised by later feminists (especially Black feminists) for ignoring other sites of inequity, and the ways in which race/ethnicity, class, sexuality, (dis)ability and gender intersect (Beasley, 2005; Bryson, 2003). Nevertheless, the feminist notion of patriarchy remains important because it "enables us to see the extent to which male needs and assumptions are still central to political, cultural and economic life, and the norm against which women are measured" (Bryson, 2003, p240). Feminism and feminist theories alert us to the (often hidden) mechanisms that produce and reproduce power imbalances between women and men generally and between women and men within various social, ethnic and cultural settings specifically (Travis & Compton, 2001).

#### *Feminist critiques of medicalisation*

An area that has generated a great deal of feminist debate is western medicine. From the 1970s, notably from within the women's health movement, many feminists have argued that the medicalisation of women's lives is based on the premise that women's bodies are deviant (from men's bodies) and therefore require fixing (Broom, 1989; Ehrenreich & English,

1979; Martin, 1987). The term “medicalisation” “refers to the process by which human experiences are redefined as medical problems” (Becker & Nachtigall, 1992). The medicalisation of women’s lives is seen as being deeply embedded within the patriarchal roots of western society (Thornton 1995). In this view, the scientific-medical institution is a social and political product, which has its foundation in Aristotelian thinking. The privileging of mind (rational, objective, man) over body (emotional, subjective, woman) was taken up by Descartes and is commonly referred to as Cartesian dualism (Thornton, 1991, 1995). This dualism is firmly entrenched within the socio-political structures of western society, within which medicine plays a major role (Grosz, 1988).

Structuralist sociologists and anthropologists expanded Descartes’ theorising about mind and body, applying binary divisions to almost all human experience; body/mind, nature/culture, private/public, emotional/rational, profane/sacred, raw/cooked, and this has been a thorn in the side of feminists (and other social scientists and philosophers more generally) for many decades (Bordo, 1993; Holmes, 2007). One of the feminist critiques of the creation of binary pairs is that in each of these binary pairs, the feminine or feminised half is subordinated to the masculine. In the 1970s some feminists necessarily used these binary pairs to highlight ways in which women were devalued in relation to men. This has been associated with arguments for equality (same as men) or for difference (different from/better than men), depending on which argument may be deemed more helpful for improving the status of women (Bacchi, 1990). More recently, feminists, along with the social sciences more generally, are less inclined to speak in dualistic terms and have tried to find ways in which the divisions of binary pairs can be seen as blurred, merged or interconnected (Broom, 2008). Similar arguments are put forward about lay/expert binaries, because people who are involved in science and medicine have their own lay theories (pre-suppositions, values) and similarly, lay people use the language of science and medicine (Hansen & Easthope, 2007).

### *Feminist theorising of ideologies of motherhood*

Women's biological capacity to bear children is arguably the most important site for Western feminist theorising of inequities between women and men. The ways in which the women in this study construct motherhood may influence their responses to information about health benefits of physical activity, given that women with dependent children are one of the least likely groups to participate in sufficient physical activity according to the literature reviewed above. Feminist critiques of the concept of motherhood, while not entirely a new area for feminist theorising, have proliferated over the past few decades. Feminist interest in social constructions of motherhood, and women's experiences of mothering, include debates about pregnancy, abortion, new reproductive technologies, childbirth and the practices involved in raising children (Arendell, 2000; Craig, 2007; O'Reilly, 2004).

Early materialist feminists, beginning with existentialist feminist Beauvoir (1988) viewed women's biological bodies as physically situating them as women, but not as *the* determinant of their destinies (Lovell, 2004). Following this line of thought, Beauvoir (1988) and other feminists such as Firestone (1979) critiqued motherhood in terms of the potential for technological advances to enable women to improve their social status, for example by increasing control over their fertility and to reduce pain and suffering of labour and the danger of maternal death from childbirth. The dominant feminist agenda was for women to gain equality with men (Everingham, 1994), tying in with the "same as men" (Bacchi, 1990) argument described above.

Rich's seminal book *Of Woman Born* (1986) written during the time of mobilisation of the women's and women's health movements, sparked intense feminist interest in the meanings of motherhood. In her original book published in 1976, she outlined the potential for motherhood to be a site of empowerment for women, in spite of being historically controlled by men and powerful patriarchal institutions (Rich, 1986). Rich (1986) argued that motherhood is a patriarchal institution and therefore oppressive to women. Oppressive motherhood is premised on two main assumptions: 1) that

mothering is “natural to women” and that 2) “child rearing is the sole responsibility of the biological mother” (O’Reilly, 2004 p5). Further, while the biological mother is solely responsible for carrying out the work of raising children, she has little or no power, control or access to resources with which to carry out her responsibilities (Rich, 1986; O’Reilly, 2004).

Lively feminist debates about motherhood and mothering followed the publication of Rich’s (1986) book, and have continued in the decades since. Central to current feminist theorising of mothering are the ways in which motherhood, the ideologies and the practices, affects the status of women in relation to men, plus a range of intersecting social inequities and tensions such as class (Reay, 2004), culture, race/ethnicity, paid work, time/ time constraints (Craig, 2006, 2007; Hochschild, 2001) and sexuality (Calhoun, 1997; McCullough, 2004).

Pertinent to this thesis is how the mothers in this study construct motherhood in terms of their views on their roles in the work of caring for their children and caring for themselves in the context of having/ had breast cancer. Feminist literature on motherhood that could be useful includes literature about how women negotiate care work, particularly in the context of illness. Included in this literature is the feminist “ethic of care”, and “intensive mothering”.

The notion of a feminist ethic of care arose from Gilligan’s (1982) challenge to Freudian psychoanalysis and Kohlberg’s stages of development that argue males develop a capacity for moral reasoning regarding rights and fairness whereas females do not (Gilligan, 1982; Tong, 1989). Gilligan contends that women and men negotiate moral dilemmas differently. She argues that men tend to respond to moral dilemmas in the abstract, by weighing up differences between the rights of competing agents and deciding on what is fairest (Gilligan, 1982). She describes this approach as a male ethics of justice (Tong, 1989). Women, however, solve moral dilemmas relationally in terms of responsibilities (Gilligan, 1982). Rather than choose one right answer, women tend to change the dilemma, for example by introducing

negotiation between the competing agents who find consensus (Tong, 1989). The female point of view on moral dilemmas, she argues, is based on an ethics of care. Gilligan views these differences as stemming from men viewing themselves as autonomous agents and women's identities being formed in relation to others - as being interdependent rather than independent (Tong, 1989).

Gilligan's position, although intended to show empirically that women do not lack morality rather than make generalisations, unavoidably returns to essentialist debates about differences between women and men based on sex (Tong, 1989). While Gilligan's conclusions have been debated intensely, not least by feminists, her theorising has led to new fields of scholarship investigating the nature, meanings and ethics of "care" (Held, 2006; Larabee, 1993). Her insights have been taken up by some feminists to theorise the ideologies of motherhood and practices of mothering in terms of an "ethic of care", where mothers are at once embodying dominant ideologies of motherhood and at the same time often solely responsible for negotiating decisions about the everyday/everynight work of caring for children. Included in this literature is an interest in the extent to which mothers negotiate care for their children and care for themselves, for example by participating in physical activity (Krenichyn, 2004; Lewis, 2005). It is this use of a feminist ethic of care, particularly where women are in a position where they must negotiate care for themselves because of a diagnosis of breast cancer, as well as for their children (Sulik, 2007), that is of interest to this thesis.

The concept of "intensive mothering" was coined by Hays (1996) and refers to what she views as the dominant Western ideology of motherhood. Hays highlights contradictions between the ideologies of motherhood and the market, particularly for mothers who are in the paid workforce – and especially those in senior professional positions. She defines intensive mothering as being the sole responsibility of the birth (or adoptive) mother and that:

... correct child rearing requires not only large quantities of money but also professional-level skills and copious amounts of physical, moral,

mental, and emotional energy on the part of the individual mother (1996, p4)

Hays shows how the intensive mothering ideology, where mothers must place selfless energy into their children, is in direct opposition to the selfish ideology of the market (1996). Similarly, Lewis (1991) argues that “the ideal mother” is expected either not to work outside the home or to “fulfil all the demands of full-time exclusive mothering and full-time work without modifying the demands of either” (Lewis 1991, p195).

Feminist studies of families explore, among other things, ways in which women construct and attend to boundaries between mothering, unpaid labour at home and paid work outside the home in the context of their social and family lives (Cunningham-Burley, Backett-Milburn, Kemmer, 2005). The use of the concept of a boundary as dynamic and subject to conflict or cooperation and thus permeable and malleable (McKie and Cunningham-Burley, 2005) moves away from clearly defined and oppositional spheres such as public/private and work/home which as argued above, are limited in the extent they can represent the blurring between.

Cunningham-Burley, Backett-Milburn, and Kemmer (2006) examined mothers’ accounts of managing their own and their children’s illness in the context of paid work. The authors found that women remain the key family members responsible for taking care of sick children, and that the “women’s own feelings and cultural values about combining working and mothering were forcefully confronted, as the competing demands of home and work directly clashed” (Cunningham-Burley, Backett-Milburn, and Kemmer 2006 p 397). They also found that the women were careful to keep their sick days to a minimum in case their children were sick. This literature will inform the analysis of the extent to which women attend to their own health in the context of being diagnosed with a life threatening disease, and how they negotiate their boundaries between their children, home and work.

#### *Motherhood, social support and health*

Social support, as it is used in this thesis, includes support from family,

friends and broader social networks and the type of support includes practical, emotional and physical support (Oakley, 1992). There is now strong evidence that social support is an important determinant of health (Oakley, 1992; Baum, 2008) and there is growing evidence that social support affects breast cancer disease progression and survivorship (Kroenke et al., 2006; Nausheen et al., 2009).

The motherhood and feminist family studies literature suggests there is little social (particularly partner or workplace) support for women in the role of raising children at least in Western societies. The literature reviewed in the previous section of this chapter suggests that mothers' participation in physical activity is influenced strongly by the level of social support they can access; especially family and partner support (Brown et al., 2001). This study will explore the extent to which social support, and social constructions of motherhood, work and family play out in the study sample's experience.

#### *Feminist leisure theory*

Germane to this thesis because of its emphasis on physical activity participation is the relatively new discipline of feminist leisure theory, which has emerged along with critical leisure theory. Over the last two decades, the sociology of sport and critical leisure theorists have examined the production and maintenance of unequal leisure time and leisure types between those advantaged and disadvantaged in society (Dempsey, 1989; McKay, 1986). In Australia, sociology of sport theorists such as McKay (1986) have long questioned industrial capitalist societies' pursuit of lifestyle change that expects people to make healthy leisure choices (participating in regular physical activity) without redressing structural inequalities, including class, wealth, (dis)ability and ethnicity.

Feminist leisure theorists have applied feminisms, social theories and psychology to the study of sport and leisure. This body of literature examines the gendered nature of leisure in some detail, and in so doing, critically examines ways in which gendered power relations operate to constrain women's leisure pursuits (Broom, Byrne and Petkovic, 1992; Brown, 2002;



Gahagan *et al.*, 2007; Henderson, 1991; Shaw, 1994; Warner-Smith & Henderson, 1994).

Feminists have been critical of physical activity promotion campaigns that do not attend to gender:

Even after extensive government campaigns are repeatedly used to educate the public, fewer women than men participate in every age group. Something is drastically wrong when exercise is said to be associated with so many health benefits, yet only a small portion of the female population exercises sufficiently to accrue these benefits. It is important to critically evaluate the challenges inherent in achieving social equity in opportunities for healthy physical activity for all women. (Vertinsky, 1998 p.81)

Vertinsky's quote remains relevant in the Australian population, as women's participation continues to fall behind men's (Armstrong, Bauman & Davies, 2000; Bauman *et al.*, 2002; Gill & Taylor, 2004), and participation of women who are mothers of dependent children is showing no sign of increasing (Brown *et al.*, 2001).

Most intervention programs for women with young children have foundered in the long term because of social and environmental constraints, in particular social expectations that mothers put others' needs, especially children's, first (Lewis, 2001; Lewis & Ridge, 2005; Brown *et al.*, 2001b; Miller & Brown, 2005). There is some evidence that women who are mothers of young children are influenced more positively by the social, fun and "time out" aspects of participating in physical activity than by their knowledge of later risks to health if they don't exercise (Lewis, 2001). In Australia, women with dependent children are increasingly likely to be in the workforce, with many working part-time (Holmes, 2009). Yet, there is a great deal of evidence that while women and men often share paid work equally, they continue to share unpaid labour unequally (for example, care for children, elderly and people with disabilities, emotional work and housework) with women taking on the greater share - the "second shift", first named as such by Hochschild in her seminal book *The Second Shift* in 1989 (Connell, 2005; Craig, 2006; Emslie & Hunt, 2009; Strazdins & Broom, 2004; Thomsson, 1999; Hochschild,

2003). There is a danger that limiting interventions to addressing women's immediate needs, such as child care provision during work hours, without simultaneously attending to unequal divisions of labour at home, means that power relationships between women and men would remain unchanged (Bacchi, 1999; Bacchi, 2004).

Participating (or not) in physical activity is not, therefore, simply a matter of individual "choice" for mothers of young children. Lewis examined ways in which mothers of young children reconstruct physical activity in terms of a tension between being "good mothers" and "taking time for themselves" (Lewis, 2001; Lewis & Ridge, 2005). She used the concept of an "ethic of care" as defined above to theorise the ways in which the mothers framed this tension. In her study, mothers' participation in physical activity was partly dependent on a mothering ethic of care. Those mothers who reframed their ethic of care as meaning that if they have time out and participate in physical activity, then they are looking after themselves and therefore are better at looking after others, were more likely to participate in active leisure. Conversely, those who felt that they need to always "be there" for their children and not take time for themselves were less likely to participate in physical activity.

Bialeschki and Michener (1994), in their study of 53 women who were on the cusp of their children becoming less dependent on them, found that the women had placed their children's needs as their first priority. They found that in their study sample, the women's partners were often unavailable to help with everyday practices of child-rearing. This meant that the women often felt that they had no alternative but to accept the gendered role of motherhood and as a consequence, forego participation in their own personal leisure pursuits. Bialeschki and Michener argued that the women in their study had been "adhering to social expectations that ultimately impinged on their leisure", using feminist literature that critiques social constructions "that benefit the patriarchal society, reinforce androcentric power relations, and maintain an unequal division of labor" (Bialeschki & Michener, 1994 p64). There is some evidence in feminist leisure literature that when (some)

women retire, and/or when their children become independent (as above), there is a life transition when priorities change, and it is possible that the second shift loses its importance in their daily lives.

Some feminist leisure theorists have examined women's participation in leisure as an act of resistance against patriarchal oppression (Shaw, 2001; Wearing, 1990). Wearing (1990) found in her study of women who had newly become mothers that the women drew on competing discourses of motherhood and human rights in their resistance to dominant gender-power structures. She found that some of the new mothers negotiated leisure time as part of their resistance, for example by co-opting the fathers to share the unpaid work load and other family members to provide child care so that they could pursue leisure time activities. Shaw has argued that participation in leisure, for some social groups, is an act of resistance because "leisure practices are linked to power and power relations in society" (Shaw, 2001 p186). She argues that participation in leisure can represent both individual and collective resistance, and that for women, an individual act of resistance has implications for the collective.

There is some evidence that women's leisure behaviour and leisure preferences change following major life events, such as entering motherhood, or experiencing chronic and/or life threatening illness (Shannon & Shaw, 2005). Shannon and Shaw (2005) explored the effects of women's breast cancer experiences on their participation in leisure, at least one year post-treatment. In their phenomenological study which included eight participants from rural Nova Scotia, Canada, women changed how they viewed, and participated in, leisure following their breast cancer diagnosis. Because of the experience of breast cancer, the women began to view their own lives as more important than they had prior to diagnosis, and shifted their priorities toward leisure and family from paid work and housework. Secondly, the women sought leisure that was more meaningful, with a greater emphasis of making worthwhile use of their time. Thirdly, the women were more likely to engage in "health promoting leisure", that is, leisure pursuits that felt good for their mental health, or for general physical health

and fitness, with an emphasis on preventing recurrence. These findings resonate with some of the premises of Giddens's fateful moments and the teachable moment described above. In Chapter Seven I explore to what extent such changes were relevant for the study sample.

Feminist leisure theory provides useful insights into the potential for women to resist gendered social roles as a consequence of serious illness, and more specifically by actioning resistance through participation in leisure. Along with a social view of health, feminist theories of leisure provide useful theoretical perspectives on how women may respond to information about health benefits of physical activity in the contexts of their everyday/everynight lives, and how they feel about their own participation. This thesis will apply feminist leisure theory to explore to extent to which the literature helps to understand the experiences of women in this study.

#### *Feminist theories of the body*

Despite growing social science interest, one of the relatively neglected areas of consideration in public health literature regarding health promotion is the significance of the body (Broom, 2001a). This study seeks to investigate women's experience of physical activity promotion and participation following a breast cancer diagnosis by incorporating their bodily experiences as part of their lay theorising about health promotion. Theorising the body is potentially useful for moving away from dualistic notions of mind/body and instead focussing on bodies in social context (Gatens, 1988) and thus useful for health promotion strategies.

A return to interest in the body has, however, been hotly contested by some feminists because of the danger of association with essentialist ideas about women and men. Essentialism refers to the idea that women and men hold an essence which differentiates women from men. Essentialist feminists argue that there is an essential feminine (essence of a woman) and an essential masculine (essence of a man), and that the feminine has historically been subordinated to the masculine. The essentialist argument is that the essence of women is derived from women's bodies and that women

are more naturally caring because of the fact that women have the potential to bear children (Holmes, 2007). Some feminists have criticised attempts to theorise the body because of the danger of reverting to an essentialist, dualistic notion of women being defined as bodies and men as minds (or absent from theoretical analysis altogether) (Witz, 2000). Thus, these feminists view theorising the body as a backward step that moves toward perpetuating dualistic definitions of women and men.

The extent to which bodies are argued to be biologically determined and/or culturally constituted, and the ways in which the mind and body interrelate, are continuing debates in the social sciences (Holmes, 2007; Petersen, 2007; Schilling, 2003). Tensions between on the one hand, viewing the body as discursively constituted (post-structural theorising), or on the other hand as being materially constituted, thereby falling into essentialism has therefore frustrated feminist theorising of the body. Feminist proponents of theorising the body such as Grosz (1994, 1988) and Gatens (1988) however, attempt to bridge this divide by arguing that bodies are not simply inscribed by history and society, but operate within historical and social contexts whereby they are at once part social and part individual body. Consequently, in addition to challenging the mind/body split, they challenge the notion of bodies being separate from culture. In particular, feminist body theorists have argued that knowledge, choice and culture are inseparable from material bodies (Gatens, 1992; Gatens, 1988; Grosz, 1994; Martin, 1987; Rothfield, 1992). Gatens (1988, 1992) and Grosz (1994) argue that women are their bodies and that bodies do not stand outside culture. In their theorising of the body, therefore, our experience of our bodies is equal to and not separate from our minds (Beasley & Bacchi, 2000; Broom, 2001a; Gatens, 1988; Grosz, 1994).

Another criticism of some theories of the body is of those that focus on bodily practices as performance, as though the body is instructed by a separated mind to clothe and move through space in specific and particular ways (Howson, 2005; McNay, 1999). Included in these debates is the extent to which people's everyday practices are conscious, unconscious or pre-reflexive. Feminists interested in socially constructed (gendered) bodies

include theorising women's socially imposed bodily limitations, for example Young's *Throwing Like a Girl*, to show ways in which not only gender, but also biological sex, is at least to some extent socially constructed (Young, 2002, 1990). Young has argued a case for the embodiment of gender being such that there are biological effects of the gendering of women's bodies, using the example that women at an early age learn to "throw like a girl" because of social rather than biological influences (Young, 1990). Young's analysis blurred the boundaries between what was previously theorised as a binary division between biological sex and socially inscribed gender to show that biology can also be determined by the social.

Feminist theories of the body, or theories of embodiment, are directly relevant to this thesis because bodies live in social contexts and are indeed what constitutes the social (Beasley & Bacchi, 2000). The focus of this thesis is breast cancer, for which medical treatment – including surgical, chemical and radiological - have direct effects on women's material and social bodies. Theorising the body in the context of breast cancer involves the intersection of a range of complex and contradictory social meanings that are largely defined by patriarchal sexist cultures (Cromptoets, 2006; Young, 1992). Breasts are at once a site that represents (at least) womanhood and potential motherhood, woman's sexuality, an object of desire, and danger (for their potential for disease) (Bartlett, 2002; Broom, 2001b, Cromptoets, 2006; Young, 1992). As Young (1992 p. 215) states: "For her and for others, her breasts are the daily visible and tangible signifier of her womanliness, and her experience is as variable as the size and shape of breasts themselves."

Furthermore, participation in physical activity also involves the body and its promotion incites a range of socially constructed moral and gendered meanings: body beautiful; bodily control; bodily strength and fitness; bodily suppleness; body health. Physical activity, as described above, can also be viewed as a bodily attempt to resist patriarchy (Fullager, 2003; Shaw 2001; Wearing, 1990).

Broom (2001b), in her quote below, epitomises the intersection of a range of

socio-cultural meanings of breasts, including what she views as an ongoing stigmatising effect of breast cancer surgery/ies that are perhaps not so apparent for other types of surgery:

After the hip replacement, I was eager to get back to swimming as soon as the wound healed, and it never occurred to me that I should wait until I was off crutches or to conceal the dramatic half-metre scar that arcs up my thigh onto my hip. I've been going to public pools all my life, and I long ago abandoned the pre-pubescent modesty that compels young girls to change in a cubicle or under a towel. But when I was ready to return to the pool after the breast surgeries, I found myself hesitating to walk around the changing room as I had before. Unlike the scar on my hip, these wounds were somehow shameful or obscene. I suddenly realized that in all my years of seeing other women's bodies in these changing rooms, I had never seen a woman who had a mastectomy or other damage to her breast. (Broom, 2001b:254)

Broom's quote suggests that in spite of, or perhaps as a result of, 20 years of breast cancer awareness raising, the corporeal damage to breasts resulting from breast cancer treatment/s is largely invisible, and as Broom argues, remains socially unacceptable. Broom's quote is important for this study because if women are feeling that they should avoid exposing their damaged breasts, there are social implications for their physical activity participation that go beyond practical social constraints such as child caring responsibilities.

Therefore, this study engages with theories of the body and endeavours to keep the body in the frame. There is a range of ways in which the body may be theorised and below I describe how theories of the body will be used in this thesis.

### **Theorising the body and public health**

In the literature reviewed above, part of the problem of promoting risk/protective factors as the dominant health promotion strategy in regard to physical activity is that the underlying assumption is that people can, and perhaps will, make rational choices to change their everyday/everynight lives, once they are informed about what medical or epidemiological evidence says is risky or healthy behaviour. Thus, an assumption of a separation of mind

and body, stemming from Cartesian dualism remains inherent in health promotion lifestyle discourses in their expectation of a rational response to risk whereby the mind is separate from and able to control the body. In this interpretation, individualist approaches to health promotion commonly used in physical activity promotion assume people are able to stand outside their bodies (Beasley & Bacchi, 2000), and likewise their social environment/s, to make healthy choices.

Theorising the ways in which both agency and structure operate through individual material bodies and the broader “social flesh” (Beasley & Bacchi, 2000) and how socially determined constructs such as gender are contested and dynamic (Broom, 2008) is central to understanding how people respond to health promotion messages. Research into lay theorising has shown how people interpret health promotion in terms of their social contexts (Backett-Milburn *et al.*, 2006; Backett, 1992b; Lawton, 2002; Popay & MacDougall, 2007). Theorising the body offers potential for understanding *how* and *why* people respond in the ways that they do (Williams, 1995). Thus, theorising the body, through examining its place in lay theories of health and illness, offers potential alternatives to focussing on “lifestyle” approaches to health promotion. A focus on the body enables an exploration of how factors such as class and gender are embodied and why they influence the ways in which health-related knowledge is interpreted and actioned (Williams, 1995). Williams (1995) suggests that Bourdieu’s Theory of Practice offers some useful tools for understanding health behaviours by exploring embodied intersections between class, health and lifestyle. While Williams does not include gender in his analysis, for the purposes of this thesis, theorising the embodiment of gender and class together is crucial because these dimensions cannot be separated one from the other (Broom, 2008; Young 1992).

A determinants approach to women’s health emphasises the effects of socially determined inequitable distribution of power and resources (or different forms of capital) on people’s health (Baum, 2008; Keleher, 2009a). Bourdieu’s conceptualisation of embodiment is therefore useful for exploring



how the women in this study respond to messages about health benefits of physical activity in terms of how and why they interpret messages in the ways that they do and how and why they action them.

### *Bourdieu's Theory of Practice*

In the Bourdieusian sense, embodiment is a dynamic process whereby the *habitus* internalises socially determined practices and dispositions, including gender, class and culture, and that all knowledge and experience is embodied and interpreted through the *habitus*. Bourdieu's definition of embodiment uses a dialectical relationship between body and society, with the addition of history, to his concepts of *habitus* and *field*. Bourdieu's theory of practice offers ways of thinking about embodiment as a dynamic, historical process, by maintaining two-way connections between structures and agents (Bourdieu, 1977, 1990). Unlike Foucault's notion of "docile bodies", on which socialised norms such as gender and class are inscribed (McNay, 1999), Bourdieu defines the *habitus* as being "embodied history, internalised as a second nature and so forgotten as history – is the active presence of the whole past of which it is the product" (Bourdieu, 1990, p56). Bourdieu's theory of practice draws on a combination of Marx, Mauss, Weber and Durkheim (Lechte, 1994; Mahar, Harker & Wilkes, 1990). Bourdieu's concept of habitus is indebted to Mauss, who recognised that "because social facts are only manifest in individuals, society is in the individual as much as, or even more than, the individual is in society" (Lechte, 1994).

Bourdieu's theory of practice purports that people are born into an existing society (made up of a range of *fields*, for example the political *field*, the religious *field*) with an historically produced specific range of *capital*. The social order is historically constituted and reproduced, over time, through people's bodies (*habitus*), as social agents that reproduce the *fields* and thus the social order (Bourdieu, 1990; McNay, 1999). People within any given society embody a range of knowledges from the different *fields*, including how to move in their bodies, and how to practice social (cultural, classed and gendered) norms (Bourdieu, 1984). The bodily internalisation of social norms (interconnected with multiple *fields*) can perhaps be best understood as an

ongoing process which simply goes unnoticed as “second nature” or “a feel for the game” (Bourdieu, 1990 p66; Williams, 1995). In the Bourdieusian sense, gendered identity is practised through material bodies (McNay, 1999).

Criticisms of Bourdieu include that he did not sufficiently theorise gender (Skeggs, 2004), and that his Theory of Practice is overly deterministic (Lawler, 2004; McNay, 1999). Lawler (2004), argues that his theorising should be viewed as pessimistic regarding the extent to which individuals can influence social structures rather than deterministic. Feminists have theorised the embodiment of gender more thoroughly and in more conceptually nuanced ways than Bourdieu did himself in *Masculine Domination* (Adkins, 2004; Kraus, 1993; Lawler, 2004; McNay, 1999; Warin and Davies, 2008; Bourdieu, 2001). Thus, he provided critical sociological tools that some feminist scholars have applied in a range of ways over the last decade and a half. Feminist theorists have used a Bourdieusian understanding of embodiment to argue that gender identity can be viewed as embodied as a durable yet not immutable social norm (McNay, 1999, 2003). Thus, gender can be conceptualised as a dynamic dimension of people’s lives, along with class and culture (Broom, 2008) that is socially constituted within material bodies.

Bourdieu’s Theory of Practice is not entirely deterministic as he also offers a way of theorising how transformations resulting from a crisis occur within broader social contexts, by involving tensions between *habitus* and *field*. Bourdieu’s concept of a crisis occurs in “periods in which *habitus* fall out of alignment with the fields in which they operate, creating a situation in which ‘belief in the game’ (*illusio*) is temporarily suspended” (Crossley, 2003 p44). Crossley argues that the subsequent disruption of *illusio* can be maintained after the crisis, using research on people involved in social movements as an example (Crossley, 2003). The notion of transformation after a crisis could provide insights into whether the women in this study transformed the extent to which social structures influenced their participation in physical activity after their breast cancer diagnoses.

### *Definitions of embodiment*

In addition to Bourdieu's definition of embodiment, a range of concepts of embodiment are drawn upon in this thesis. While the terms embodiment or embodied knowledge are often used in health and illness literature, they are not always clearly defined. The phenomenological definition of embodiment is "the idea that body is not simply an object controlled by mind, that we are our bodies and that body and society exist in a dialectical relationship" (Thomas-MacLean, 2004a p630). The term embodiment (of bodily processes including but not limited to illness, for example pregnancy and childbirth) has been used in phenomenology and feminism to move away from medical interpretations of bodies and their subsequent medicalisation (Thomas-MacLean, 2004a).

The concept of *embodied experience* is used extensively in phenomenological studies, including those on women's embodied experience of breast cancer (Langellier & Sullivan, 1998; Thomas-MacLean, 2004a, 2005). Phenomenology is grounded in the subjective, lived experiences of concrete bodies, from which it interprets material consequences of social constructions (such as gender, class, ethnicity) (Uhlmann & Uhlmann, 2005). Embodied experience of illness refers to subjective accounts of people who have experienced illness, and how their illness experiences modify their everyday lives. Embodied experience contributes to and shapes embodied knowledge (Fosket, 2000).

*Embodied knowledge* incorporates all forms of information that become internalised in memory: social practices, emotions, texts, sensations (Ignatow, 2007). Embodied knowledge is the knowledge that people draw on in order to respond to any social situations, or to make decisions, for example. Here, Fosket's example of the knowledge women draw upon when they are first diagnosed with breast cancer is useful.

[W]omen often turn to their present store of information about breast cancer, whatever that may be. Knowledge may be drawn from experiential resources such as interactions or past experiences with family, friends, or other women with breast cancer... Women also describe drawing knowledge from information gathered through media

or biomedical information gathered from any number of sources (Fosket, 2000 p22).

Embodied knowledge, viewed in this way, is eclectic and accumulative and is drawn upon and interpreted and filtered as required.

Krieger's definition of *embodiment* for use within epidemiology, which suggests a Bourdieusian influenced historical element, could be useful in the context of this thesis because the health effects of people's social and environmental contexts are evident:

A concept that refers to how we literally incorporate, biologically, the material and social world in which we live, from in utero to death; a corollary is that no aspect of our biology can be understood absent knowledge of history and individual and societal ways of living.

Epidemiologically, "embodiment" is thus best understood:

- (1) As a construct, process, and reality, contingent upon bodily existence;
- (2) As a multilevel phenomenon, integrating soma, psyche, and society, within historical and ecological context, and, hence, an antonym to disembodied genes, minds, and behaviors;
- (3) As a clue to life histories, hidden and revealed; and
- (4) As a reminder of entangled consequences of diverse forms of social inequality (Krieger, 2008 p225)

Kreiger's definition of embodiment is explicit in showing how people embody their whole environments. In this view, people cannot be considered as separate from their social or material worlds, illuminating how attempts to understand behaviour on its own (or any other single part of the whole picture of health) are understandably inadequate. Thinking about health promotion in this way suggests that how people respond to health promotion messages needs to be considered within the whole context of their historical social and ecological worlds. Applied to health promotion practice, therefore, this concept of embodiment potentially provides a way of synthesising the different models of health promotion described above.

#### *Embodied expertise*

Brown *et al* (2004) developed the term *embodied health movements* to describe a particular type of health movement made up of activists who mobilise to challenge mainstream biological science regarding causation,

prevention, diagnosis and treatment. The authors define embodied health movements as being different from other health movements in that:

1) they introduce the biological body to social movements, especially with regard to the embodied experience of people with the disease; 2) they typically include challenges to existing medical/scientific knowledge and practice; and 3) they often involve activists collaborating with scientists and health professionals in pursuing treatment, prevention, research and expanded funding (Brown *et al.*, 2004 p50).

The authors view embodied health movements as blurring “the boundaries between lay and expert forms of knowledge, and between activists and the state” (2004 p54). They used the environmental breast cancer movement, which is primarily made up of women who have/ had breast cancer who have a “lived perspective that is unavailable to others” (p56). This use of a synthesis of lay theory and embodiment with activism fits well with the new public health, which has its origins in 1960s protest movements (Broom, 1991; Shuttleworth & Auer, 1995).

Potts (2004b; 2008) uses the term *citizen expertise*, defining it as being grounded in embodied, situated knowledge. She refers to women who have/ had breast cancer as having “embodied expertise in relation to risk” because, drawing on a statement of one of the activists, women’s bodies that have/ had breast cancer are “the body of evidence” (2004b p141). Potts contends that making use of *embodied expertise* has the “transformational vision” to potentially “produce a new social contract for epidemiology, and to remedy the features of the physical, political, economic and social environment that causes breast cancer” (Potts, 2004b p143). Here, Potts is calling for epidemiological endeavour to extend its interest in modifiable causes of breast cancer from women’s behaviour/lifestyle to include other socially and politically determined causes. Potts’s analysis of embodied expertise is important to this study for theorising how the women’s experiences of breast cancer in the study sample influence their responses to physical activity promotion messages and lifestyle health promotion more broadly.

## ***Conclusion***

In this review, I have demonstrated the public health importance of exploring ways in which women who have/ had breast cancer may be enabled to participate in regular physical activity. Exercise intervention studies unequivocally show that participation in physical activity ameliorates a range of adverse health effects of breast cancer treatments. The evidence is clear, however, that there are inequities in physical activity participation rates across populations, and that women with dependent children are one of the least active groups with the least amount of free time within all population groups.

Recent studies give some indication that following a breast cancer diagnosis, women (and potentially their family and friends) may be more likely to want to take on health promoting practices. There is limited evidence in the feminist leisure theory literature that suggests that a change in health circumstances (such as chronic illness, including breast cancer) may be a catalyst for women resisting gendered roles by ensuring their own participation in leisure (which may or may not include physical activity). Giddens's (1991) concept of the fateful moment supports this suggestion; that there is the potential that women may review and change their everyday/evernight routines following a breast cancer diagnosis as a sudden and disruptive event. Although, in this view, there is an assumption that women are individual agents who can make such changes outside their social contexts. Bourdieu, in utilising the *habitus*, brings in structure, enabling an exploration of the dialectic between agency and structure that operates internally – within material bodies. Such an approach potentially helps to examine critically the ways in which simple instruction to behave in particular ways does not work on its own, as demonstrated by lay theorising, and reveals the possibilities of alternative, or additional, approaches to health promotion that include a Bourdieusian concept of embodiment (Williams, 1995). In agreement with Broom's (2001) assertion that public health research and practice commonly excludes the body, in this thesis I strive to keep the body and its connection to the social in the picture throughout.

This literature review has provided a backdrop from which to examine critically how women who have had a breast cancer diagnosis while mothers of dependent children respond to health promotion messages, both in their views about physical activity promotion messages and in their accounts of their own participation in physical activity.

Based on the literature that I have reviewed, it follows that I take a methodological approach that is likely to draw out women's embodied experience of breast cancer in the context of their daily lives in order to understand how they respond to health promotion messages. In the next chapter I present my methodology, which includes a theoretical justification of my study methods, building on the lay, feminist and critical theoretical approaches that I have outlined in this chapter.





## **Chapter 3: Methodology**

### ***Introduction***

In this chapter I build on the theoretical perspectives, developed in the previous chapter that informed my methodology and enabled the design of a study to address my research questions. The epistemological foundations outlined in the previous chapter and on which this thesis is based are largely informed by feminist and critical theories (Crotty, 1998; Patton, 2002; Travis, 2001). Reflecting this, the study is designed to firstly elicit and to listen to women's accounts of their everyday/everynight lives in the context of having/had breast cancer. Secondly, applying a critical feminist epistemology is intended to enable an analysis of ways in which the women reveal, through their accounts, the social structures in which they live. My dual aims in this study are to examine social structures that continue to impact on women and to use this knowledge to suggest strategies for health promoters to consider, in their efforts to enable women who have/ had breast cancer to participate in regular physical activity. The critical purpose for this research is therefore to explore possibilities for change (Baum, 2002; Crotty, 1998), based on what women have to say about their experience of breast cancer as it relates to participation in, and feelings and views about, physical activity. Based on the literature reviewed in the previous chapter, physical activity improves several health outcomes for women who have/had breast cancer. Therefore this study is designed to explore how women with breast cancer may be enabled to participate in regular physical activity.

This chapter is structured by first of all reviewing the literature that informs the study design. I include a description of how this study deals with issues such as voice in feminist research and methodological rigour. I then outline the study methods and processes, including ethical considerations, and go on to describe the methods of analysis.

### ***Feminist research principles and methodological rigour***

The critical feminist methodology that I apply in this thesis is underpinned by a feminist social constructionist approach, in that I endeavour to reveal the ways in which the women's accounts of their everyday lives are socially constructed (Bacchi, 1999). Social constructionist epistemologies emerged in the 1960s as part of broader social, political and philosophical movements when scholars from a range of disciplines, including radical science, began to challenge presumptions about the objectivity of scientific knowledge (Bacchi, 1999). Berger and Luckmann (1971) were among the first sociologists to systematically theorise the extent to which knowledge is socially constructed.

Social constructionists reveal the ways in which social and political understandings of reality are dependent on the perspective of particular agents from different social groups (Bacchi, 1999). In this way, they can highlight the ways in which social problems are viewed differently from different perspectives but are not compelled to suggest changes that could reduce inequities between social groups (Crotty, 1998). Simply using a social constructionist approach, therefore, does not necessitate an agenda to bring about change to the social and political status quo. Feminist social constructionism leans more toward critical feminism in that there is a political agenda motivating the exposure of the ways in which everyday life is constructed (Bacchi, 1999). The use of social constructionism in this thesis does have the intent to reveal ways in which gender and class operate in the women's everyday/everynight lives, with the purpose of examining how unequal power relations could change.

### **Feminist research principles**

Feminist research has evolved since the 1970s, in response to disenchantment with the ways in which research was conducted within science and medicine. This was in part because of the expectation that sociological and medical research be objective - that is, assuming that researchers were able to separate themselves from their own embodied ontology and values. At the same time, research participants were separated

from the context of their lives. Feminists began to question whether an expectation of objectivity was even attainable (Oakley, 1981; Olesen, 2005; Smith, 2005). At that time feminist and qualitative researchers more generally were struggling to have their research viewed as legitimate by powerful, patriarchal institutions, particularly medicine and sociology (Harding, 1991; Oakley, 1981). Over the last twenty years, qualitative research has become viewed as credible and necessary for exploring complex social phenomena and it is increasingly common for public health research to include either or both quantitative and qualitative methods (Baum, 1995, 2002). While social researchers are now less inclined to claim objectivity, ontological debates continue:

Complexity and controversy characterize the qualitative research enterprise: the nature of research, the definition of and relationship with those with whom research is done, the characteristics and location of the researcher, and the creation and presentation of knowledges. (Olesen, 2005 p238)

The research methodology for this thesis is influenced by feminist theories which are derived from a history of emancipatory research that has its roots in the Women's Movement (Smith, 2005) and in particular, the Women's Health Movement (Olesen, 1994). In relation to health research, Travis and Compton (2001 p314) argue that:

In many cases, the conceptualization of a problem reflects the world view of those who are already most privileged. Thus, solutions are likely to focus on interventions that will have minimal impact on the social and political structures that protect that privilege. Feminist philosophy helps uncover potential hidden interest and power by asking whose interests are served in the conceptualization of a problem or in intervention approaches.

Travis and Compton's statement reflects the epistemological underpinnings of feminist standpoint theorists (see 1991; Harding, 2004; Smith, 2005), in that the experience of being a member of a marginalised group promotes a propensity for being more reflective and more able to see ways in which power operates. Standpoint theory has been criticised for essentialising women as being inherently or naturally more able to be reflective because of their subordinate position in society (Bryson, 2003). Smith's "women's standpoint", however, shifts from essentialising women as better placed to be

reflective toward a critique of the everyday/everynight work that women do in the context of a set of “ruling relations” which she defines as:

...that extraordinary yet ordinary complex of relations that are textually mediated, that connect us across space and time and organize our everyday lives - the corporations, government bureaucracies, academic and professional discourses, mass media, and the complex of relations that interconnect them. (Smith 2005 p10)

Smith views our everyday/everynight lives as being shaped by the ruling relations, an influence that is revealed through the discourses of research participants as well as by texts (printed or other media such as television). Smith uses the term ruling relations rather than other structurally orientated terms such as patriarchy to demonstrate the complex nature of social systems that may include patriarchy as one element of power.

The methodology for this study therefore takes as a starting point that unequal power (and knowledge) relations exist in society and feminist research can “reveal otherwise hidden mechanisms of power and privilege that maintain the oppression of particular groups of people based on sex, class, race, ethnicity, age and disability” (Mackenzie, 2007 p107).

### **Voice and feminist research ethics**

To operationalise lay and feminist perspectives, it is of particular relevance to this research to negotiate the contested notion of voice in feminist research. Thomas-MacLean states, “women speaking for themselves, about their experiences, can contribute much to knowledge about the complexity of life after breast cancer” (Thomas-MacLean, 2004a p629). It is crucial that women's voices are included as part of the research effort into breast cancer (Blaxter, 1983; Wilkinson, 2000). However, there is a tension between ensuring an insightful analysis of the data and simply including voices as they appear in the transcripts. As Janice Morse has stated (2003 p892), it is essential qualitative researchers do not fall into a fear of:

actively interrogating these data, systematically challenging alternative theoretical and participant explanations, working reflexively between data and the analysis, and using the ongoing analysis to guide sampling. Similarly, by refusing to synthesize data or to take results to the conceptual level, some researchers report what participants said

one by one, in endless lists of quotations. Thus, although “giving participants voice,” they are at the same time muffling their own informed commentary. This research is often so undeveloped that the researcher’s analytic work is neglected or omitted, and the results appear as *transcription*, not research.

Key to the dilemma of voice is framing women’s dialogue – which quotes or pieces of transcript are chosen and which are left out by the researcher are decisions that mean the women’s voices cannot be heard outside the power relations embedded in the research endeavour (Olesen, 2005). Thus, the only way that women can speak in their own voice, or at least in the voice they wish to have heard, is through autobiography (words, art or other media), and there have been a number of powerful accounts by women who have/ have had breast cancer (for example Ehrenreich, 2001; Lorde, 1980; Matuschka; Rollin, 1976/2000; Wadler, 1992/1997). Crucially, power relations are embedded in talk, which is always spoken in the context of the social fields to which the speaker has access.

Related to the dilemma of voice is how to deal with what women say about their experience/s when it does not fit with feminist principles. Kitzinger and Wilkinson (1997) use examples from their research on women’s experience of breast cancer. They ask (1997 p567):

What does it mean to ‘validate’ the experience of a woman who says she believes she has breast cancer because she chose not to breast feed her child, that her breast cancer is a punishment for past sins, and that her post-mastectomy body is mutilated, deformed and ugly? How are we to address the experience of such women, which does not fit our (feminist) theoretical frameworks?

Viewed in this way, representing women’s views as “data which ‘speak for themselves’” does not “constitute feminist research” (1997 p568). In this study, I work with the tensions involved in, on the one hand listening to women, while on the other hand applying a critical analysis to tease out embodied social constructions, or in other words, by identifying the social filters through which people speak (Cromptoets, 2006).

### **Voice, lay theorising and embodied expertise**

The concept of lay knowledge can provide a useful way of thinking about

voice, because lay knowledge presupposes the influences of the socio-cultural and temporal contexts in which knowledge is formed. “Lay knowledge reflects how we make sense of our world at any particular time and in any particular place” (Popay & MacDougall, 2007 p71). As such, lay knowledge expressed in talk reveals the relationship between Bourdieu’s *habitus* and *field/s*, because “in its structure and use language is one of the central vehicles of habitus” (Hanks, 1993 p139). Examining lay knowledge is essential to the process of illuminating structural roots of individual health promoting (or not) behaviour/s (Popay & Williams, 1996). In relation to women's accounts of their everyday/everynight lives, lay knowledge is crucial to understanding how they think about health and illness, and for this thesis, how they think about the promotion of, and their participation in, physical activity (Backett *et al.* 1994; Popay & MacDougall 2007; Popay *et al.* 2003 Popay & Williams 1996).

Advocates for the importance of lay knowledge worked hard at achieving its validation within the sciences as *knowledge* rather than *beliefs* (Popay & Williams, 1996). Popay and Williams (1996) note that key to the struggle for lay experts to have their knowledge validated is the devaluation of women's knowledge, identifying women as “the informal guardians of public health” (p 765) and stating that:

The fact that it is women who are often at the heart of lay action for health further re-enforces the tendency for professional scientists to discount lay knowledge (1996 p765)

In this study, in addition to lay knowledge, I use the term “embodied expertise”, defined in the previous chapter and derived from Potts’s “citizen expertise” and Brown *et al*’s “embodied health movements”. They argue that women with breast cancer are experts in the experience of having breast cancer (Brown *et al.*, 2004; Potts, 2004b). While Potts and Brown directly refer to women with breast cancer being activist in lobbying to have their embodied expertise heard as legitimate knowledge, the term is relevant for all women who have had a breast cancer diagnosis (including those involved in this study). That is not to say that the women’s embodied expertise is more or less legitimate than medical expertise, rather that it is legitimate

knowledge developed in specific socio-cultural context/s. In this study, I draw on principles of feminist and lay research to ensure that the methods integrate with the research goals and to gain high quality data.

### **Methodological rigour and reflexivity**

The concept of rigour is contested in qualitative research. While the concepts of validity and reliability are basic requirements for rigour in quantitative research, qualitative researchers have developed techniques to address the “complex interplay of the observer and the reality of what they observe” (Ezzy, 2005 p. 34). Oakley contends that methodological rigour includes clearly stating the aims, methods and sample selection of a particular piece of research, and the ethics of doing it. She places the emphasis on transparency and honesty (Oakley, 2004). Ezzy (2005) outlines specific techniques that can be applied to a qualitative research endeavour to ensure rigour including (2005 p. 33):

theoretical rigour, methodological rigour, interpretative rigour, triangulation, evaluative rigour (including ethical and political considerations), and rigorous reflexivity (which examines the role of the researcher in the research).

The steps I have taken in this study to achieve theoretical rigour include stating my study aims and research questions (Chapter One), explaining the theoretical position of the study, and ensuring that the study methods are integrated with the research goals. I return to a discussion of theoretical rigour at the end of this thesis, as theoretical rigour relates to the ways in which analysis is supported by evidence from this study and the literature (which then includes theoretical triangulation). In this chapter, I explain in detail how the study was conducted, in order to demonstrate methodological rigour.

My approach to interpretive rigour begins by explaining clearly how I analysed the interviews, and by including “plenty of direct quotes” (Ezzy 2005 p39) from the broadest range of interviews possible, while balancing this with my own analysis (Morse, 2003). Secondly, I applied interpretive rigour as part of my research process, by checking my interpretation with the advisory

group (see below) and by sending my analysis to research participants for comments, and through usual university processes of supervision meetings and seminar presentations (part of the university assessment process). These latter steps also assist in ensuring triangulation (Fontana & Frey, 2003). Triangulation in qualitative research means attempting “to secure an in-depth understanding of the phenomenon in question” (Denzin & Lincoln, 2005 p5). There is a range of different approaches to achieving triangulation, including using multiple methods, more than one researcher analysing the data (which is challenging for a PhD study that is not part of a team managed project), and applying different theoretical lenses to the data (Atkinson & Delamont 2005; Denzin & Lincoln 2005; Ezzy 2005).

Research is an inherently political endeavour, which produces real consequences for the people involved in the research (Ezzy, 2005). Later in this chapter, I describe the procedural dimension of obtaining ethics approval from the organisations involved in the research; the university and the organisations which assisted with recruitment of participants. I have discussed dilemmas of an ethical and political nature above, particularly in relation to voice. Below, I explain the importance of rapport in interviewing women, particularly when the topic is expected to be sensitive.

Qualitative research requires researcher reflexivity. One way that I increase reflexivity is by using first person, so that my role as the researcher is clearly in the frame. I clearly state my own critical feminist position in this research endeavour, thus being honest about my own particular political position. I maintained a journal to record reflections and decisions about the study process over the course of the PhD study. Finally, throughout this thesis, I include reflections on the research process, beginning with the following section which explains my research methods.

### ***Study Methods***

The methods of this study are underpinned by my critical feminist theoretical grounding described above. The study is based on reflective research principles, which include taking steps to ensure that the women could be



involved in the research from the outset, as described below. I use qualitative methods so that my analysis answers the research questions by including the complexities and ambiguities inherent in what women have to say about living their bodies, both through their experience of breast cancer and in various physical and social contexts of their lives (Baum 2002; Kvale 1996; Thomas-MacLean 2004).

Interviewing women with breast cancer requires an engaged, sensitive, reflective approach on the interviewer's part to elicit more meaningful, in-depth responses from the women (Baum, 2002; Oakley, 1981). I expected the experience of breast cancer to be a sensitive and personal interview topic and that, as for most in-depth interview processes, it would be particularly important to build rapport and trust with the women (Oakley, 1981; Thomas-MacLean, 2005). Like the objectivity/subjectivity divide, in more recent feminist research, a major break from Oakley's early work is to understand that there is a difference between ordinary friendship and the relationship between a researcher (interviewer) and research participants (interviewees). While the line between objectivity and subjectivity is arbitrary, as mentioned above there is a distinct power difference between those who are doing research and those who are being researched. Therefore, I would not presume that the friendliness between the women I interviewed and myself could be called "friendship". Having said that, at times I felt that I would under ordinary social circumstances have enjoyed a friendship with many of the women, and we did enjoy cups of tea and some laughs and tears (sometimes mine) in the interview process.

In brief, four main methods were used in this study:

- 1) Two small group interviews with 1) two women who have/ had breast cancer and 2) people involved in the care or support of women who have/ had breast cancer. The purpose of the small group interviews was to refine an in-depth interview guide and to assist in establishing a critical reference group.
- 2) In-depth interviews with 36 women who have/ had breast cancer and were mothers of dependent children at the time of diagnosis. The in-

depth interviews formed the central part of the original research for this study and were key to answering the research questions.

- 3) Establishment of an advisory group comprising women who have/ had breast cancer and professionals involved in the care/support of women with breast cancer and/or health promotion policy development. The purpose of the advisory group was to guide the research, to explore possible action/s based on research findings, to ensure that a broader group of people concerned with a detailed understanding of breast cancer could contribute to the research and its dissemination and to increase researcher reflexivity.
- 4) Analysis of health promotion sources (organisations) and materials (information) identified by the women to provide insight into the information the women were responding to.

### **Purposive sampling method**

My research questions represent an inquiry into the lives of a particular group of women, with a focus on how women may include participation in physical activity at a level that provides them health benefit, without simultaneously causing them harm. My focus on women who have/ had breast cancer is, as detailed in Chapter Two, related to evidence that physical activity is particularly helpful for this group of women.

Thus far, conceptualisations of breast cancer rarely reflect the world view of women who actually have (or have had) breast cancer themselves, in particular, those who are mothers of young children (Gould *et al.* 2006; Langellier & Sullivan 1998; Potts 2004a; Thomas-MacLean 2004). The sample in this research assists in redressing this gap.

The sampling approach used in this study was constructed in order to answer my specific research questions (Ezzy, 2005), supported by Janice Morse's argument that:

One common error is to first seek the average, typical, or usual instance of the event, rather than purposefully sampling the best case. [...] Selecting the ordinary, rather than the extraordinary or the best examples, means that the characteristics of the phenomena being

studied do not stand out but, rather, are merged with other “noise.” It means that the researcher must then struggle to sort out what he or she is actually studying from the surrounding confusion, sifting and sorting what is or is not actually a part of the category or concept (Morse, 2003 p891).

For this study, I recruited a purposive sample of women who, based on evidence I reviewed in Chapter Two, were most likely to reveal gender-based constraints and enablers for physical activity, in the context of having, or having had, breast cancer. That is, women who have dependent children, (particularly children younger than 12 years old) are one of the least active groups in Australia (Australian Bureau of Statistics 2006; Australian Bureau of Statistics 2002; Bauman *et al.* 2002; Brown *et al.* 2001). At the same time, I purposefully sought “outliers” (Ezzy, 2001), which in the context of this study means women who were most and least likely to participate in physical activity, and/or to have diverse views about the promotion of physical activity. The sample includes women involved in dragon boat paddling and the Young Women’s Christian Association (YWCA) Encore program (described below) to ensure inclusion of women who were most likely to be active. I actively sought women who were from demographic backgrounds which statistically have lower physical activity participation rates by recruiting women attending a public hospital in South Australia.

Women from both metropolitan and rural areas were recruited because of evidence of different medical treatment and survivorship rates in Australia based on location and possibly class and socioeconomic status. There is evidence that more women from rural areas have a mastectomy rather than breast conserving treatment and chemotherapy and/or radiotherapy because of the need for travel to have treatment (Davis *et al.*, 1998; Hall *et al.*, 2004b; McMichael *et al.*, 2000; Pendlebury *et al.*, 2003). I hoped this sample would reveal the extent to which treatment decisions may influence physical activity participation. For example mastectomy without chemotherapy could be an enabler, because of not feeling ill from treatment, or a barrier, because of concern that sports clothes show up mastectomy and/or a prosthetic could move or fall out (Thomas-MacLean, 2005).

The sample included women who were between six months to eighteen years post diagnosis, with most of the women being one to five years post-diagnosis (see table 1). This was to ensure the study would be relevant for current experiences of treatment and also for seeing how women may respond to physical activity information later down the track post-treatment as well as once their children were older. I expected some differences over the time period such as women being diagnosed more recently potentially experiencing 1) improvements in chemotherapy treatments meaning fewer adverse effects, 2) greater use of radiotherapy - at least for urban women and 3) more likely to have breast conserving treatment than mastectomy. I expected that women who were more than five years post-diagnosis could provide insights into women's experiences after the five-year survival breast cancer journeys because of medical evidence that regular physical activity is important for the rest of a woman's life, once she has had a breast cancer diagnosis.

The sample included women who had reconstruction surgery and women who had not. Reconstruction surgery may impede or enable physical activity participation, for example, looking the same on both sides (without fear of prosthetic falling out) may be more conducive for wearing clothes necessary for sport, and could feel more balanced. On the other hand, pain or other problems associated with extra surgery could impede activity (Cromptvoets, 2006; Thomas-MacLean, 2005).

### **Sample recruitment**

I recruited a sample of 36 women from South Australia, Victoria (including Albury-Wodonga which includes southern New South Wales) from The Cancer Council South Australia's Cancer Connect peer counselling service, Flinders Medical Centre's Lymphoedema Assessment Clinic and Breast Cancer Unit, Breastscreen Services and a breast care nurse based in Bendigo (Victoria), the YWCA Encore program, The Young Ones Leap (a Victorian breast cancer support and action group, snowballed from YWCA Encore program), Dragons Abreast Australia – South Australia and Victoria,

SA Dragons Abreast Inc., and an oncologist involved in the critical reference group. Contact people working in the organisations either posted or gave in person a flyer (appendix 4) to potential participants, based on the selection criteria as above. Some of the women were recruited through snowballing contact with other women who knew about the study (for example, women from Young Ones Leap were recruited through their association with the YWCA Encore program and/or Dragon Boat Clubs) and also through contact with advisory group members. The rationale for each group is provided below.

*The Cancer Council South Australia - Cancer Connect*

The rationale for selecting women who were peer support counsellors was based on the assumption that they were likely to be further down the track from their diagnosis and treatment, and that they had already offered to talk about their experience with strangers (Shannon & Shaw 2005).

*Lymphoedema Assessment Clinic and Breast Cancer Unit (Flinders Medical Centre)*

Women who attend the Lymphoedema Assessment Clinic have had a diagnosis of lymphoedema (swelling caused by lymph not draining effectively) of the arm adjacent the affected breast as a result of their breast cancer treatment. In Australia, a large number of women who have breast cancer treatment develop lymphoedema of the arm on the side of the affected breast (Moseley & Piller, 2002). As explained in my literature review, the actual percentage of women who develop lymphoedema is uncertain, mostly because of differing methods of measurement, including whether lymphoedema should be a subjective (whether a woman feels like her arm is swollen) or objective (circumference, fluid measurement) assessment (Hayes *et al.* 2005b; Hayes *et al.* 2005a; Moseley & Piller 2002; Pain & Purushotham 2000).

Women with lymphoedema are more likely to experience other unpleasant symptoms and poorer quality of life than women who do not have lymphoedema resulting from breast cancer treatment (Gould *et al.*, 2006;

Lane *et al.*, 2005; Loudon & Petrek, 2000). The views of women who have lymphoedema and were mothers of young children at the time of their breast cancer treatments were important, for example to find out how they managed their lymphoedema, in the context of their everyday/everynight lives.

The Lymphoedema Assessment Clinic is linked to the Breast Cancer Unit at Flinders Medical Centre, a major teaching hospital in South Australia, and women were recruited from both by the same contact person. The rationale for involving women from the Flinders Medical Centre Breast Cancer Unit is that half of all women treated for breast cancer in South Australia attend the Breast Cancer Unit. Women who attend the Unit (and the Lymphoedema Assessment Clinic) come from a range of social and demographic backgrounds. This group of women was included to assist in answering the question about links between socioeconomic status and location, and participation in physical activity. Furthermore, these women were likely to be relatively recently diagnosed, and could provide valuable insights into how women temporally closer to their breast cancer treatment/s feel about their bodies, their everyday/everynight lives and how their experience fits with health promotion messages, such as participation in physical activity.

#### *The YWCA Encore Program*

The Encore program was initially established in the USA by a woman who had had a breast cancer diagnosis, to help women rebuild their physical activity post breast cancer treatment. Eight weekly YWCA Encore programs are conducted at 40 locations Australia-wide and attendance at one course per year is free (YWCA, 2005). There is some evidence that women who have had a breast cancer diagnosis prefer guided exercise programs (Rogers *et al.*, 2004). Women who have participated in an established program for women with a breast cancer diagnosis may help to ascertain what could work for the larger population of women who have had a breast cancer diagnosis.

#### *Dragons Abreast (SA, Victoria and Albury NSW) and SA Dragons Abreast Inc*

Dragon boat racing for breast cancer survivors began as a Canadian research project called “Abreast in a Boat” in 1996 (McKenzie, 1998). In Southern Australia, there are several dragon boat teams which include women who have or have had breast cancer and their supporters. There have been a few studies which have explored women's physical experiences and psycho-social benefits of dragon boat racing after breast cancer (Courneya et al. 2001; Culos-Reed *et al.* 2005; Mitchell *et al.* 2007; Parry 2007). Women involved in dragon boat teams may give insights into what has enabled them to participate in dragon boat paddling, as well as physical activity or planned leisure more generally.

#### *Additional recruitment strategy*

In addition to recruiting women via breast cancer-related organisations, I advertised in the local newspaper in lower socioeconomic areas of metropolitan Adelaide, and published editorial pieces in two rural newspapers, the *Border Chronicle* which is circulated in the South Australian South-East region and the *Port Lincoln Times*, which is circulated in the Eyre Peninsula, South Australia. I also participated in a radio interview while in Port Lincoln with the local ABC radio station which is aired throughout the Eyre Peninsula. The more targeted approach did indeed turn out to be the best method of recruitment, as out of all the additional advertising and editorial described here, only one participant was recruited and this occurred via the *Border Chronicle*.

#### *Moving beyond South Australia*

Initially, I had planned to restrict the study to South Australian women. After several months, I found that I had not reached data saturation. South Australia has a relatively small population and just over 1,000 women are diagnosed with breast cancer annually, compared with over 3,000 in Victoria and 12,000 nationally (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006). Of these, almost 30% of the women are under 50 years old and 6% are under 40 years old (Australian Institute of Health and Welfare and National Breast Cancer Centre, 2006; The Cancer Council South Australia, Date accessed 16-10-07). Therefore, only around 300

women younger than 50 are diagnosed each year in South Australia, and fewer would have dependent children. Therefore, I expanded the sample to snowball to Victoria and Albury in New South Wales. Albury is a town bordering Victoria and shares services (for example radiotherapy) with Wodonga, a town on the Victorian side of the border.

### **Sample description**

I included a one-page demographic form with the ethics forms which I sent the women, and asked the women to complete it and give to me at the time of their interview (see appendix 5). All except one of the women returned the demographic form either at the time of the interview or soon afterwards in a reply paid envelope which I gave the women at the time of the interview in cases where they had not as yet completed it. I gained some demographic details during the course of interviews, so therefore have those details from the woman who did not return the form.

The women came from a broad range of demographic backgrounds. Seventeen women were living in rural and 19 in metropolitan or outer metropolitan locations (see table 2). The women's ages ranged from 28 to 52 years old at the time of their first breast cancer diagnosis, with a mean age of 40. The women had between one to four children, at least one of whom was dependent at the time of the women's diagnosis. Twenty-five women had between one and two children and 11 women had between three to four children (see table 2). Thirteen of the women had a University degree or higher, eight women had a certificate or diploma, five women had completed year 12 and nine women had not completed year 12 (see table 2). Ten of the women who answered the question about private health insurance status responded that they did not have private health insurance (one had extras only), whereas 25 responded that they did. I did not include a question about cultural or ethnic background in the demographic form, however most of the women talked about their cultural background during the interviews. Of those who stated they were not of Anglo-European descent, one woman was first generation Thai descent, and one woman had immigrated to Australia from Malaysia. Thirty-one women were in intimate relationships at the time of the



interview, one of whom was in a lesbian relationship. One of these was in the process of separating and one had divorced and re-partnered since her second breast cancer diagnosis. Two of the women were widowed and three of the women were either separated/divorced at the time of their interview. Thirty women completed the question on household income; one stated her household income was less than \$20,000, four women stated their household income was between \$20,001-\$40,000, five stated their household income was between \$40,001-\$60,000, six between \$60,001-\$80,000 and 15 more than \$80,001. I used household income groupings based on the South Australian Monitoring and Surveillance System (Dal Grande *et al.*, 2004). The women and their partners had a broad range of occupations which I have grouped according to the closest fit (table 2). Overall, the sample is weighted toward women from higher socioeconomic status, which is a common occurrence for breast cancer research, potentially in part because the breast cancer incidence as well as survivorship is higher in women from this group.

**Table 1: Purposive sample description – breast cancer diagnosis and treatment**

<b>Women's age at diagnosis</b>	<b>n=36</b>
25-30	2
31-35	5
36-40	14
41-45	5
46-50	6
51-55	4
<b>Year of (first) diagnosis</b>	<b>n=36</b>
1983-1987	1
1988-1992	2
1993-1997	2
1998-2002	10
2003-2007	21
<b>Treatment/s</b>	<b>n=36</b>
mastectomy	21
lumpectomy (not followed by mastectomy)	13
partial mastectomy	2
chemotherapy	25
radiotherapy	23
Lymph/axillary clearance	28
sentinel node biopsy	4
hormonal drugs or herceptin	21
oophorectomy	5
immediate reconstruction	2
later reconstruction	6

**Table 2: Purposive sample demographic description**

<b>Number of dependent children at diagnosis</b>	<b>n=36</b>
1 to 2 children	25
3 to 4 children	11
<b>Location</b>	<b>n=36</b>
rural SA	6
rural Vic/border NSW	11
Adelaide/Hills/Outer Adelaide	12
Melb/Outer Melb	7
<b>Household income</b>	<b>n=31</b>
<\$20,000	1
\$20,001-\$40,000	4
\$40,001-\$60,000	5
\$60,001-\$80,000	6
>\$80,000	15
<b>Education</b>	<b>n=35</b>
degree	13
diploma/cert	8
yr 12	5
<yr 12	9
<b>Occupation - women</b>	<b>n=36</b>
Professional	3
Health professional	4
Manager/executive	3
Project/program manager	1
Customer service/retail assistant	1
Home duties plus PT paid work	4
Home duties	6
Self employed	4
Fitness industry	2
Academic/researcher	2
Administration	4
Teacher	1
Public servant	1
Unemployed	1
<b>Occupation - partners</b>	<b>n=29</b>
Professional	6
Health professional	1
Manager/executive	5
Project/program manager	3
Tradesperson	3
Self employed	5
Fitness industry	1
Academic/researcher	1
Teacher	1
Public servant	3
<b>Private health insurance</b>	<b>n=35</b>
Yes	25
No	10

## **Ethical considerations**

I sought and was granted ethics approval for this research from the Flinders University Social and Behavioural Research Ethics Committee and the Cancer Council South Australia's Human Research Ethics Committee (see appendices for documents approved). I expected that the women's recollections of their experiences of breast cancer could be traumatic. Besides the women who participated through snowballing contact with other participants, potential participants were initially approached by the contacts from the organisations, with whom potential participants were familiar. The contacts either discussed the research project with potential participants in person or by telephone, or introduced me with a covering letter which accompanied the "invitation to participate in an interview" flyer (appendix 4). Telephone numbers for the Cancer Helpline and Lifeline were included in the Information Sheet, in case any of the women felt distressed by their involvement in the research and chose to discuss their feelings with a counsellor. All of the women stated that they read the letter of introduction and information sheet and all signed the consent forms (appendix 3).

Some of the women were invited to attend advisory group meetings to see what actions may occur as a result of their interviews, and to have the opportunity to speak for themselves over the course of the research. Women were invited, at the time of their interview, based on their health and circumstances and willingness to continue their involvement. I explained that I did not expect that the same women would attend all (or any) meetings, given other priorities in their lives. Two women attended the advisory group meetings; one at each meeting. At the completion of each interview, I stated that I would post the analysis summary and seek their comments.

## ***The study process***

### **Small group interviews**

I began my research with two small group interviews. The purpose of these interviews was to refine my in-depth interview guide, to generate discussion about the topic of breast cancer and physical activity, and to increase the

knowledge of all people involved. This method to develop interview questions has been used by feminist researchers, for example Thomas-MacLean (2005). Similarly, Smith's (2005) method of inquiry often begins by interviewing a small group of people intensively to create a standpoint from which to begin the research and to define the research "problematic". I used these ideas to refine the questions in the interview guide. This early approach to interviewing was an important contributor to my reflective research practice, requiring me to engage in critical dialogue with women and consider how to combine their insights and my research aims to develop the final interview guide.

I invited people to attend one of two small group interviews. The first group comprised two women who have/ had breast cancer and were mothers of young children at the time of their diagnosis. One woman was first diagnosed with breast cancer three years before the interview, and at the time of her diagnosis had three children; three months old, two years and four years of age. Her treatment included a lumpectomy, a second operation to remove lymph nodes and radiotherapy. The second woman was diagnosed eight years previously and had surgery and a course of chemotherapy. Her two children were eight and ten years of age at the time. The two women were selected from The Cancer Council South Australia's Cancer Connect program, which is a peer counselling service. The rationale for inviting women from this sample is 1) they would be able to draw on their own experience, as well as their experience of talking with other women who have or have had breast cancer and 2) they had already committed to talking about their experience to strangers, by choosing to be peer counsellors. This rationale is supported by other researchers who sampled women from breast cancer support groups on the basis that the women had already committed to talking about their personal experience of breast cancer with people they did not previously know (Shannon & Shaw, 2005).

The second small group interview comprised three professionals responsible for the care of women with breast cancer, and/or for the promotion of physical activity, including The Cancer Council South Australia Cancer

Support staff, Flinders Medical Centre's Lymphoedema Assessment Clinic and the YWCA Encore Program. The sample was selected from the organisations involved in recruiting women for interviews.

I held the small group interview with women first so that women who have/had breast cancer would be involved from the beginning of the main research phase of the study. I wanted to draw on the women's experience in designing the research to ensure that it would be relevant by ensuring they had the first opportunity to review a draft interview guide.

I initiated discussion by explaining the project and what my research questions and aims were (see appendix 6). I explained to the women that as I had not had breast cancer and because different women have different experiences, I wished to explore with them the best ways to ask women the questions in the draft interview guide, to ensure that the questions would be appropriate and useful. I asked the women to tell me how they felt about the questions in terms of whether they thought I could ask them in different ways, whether I had left anything out, or whether they thought I ought to leave something out. I had grouped the interview questions under more general questions for discussion (appendix 6).

Based on other researchers' experience who emphasised that women who have/had breast cancer prefer to discuss their experience of diagnosis and treatment before moving on to the specific research topic (Thomas-MacLean, 2004a), I specifically asked the women whether they agreed that this question should come first in their view, and they confirmed that it should:

*I think it's a good place to start. It sets the groundwork - where we came from...what happened...you could have a couple of hours just on that...you may need to contain it! (Jane).*

In the second small group interview, I explained the project to the participants, including a synopsis of what the women in the first small group interview said was important to them. I asked participants to again review the questions, which already included changes (highlighted in colour) made by

the women, based on their experience of working with women who have or have had breast cancer.

I reviewed the in-depth interview guide by editing my original questions, plus adding questions developed from my involvement in the two small group interviews. See appendix 7 for the final interview guide.

### **In-depth interviews**

This part of the study addresses my main research question: *how do Australian women who had young children at the time of their breast cancer diagnosis, receive and act on information about health benefits of participation in regular physical activity?* Interviews with women also revealed the sources from which they gain information about physical activity and constraining and enabling factors contributing to their participation.

Fifty-five women from the sample described above contacted me over a period of 12 months, by returning the tear-off slip on the flyer in a reply-paid envelope, by telephone, or by email in response to being sent or given a flyer. I contacted the women in the way that they indicated as their preference (telephone or email) and after a brief conversation in which I explained the interview process and they described how they fit the purposive sample (ages of children, basic demographics) I invited them to attend an in-depth interview. Of the women who contacted me, 36 women made an interview time and participated in their interview as planned. Eleven women did not make a time for an interview following their original contact and my return phone message or email invitation to contact me to discuss the interview process. I did not follow up to remind women to contact me or to find out why they did not make a time since their participation was intended to be voluntary. I also felt that the experience of breast cancer is traumatic enough without a researcher pursuing them for an interview. However, regarding one of the women who returned a flier, I was subsequently informed by her partner that she had become extremely ill and he did not think she was well enough to be interviewed.

I reached data saturation after 36 interviews as no new themes relating to the research questions emerged and I had achieved interviews with women from the broadest available range of demographic backgrounds among the women who responded as per my purposive sample. Because the women contacted me over a long time frame, I had the opportunity to analyse interview transcripts and audio recordings in between conducting further interviews. This enabled me to work out at what point I had achieved saturation by ascertaining whether I still required women from my purposive sample who may provide new information. Therefore, I had not already made times with all women who contacted me, so I contacted the remaining eight women by their preferred contact method and follow-up letter to thank them for volunteering to be interviewed and to let them know I already had interviewed the number of women I needed for the study. I also asked them whether they would be willing for me to contact them should I need to interview more women after all, within the following three months, to which they all agreed. All interviews were arranged at a time and place preferred by the women. In South Australia, I interviewed most of the women in their homes. I also interviewed three of the women in their place of work, one woman in her parents' house while she was in Adelaide for doctors' appointments, and one woman in my home because she lived in the country and was in Adelaide for a few days, and one woman I interviewed in a park. In Victoria and Albury, I interviewed five women in their homes, eleven in the accommodation in which I was staying and two women chose to be interviewed in a park. I wrote thank you letters to all interview participants and enclosed Coles-Myer gift vouchers to the value of AUD\$20.00 to cover any expenses they may have incurred as a result of their participation (e.g. travel time, child care).

### *Interview method*

My feminist approach to interviewing is based on Oakley's (1981) *Interviewing Women*, where she argued that traditional positivist interview techniques require interviewers to be objective, rational and detached. Oakley insisted that the then dominant masculine approach is not at all



useful when interviewing women. Instead, she argued that “when a feminist interviews women” the use of such practice is “morally indefensible” (1981 p41). In addition to Oakley’s approach, Kvale’s (Kvale, 1996) traveller metaphor offers a style of interviewing I have chosen to best fit this study. Kvale identifies two metaphors of the interviewer; the “miner” and the “traveller”. The interviewer-miner understands knowledge as buried metal, which must remain (or become) pure through the entire process of interviewing, transcribing and analysing. The interviewer-miner assumes that the interviewee’s experiences are static, and can be uncovered carefully by, for example, by avoiding leading questions (Kvale 1996). In other words, the raw data embedded within the interviewee holds a kind of unchangeable, given truth that the interview-miner need only locate. The interviewer-traveller on the other hand, engages in conversations with the people. The traveller encourages people to tell their stories, interprets the stories, and remoulds them “into new narratives, which are convincing in their aesthetic form and are validated through their impact upon the listeners” (Kvale 1996 p4).

Based on the qualitative literature, as well as the often inconsistent and vague information regarding physical activity and health, I expected that contradictions could exist within conversations with women about information on the benefits of physical activity. Rather than see contradictions as a problem, feminist body theory shows us that living within culture creates the embodiment of contradictions. So too, Kvale is interested in the complexities and contradictions that are brought to light through the interview process. Indeed, he points out that it is “a strength of the interview conversation to capture the multitude of subjects’ views of a theme and to picture a manifold and controversial human world” (Kvale 1996 p8).

The approach to interviewing developed by the feminist theorist Ann Oakley described above fits Kvale’s interviewer-traveller model. Building upon these perspectives, Strauss (1987 p2) emphasises the importance of institutional and structural contexts which may be brought to light in the qualitative interview process. He stresses (1987 p6-7), in line with Kvale, that: “one of our deepest convictions is that social phenomena are complex phenomena”,

and that researchers should do their best to capture the complexities and contradictions, rather than simply stating their existence. Strauss (1987) also discusses the value of keeping research open-ended, with an awareness of the temporal context of the research.

For the purposes of this thesis, I chose a semi-structured in-depth traveller interviewing approach, to encourage an interactive, conversational style which I hoped would encourage the women to speak freely. The structuring of the questions is based upon the Minichiello *et al* (1995) funnelling process. The funnelling method they prescribe is designed to get interviewees thinking about the topic in general without being confronted by personal questions. Women's experience of breast cancer can be seen as private and personal experiences, the funnelling approach seemed the least confronting interview method for this thesis. Minichiello *et al* (1995) exemplify the funnelling process with questions around adolescent body images and eating disorders. As the interview progresses, the questions move from the topic of interest generally (for example, what they may have seen about it in the media) toward finding out how the interviewees feel and think personally about the issue (such as their own body image).

According to Grosz (1994), body image can be seen as a site of connection between choice and culture. Accordingly, I posed questions which would allow the body images of the interviewees to illuminate the connections between their views on and participation in physical activity, and their everyday/everynight social worlds. Secondly, following Marshall (1996), I posed questions that relate to "other bodies" present in the women's mind/body. Marshall includes what we have read, who we have conversed with, and what images we have seen as other bodies. Marshall (1996) notes that during labour, she remembered particular other bodies to help comprehend what was happening within her body. In the context of this study, I was interested in finding out what other bodies – health professionals, friends and family, health promotion campaigns – may have contributed to how the women made sense of their experiences of their

breast cancer journeys and the health decisions that they made.

Accordingly, in my interview guide, early questions are more general, probing the relationships the women have with “other bodies”, for example “since your diagnosis, what sorts of things have your health professionals suggested would be helpful for your health and wellbeing?”. Talking about “other bodies” is also referred to as “footing”, whereby people can either directly refer to what someone else said, or use it as a discursive technique to distance themselves from particular beliefs or ideas (Wilkinson, 2000). The interviews progressively become more specific and personal over the course of the interview, for example “when you think about doing some exercise, how do you feel?”, and “how do you feel, in your body, when you actually do some exercise/physical activity?”

The key departure from the funnelling method in this study is that the first question asks participants to tell me about their personal experience of breast cancer from diagnosis onward, in accordance with the experience of other researchers, and confirmed by the small group interview with women as described above. This method of interviewing women who have/ had breast cancer may contribute to promoting the rapport and trust needed in order to pursue the topic of interest to this study.

In order to answer the research questions, the interview questions were designed to explore 1) how the women responded to information about health benefits of physical activity, 2) whether there were specific factors which influenced their responses to, and participation in, physical activity and in order to explore this more deeply, ways in which their participation has changed over their lives (including types of activities and regularity). The interview questions were framed to answer these questions, and therefore did not seek to know specific *levels* of the women’s participation. Nevertheless, because the interview questions did seek to know about changes to types of activities and regularity (see appendix 7), over the course of the interviews all of the women spoke about the level of their

participation at the time of the interview (length of physical activity sessions *as well as* regularity and type of activity). Based on the women's responses, I therefore designed a qualitative assessment of *level* which has aided a more in-depth exploration of factors which affected their participation (Chapter Six). Together with their level of participation, in the analysis chapters I outline the constraining and enabling factors that the women identified as influencing their participation over the course of their breast cancer journeys. I include the women's accounts of the support structures that enable them to participate (or not), how they said their bodies felt during physical activity and how they thought about participating in physical activity.

### **Advisory group**

I established an advisory group to provide a forum for discussion of results, to provide an opportunity for reflection and to ensure the interview questions continued to be appropriate and relevant. The group was convened twice over the course of the PhD at specific PhD milestones; to present preliminary findings and later, the analysis and discussion. The aims were to 1) contribute towards answering the research question "what would it take to enable women with a breast cancer diagnosis to undertake physical activity at a level that is likely to produce health benefit?" 2) involve study participants in discussions with professionals 3) encourage action (based on the findings from the research) from professionals that would benefit women with a breast cancer diagnosis if there were findings with implications for practice.

### **Health promotion sources and materials**

I selected health promotion sources (organisations) based on the women's accounts of the sources of information that they used, as well as specific resources. The purpose of examining health promotion sources was to look for 1) the types of information that the women were accessing, 2) the content of health promotion information (whether it included information about health benefits of physical activity, and if so, what information) and 3) how health promotion information was framed. Examining the sources and types of information the women were using, along with how the women responded to

them, assisted in exploring what sources and types of information are helpful (or not) and in what ways they could be more helpful.

### **Sample/study limitations**

Whereas the study sample was purposefully selected, it is possible that the sample could be unintentionally skewed as a result of the particular group of women who volunteered to be interviewed for this study. In particular, as mentioned above, the sample is weighted toward women from higher socioeconomic status. Other than limited advertising and editorials in local South Australian newspapers, the sample was recruited through contacts working in cancer/breast cancer-related organisations, so women who have not been in contact with such organisations may have been excluded. It is possible that, based on the literature reviewed in Chapter Two, for example, women from more disadvantaged backgrounds may not have been faring well enough to volunteer their participation.

Conversely, it is possible that women who feel unsupported may be more likely to seek to be involved in an interview because of the opportunity to speak about their experience of breast cancer. This sample, however, comprises reasonable numbers of women who talked of feeling supported and women who talked of feeling unsupported. Twenty of the women spoke of having support from their partners, while eleven women spoke of feeling unsupported by their partners. Fifteen of the women said they were involved in formal or informal support groups. Six of the women who were not involved in a support group were involved in dragon boating teams, which the women spoke of as being extremely supportive although did not describe their team as a “support group”. The remaining 15 women specifically said they were *not* involved in a support group or did not speak about support groups during the course of the interview.

I conducted and analysed all interviews myself, and I speak and understand only English fluently, therefore all of the women spoke English which may have excluded women from non-English speaking backgrounds.

## ***Method of analysis***

I analysed the data using a synthesis of the Framework method (Ritchie & Spencer 1994), and critical feminist techniques. Framework entails a process of familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation, and is a useful way to systematically manage and interpret large amounts of data. I digitally audio recorded all interviews, which were professionally transcribed verbatim. I immediately commenced using pseudonyms to maintain confidentiality. I selected pseudonyms based on first names of female authors and internet name sites and did not use any names that were the same as other women in the study.

I began the analysis process after the first three interviews were transcribed to develop an indexing and coding framework and to look for emergent themes. In subsequent interviews, I followed up themes that either confirmed or provided alternative explanations from early interpretations (Patton, 2002; Wetzman, 2003). I coded the first three transcripts manually and then used the qualitative data analysis software program N-Vivo 7 to assist in the indexing and coding process. Wetzman (2003) has outlined the usefulness and the pitfalls of using qualitative data analysis software. The main ways in which software assists in the analysis process are 1) increased speed, for example in the initial coding of transcripts and in reviewing themes and cross-checking, 2) easier to maintain and review consistency, 3) representation of themes in ways that assist in theorising during the analysis process, for example in matrices or models, and 4) consolidation of all data collection, including transcripts, audio/video files, field notes, memos, demographic variables, annotations, reflections, theorising and diagrams in the one place (Wetzman, 2003 p317). Pitfalls include trying to use the software to do the analytical thinking work, over-coding (for example, creating too many nodes), relying on auto-coding without cross-checking to ensure it fits with theoretical themes, and that it has coded everything of importance to the researcher (Ezzy, 2002; Wetzman, 2003). I decided to use NVivo-7 because it is a code-based theory building program designed specifically for qualitative research (Wetzman, 2003). The term theory-

building does not mean that the software builds the theory, but assists the user by enabling them to work with the data progressively through the analysis. Drawing on the qualitative research literature, and keeping the above points in mind, I found the software extremely useful for the initial indexing process, for examining whole themes at once and also for quickly cross-checking themes, and for going back when new questions or theoretical ideas emerged. I did not use auto-coding because I wanted to maintain familiarity with whole interviews, and because of the potential that the software may code differently from how I would, and so that I could follow the interview context which led to particular coded passages.

When analysing interviews, I listened to recordings while reading and re-reading transcripts to familiarise myself with interview nuances and to achieve immersion. I continually went back to listen to recordings as well as checking transcripts throughout the analysis process to ensure my familiarity with the interview tone and context (Flick *et al.*, 2007).

I coded the transcripts according to 1) the specific research aims and research questions, initially framed by indexing based on the research questions and 2) emergent themes and insights that I gained during data collection and at the completion of data collection (Patton, 2002; Ritchie, Spencer & O'Connor, 2003). At the same time, I examined critically potential structural elements embedded in the women's talk. Thus, I began by looking thematically at what the women said at face value, that is, by coding their overt or literal answers to interview questions (for example, the types of physical activity in which they reported participating). Then I explored the transcripts more deeply in a critical discourse analysis style, looking for structural influences on the women's responses to and participation in physical activity in their everyday/everynight lives (for example, gendered practices, paid/unpaid work). I also looked for particular cancer discourses, such as "think positive" (Crompton 2006; Ehrenreich 2001; Wilkinson & Kitzinger 2000).

## **Presentation of findings**

I have separated the analysis into findings chapters and a discussion chapter to enable a thick description (Atkinson & Delamont, 2005; Denzin & Lincoln, 2005; Patton, 2002) of the study findings and thematic analysis, followed by a theoretical discussion of the meanings of the findings in terms of the research questions and the literature. Throughout my findings chapters, I present mini case studies to explore specific points while embedding these points within the contexts of the women's lives and embodied experiences.

## **Analysis of demographic forms**

I used the demographic forms to assist in examining demographic influences on the women's responses to physical activity promotion and their own participation. I looked for patterns between the level of physical activity in which the women described participating (as defined above) in their interviews, the resources they spoke about as being available to them, and their responses in the demographic form. The demographic form includes indicators of class, specifically private health insurance status (Zadoroznyj, 2001), education attainment, occupation, household income, partner's education attainment, occupation, and the woman's geographic location (Baum, 2008) (see appendix 5).

Measuring women's class is difficult and is contested, especially when used on its own without other social stratifiers including race/ethnicity, gender or (dis)ability (Acker, 2006; Broom, 2008; Holmes, 2007, Skeggs, 2004). Historically, women's class has been measured according to a male breadwinner's socio-economic status (their father or male spouse) (Western, 1994), which discounts women's contribution to households and their gendered social position in the family (Acker, 2006; Skeggs, 2004) and assumes income sharing between intimate partners (Broom, 2008). More recently, women's class has been measured according to education attainment, their paid and unpaid work, in addition to their intimate partners' income and education attainment. The important point to make is that class, like gender, is a dynamic concept that changes over time and in spite of using a range of measures as I have here, such measures can only work as



socioeconomic indicators rather than provide definite class categories. In this thesis, class refers to the economic and social resources (including power) that are available to, and used by, the women in this study sample as well as their gendered and social practices (Bourdieu, 1999; Zadoroznyj, 2001). Therefore, both their qualitative accounts of their available resources, their descriptions of their classed and gendered everyday/everynight practices and their responses on the demographic form are utilised in assessing class effects on their physical activity participation.

Other social factors included on the demographic form include the number and ages of the women's children, in response to literature I reviewed in Chapter Two that shows that women with dependent children are one of the least likely groups to participate in physical activity, and that as children become more independent, women become more likely to participate in leisure activities (Bialeschki & Michener, 1994; Brown *et al.*, 2001b).

Also included in the demographic form is the date of breast cancer diagnosis and the treatments that women underwent, based on literature that indicates different treatments may have different effects on women's physical capacity to participate in physical activity and also that altered body image may affect their feelings about participation. I examined links between key themes from the qualitative data with the women's level of participation, and with their demographic attributes.

### **Analysis of health promotion sources and materials**

I sorted the information sources that the women said they used and searched for the organisations on the internet, and downloaded or accessed hard copies of any materials that the women specifically referred to. I analysed the texts displayed on the websites and categorised the sources into mainstream medical-based health promotion, and complementary and alternative health promotion, depending on the types of modalities with which the organisations indicated they were aligned, which I describe in Chapter Five. Many of the women gave accounts of using breast cancer advocacy organisations for their information, so I include these as well under the category "breast cancer

advocacy”. I used a two-staged analysis of the texts. In the first stage I conducted a content analysis to examine the type/s of information the organisations promoted, in particular the extent to which physical activity is included. In the second stage I employed a discourse analytic approach to analyse the texts based on a social constructionist approach.

Discourse analysis allows an examination of broader social constructions, and power relations embedded within them, which influence ways in which particular styles and approaches to health promotion are undertaken (Burr, 1995; Lupton, 1998, 2003). I use Vivien Burr’s (1995 p64-167) three forms of deconstruction. The first form is “revealing contradictions”, which means identifying silences and assumptions within texts, including the use of passive language. The second form is the “archaeology of knowledge”, which draws on Foucault’s concept of genealogy. Foucauldian genealogy refers to “a form of history which can account for the constitution of knowledges, discourses, domains of objects, etc...” (Foucault, interviewed in 1991 by Paul Rabinow 1997 p59). Burr uses Foucault’s genealogy to deconstruct the historical context within which particular truths are constituted (for example, the political, historical development of public health as outlined in my literature review). The third form is “the analysis of discourses” which involves the identification of different discourses that are operating around the same subject.

According to Burr (1995 p48): “A discourse refers to a set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events”. The “version of events” here refers to how various discourses are applied to produce particular versions of the meaning of health promoting practices as they are promoted by different types of information sources used by the women.

### **Coding physical activity participation**

In the literature review, I described the two definitions of sufficient physical activity that have been used in quantitative surveys in Australia. In this study, I use these definitions to guide my qualitative analysis of the women’s

physical activity, by coding the types and frequency of activities in which the women described participating. All of the women are mothers of dependent children, meaning that they are in a social group with little free time available in which leisure time physical activity participation would be possible (Brown *et al.*, 2001b). In addition, all women in the sample have been diagnosed with breast cancer, some relatively recently, and it would be reasonable to expect that it would be difficult for this sample to participate in leisure time physical activity as defined in the population physical activity studies: definition 1) 150 minutes per week of moderate activity/ definition 2) 150 mins per week in at least 5 sessions. For this study, based on the women's accounts, I define the women's participation in physical activity as:

- 1) *more active* – women who described participating in non-occupational or incidental physical activity (for example, walking, dragon boat paddling, swimming, cycling, sport, treadmill, gym) at least three times per week for at least half an hour at a time, as reported at the time of the interview.
- 2) *less active* – women who participate in physical activity fewer than three times per week, as reported at the time of the interview.

I coded women as either *more active* or *less active* by reading the transcripts where I had coded the types of activities in which they reported participating, in response to the question about changes to physical activity over their lifetime. I coded the women as being *more active* if they described their participation as adding up to at least three times per week, over at least the two weeks preceding the interview (see appendix 8 for examples).

Applying the definitions above to the descriptions the women provided about their participation, 21 women were *more active* and 15 women were *less active*. I expected a reasonable number of *more active* women, because my purposive sample included women involved in dragon boat clubs and the YWCA Encore program. The study sample has enabled me to explore in depth what factors enable women with a breast cancer diagnosis to participate in regular physical activity, as well as what factors constrain their participation.

### **Coding partner support**

When analysing the transcripts, the partnered women's accounts revealed the extreme importance to them of support from their partners. When I examined all of the factors that the women spoke about that influenced their participation in physical activity, plus the factors I expected to influence their participation, based on the literature I reviewed in Chapter Two, there was a clear pattern whereby a larger proportion of the women who gave accounts of having supportive partners (no matter what type of support) were *more active* than women who gave accounts of having variably or unsupportive partners. Therefore, I coded partner support by including all references the women made to the level and type of support from their partners. The women's descriptions of support were far more complex than a simple dichotomy of supportive or unsupportive. Very few women described their partners as being entirely supportive or unsupportive. Many women described their partners as being supportive in some ways and unsupportive in other ways. The women spoke about a range of expectations that they had of their partners and also of a range of types of support that mattered to them. Expectations ranged from emotional support through to practical and physical support. Women frequently discussed their experience of their household's division of labour (for example who does the paid work, child care and housework) and their social roles (for example, who does the emotional, nurturing, relationship-building work). The women spoke of feeling especially unsupported if they felt that their partner had the capacity to provide support but did not. However, if the women said that their partner did not have the capacity to provide support, for example because of work commitments or their partner finding their breast cancer diagnosis difficult emotionally, the women spoke about the constraints and said that their partners did what they could to support them within those constraints.

To acknowledge this complexity, I coded levels of partner support as being overall supportive, variably supportive or unsupportive, based on criteria that the women spoke about as meaning supportive or supportive in some ways but not in others or unsupportive, so that the women's accounts of partner

support can be seen as a continuum rather than as a clear binary. The types of support that the women spoke about that they found important included their partner enabling/encouraging them to take time out, providing emotional support or providing practical support such as helping with the care of their children and everyday/everynight household chores. Based on the women's accounts, below are the sets of principles of partner support that I used to code level of support.

Principles for coding women's accounts of having a supportive partner were that the woman:

- gave account/s of her partner taking steps to enable her to have time out to do something enjoyable (not limited to physical activity - any leisure activity) when they have the capacity to do so.
- spoke of her partner taking on (at least some) responsibility for household/child care tasks without complaint.
- talked about her partner as "supportive" and/or giving a lot of instances of conversations with him/her which led to decisions or helped in some way – eg "bouncing off ideas" or emotional support.
- gave account/s of successfully negotiating to regularly take "time out" for her own pleasure (not limited to physical activity - any leisure activity) while her partner looked after children/household tasks without negative repercussions (eg resentment directed at her from partner).

Principles for coding women's accounts of having a variably supportive partner were that the woman:

- gave account/s of her partner sometimes taking steps to enable her to have time out to do something enjoyable (not limited to physical activity - any leisure activity) and sometimes being unwilling/unable to, when they had the capacity to do so.
- talked about her partner as being supportive when s/he could, and acknowledged that her partner has external constraints such as work commitments.

- gave account/s of her partner sometimes taking on (at least some) responsibility for household/child care tasks, sometimes with and sometimes without complaint.
- talked about her partner as “supportive” in some ways (eg cooking some meals) and being “unsupportive” in other ways (eg unable to offer emotional support).
- spoke of occasionally being able to negotiate to take “time out” for her own pleasure (not limited to physical activity - any leisure activity) while her partner looked after children/household tasks.

Principles for coding women’s accounts of having an unsupportive partner were that the woman:

- gave account/s of her partner being unwilling to take, or not thinking of taking, steps to enable the woman to take time out (not limited to physical activity - any leisure activity or “time out”) despite having the capacity to do so.
- gave account/s of her partner not considering taking on responsibility for household/child care tasks her/himself, or suggesting she arrange someone else to do it when she actually wanted her/him to do it.
- spoke of seeking alternative support because she did not receive the support she wanted from her partner.
- complained about the lack of support (e.g. emotional and/or practical) she felt she received from her partner.
- did not give account/s of negotiating to take “time out” for her own pleasure (not limited to physical activity - any leisure activity) while her partner looked after children/household tasks.

I present my analysis of the women’s reported participation in physical activity as it relates to partner support in Chapter Four, Part Three.

### **Style and language notes**

*“the women”*

In this thesis, I refer to “the women” meaning the particular women who participated in this study and I refer to “women” when I mean women generally. I use the terms “the woman/women” rather than “the participant/s”

because “the woman/women” keeps gender in the frame, whereas “the participant/s” suggests gender-neutrality which is not helpful for this thesis, based on the epistemology outlined in my literature review and methodology.

### *Transcript quoting style*

In this thesis, I indent and italicise long quotes from the interview transcripts and include the interviewee’s pseudonym at the end. When I include anything that I say, I use my initials to show I am present in the interview and that it is me, the author, as opposed to an unknown ‘I’ for interviewer (Flick *et al.*, 2007). I also include paragraph breaks between what I say and what the interviewee says, for easier reading, except if my talking came as an interjection rather than waiting for the next pause. While I had the interviews transcribed verbatim, and listened to recordings to ensure accuracy and a sense of context, I made the decision to clean quotes (for example to remove repetitions of um, sort of, you know, like) but not to change the content. For this study, unlike discourse analysis or conversation analysis, how the women said what they said in terms of pauses, “ums” intakes or outtakes of breath and so on was not relevant to the research questions, whereas the meaning of what they said and in what context, is of key importance (Flick *et al.*, 2007).

### **Conclusion**

In conclusion, while there is evidence regarding the benefits of physical activity for women with a breast cancer diagnosis, there has been little research on how women feel about the promotion of physical activity, or how best (if at all) to promote physical activity to this group of women. This study has been designed to contribute to redressing this gap in evidence.

In this chapter, I have provided the theoretical underpinnings of my study methods which flowed from the previous chapter and I have described how my study methods will answer the research questions. I have explained how I negotiated the tensions between listening to women – voice – and providing a critical analysis of the social structures which are embedded in people’s talk. The steps taken to ensure rigour have been outlined and the study

methods and approach to interpretation of the data have been described in detail.

The interviewing methods employed enabled an in-depth examination of how the women in this study sample responded to the promotion of information about health benefits of physical activity. My methods allowed for a close look at how the women responded to specific sources of information and what everyday/everynight, socioeconomic and demographic factors influence their views on and participation in physical activity.

The advisory group was useful for exploring how those working in the care and support of women who have/ had breast cancer may respond to the findings in this thesis. The group also offered opportunities for me to engage with the research in ways that I otherwise would not have done. The group broadened my knowledge about differences between South Australia and Victoria in the management of the care of women who have/ had breast cancer, such as Victorian women being able to choose between their surgeon and oncologist for their care after acute treatment. South Australian women, by comparison, automatically remained under the care of their surgeons. Such differences alerted me to look for any differences between the women's accounts of their care, and the types of information that their cancer health professionals provided, based on the state in which they lived.

The extent to which the advisory group would be able to work as an agent of change over the course of the PhD, however, was limited. Overall, their responses to findings were in the realm of program development in line with a medical model of health promotion. Examples of programs that the groups thought could be considered include seminars/workshops for women who have completed treatment to assist them in negotiating for their own needs, within their social contexts, and physical activity programs being set up that include children. Responses focussed on educating women regarding the importance of physical activity after breast cancer and empowering women to believe in their right to participate in physical activity. The advisory group alerted me to a strong emphasis on health services in the care of women



who have/had breast cancer. This led me to explore the women's accounts to ascertain the extent to which women who have/had breast cancer are involved in collective breast cancer movements, or whether they also emphasised individualist approaches that require the women to undertake individual behaviour change.

My methodology for this study is underpinned by feminist, critical research principles. My methods aim to explore in the broadest sense the effects of social context and embodied experience and the connections between them, as they appear in the women's accounts. Based on the evidence that I reviewed in my literature review, my methodology is well placed to explore intersections of gendered/classed identity in the women's accounts of their views on and participation in physical activity, and the extent to which their breast cancer journeys change their gendered/classed identities. Ultimately, my methods enable an exploration of possible ways to encourage change that enables women with a breast cancer diagnosis to be physically active without simultaneously causing harm through unrealistic physical activity promotion.

The following chapters provide a thematic analysis of the women's responses to physical activity promotion, the women's reported participation in physical activity and their information sources and materials. The analysis is divided into three chapters, each addressing different themes arising from the women's accounts, to answer discrete parts of the research questions. In Chapter Four I explore the women's accounts of physical activity participation and their knowledge of specific health benefits in the context of their breast cancer journeys. I have split this part of the analysis into two distinct stages of the women's breast cancer journeys; the acute treatment journey and the ongoing and/or adjuvant treatment journey. I consider at what points the women spoke about physical activity as important (or possible), over the time since their breast cancer diagnoses, and what meanings participation held for the women. I look to some extent at how the women responded to information about health promoting practices and where information about benefits of participation in regular physical activity fits into their journeys. By

doing this, I show how (some of) the women's knowledge of and interest in information about health benefits of physical activity increased over the course of their journeys, and at particular points.

Having established the importance of context to the women's decisions about health over the course of their breast cancer journeys, I begin Chapter Five by outlining the women's knowledge of health benefits of participation in physical activity as part of their response to information. I then describe themes that emerged regarding how the women responded to my questions about information they had gathered about supporting their health. I then examine their sources of information, and specific information materials.

Finally, in Chapter Six I analyse the women's accounts of participation in physical activity and the factors that, based on the literature reviewed in Chapter Two, may be expected to influence their participation. In this chapter I analyse the interrelationship between partner support and other factors that influenced the women's reported participation in physical activity. In this part of my analysis, I also consider the extent to which the women's knowledge of information about health benefits of physical activity influenced their participation.

## **Chapter 4: Breast cancer journeys**

### ***Introduction***

My decision to start the analysis chapters by describing the women's breast cancer as journeys is based on my analysis and reflection on the ways in which they spoke about breast cancer as a journey, and because the decisions they made about their health were influenced strongly by where they were in their journey. I start this chapter at the beginning of the women's breast cancer journeys, covering the period of time when they first discovered a breast change (or their breast cancer was detected by routine investigation), through their immediate decision-making about, and experiences of, acute treatment. It was a time of turmoil for all of the women, and thus a time where decisions were necessarily limited to those related to working out their best chance of survival. At this time, the women drew heavily on their existing knowledge about breast cancer and also found they had to absorb new information that was specifically about their acute treatment decisions.

My analysis of the women's accounts confirms that a diagnosis of breast cancer came as a tremendous shock to all of the women in this study. Not surprisingly, it appeared that physical activity participation for health benefit was not uppermost in the minds of any of the women at the time of diagnosis. Over the course of their journeys, however, physical activity participation featured in many of the women's accounts as a practice that provided specific benefits at particular stages. My analysis shows that the women's embodied experiences of breast cancer, in the contexts of their social worlds, were interconnected with their thoughts and feelings and consequently their decisions about supporting their immediate and future health. It became apparent that a feature of the women's accounts is that they talked generally about a range of health promoting practices inclusive of physical activity participation, rather than speaking about physical activity as an isolated health promoting practice. Therefore to answer the research questions, I examine the women's responses to health promotion generally

as well as physical activity promotion specifically. Many of the women talked about checking information and frequently contesting information that they had received about health promoting practices *other than* physical activity participation. By comparison, the women did not tend to dispute that participation in physical activity was beneficial to their health, except where they felt the effort required to ensure their participation was more of a cost to their health than the actual physical activity potentially benefited their health.

The women's responses to various relationships and conversations with friends, family and health professionals made up a large proportion of the content of the interviews. The women talked about their experiences in terms of their everyday/everynight tasks and responsibilities in the contexts of their social worlds. The women included accounts of various conversations, emotions and bodily experiences that affected their breast cancer journeys. In turn, their experiences influenced the decisions that they made about treatments and what they did to support their current and future health. The women's breast cancer journeys, and the decisions that they made, were therefore inseparable from the contexts and practicalities of their everyday/everynight lives. Throughout my analysis, I explore ways in which the women's social worlds, particularly their sense of responsibility towards their dependent children, influenced their decisions about their health over the course of their breast cancer journeys.

In this first section of this chapter I illustrate the ways in which the women's knowledge about breast cancer and specific health benefits of physical activity developed over time, and how increasing their knowledge from a broad range of information sources influenced their decision-making processes. I explore the women's accounts of their experiences and decisions about acute breast cancer treatments, including surgery, chemotherapy and radiotherapy. I also consider how the women decided on acute treatments for a potentially life-threatening disease, to put in perspective how decisions may be made about a longer-term health promotion action like physical activity.

I do this by describing the processes by which the women made decisions about their health over time. I illustrate representative decision-making pathways with case studies of particular women, and provide an overview of the women's experiences and knowledge/information/ decision-making intersections. I show how the women's decision-making processes at the time of discovering a breast change and about their acute care treatments sheds light on the process and timing of the ways in which the women made decisions about longer term health promotion practices, including physical activity participation.

### ***The journey begins***

#### **Finding the lump**

"Finding the lump" illustrates ways in which the women's decisions about all aspects of their health, including their thoughts about and participation in physical activity were made relative to their broader social contexts. Almost all of the women went through a process involving interactions with others close to them before making a decision to seek medical advice. Most of the women gave accounts of discovering, and/or of seeking medical advice about, their breast change by chance. At the point of discovering a breast change, they did not talk about considering physical activity participation a priority in terms of their health.

In the women's accounts of discovering their breast change, talk of seeking medical advice because of early detection messages was conspicuous by its absence. Some of the women talked about health promotion early detection messages *not* applying to them, which could have been because of the sample age range. Several of the women said that breast checks and regular mammograms are promoted to women who were over 40 or 50 years old; "you sort of know about those self-examinations but, that's for someone after 40" (Joanna).

Below I present two typical stories of women discovering their breast change and their pathways toward seeking medical advice and their subsequent diagnosis. This first step in the women's breast cancer journeys sheds light

on the ways in which even a potentially and immediately life-threatening decision may be delayed because of competing priorities in the women's lives, putting in perspective their responses to a not-so-immediate health promotion message such as participation in physical activity.

### *Emma*

Emma was living in outer-metropolitan Adelaide and had two very young children (10 months and three years old) at the time of her breast cancer diagnosis at 40 years of age in 2002. She worked as a fitness instructor and was the main income-earner for her family throughout her breast cancer journey.

Emma's account illustrates how most of the women discovered their breast change by chance and sought medical advice even though they did not expect the change to be anything sinister because of their age and/or because they assumed the breast change may be related to (relatively recent) childbirth and/or breastfeeding. Emma found her breast change after participating in physical activity as she had just been lifting some heavy weights and had sore pectoral muscles.

*I was just rubbing my pecs thinking "oh geez that's sore" [...] so I felt it with my thumb. But I didn't think a hell of a lot of it [...]. I only just finished breastfeeding probably a few months before and I thought it's just I've got lumps and bumps everywhere. So [...] it must have been an intuition a couple of days later I had a bit of a feel again and I thought "oh I don't know I reckon it is a lump". And I asked my husband - obviously you think you're being a little bit paranoid because I was younger as well - and he said "oh no it definitely feels different". So I rang the breast clinic [...] because I didn't know what to do [...] and they just basically told me I was too young and to go away.*

*And then I went to my doctor and lucky my doctor was very thorough and she did an ultrasound and a mammogram. [...] And yeah it was [cancer].*

*[...] I guess being [...] in the fitness industry, I'm very aware of my body. As women we're more in touch with our bodies as well, we know the changes, the differences (Emma).*

Emma's story is typical of the three women who gave accounts of either intuition, or "someone looking out for me", ensuring they followed up about

their breast changes. Emma said she believed that her intuition and her relationship with her body as a fitness trainer contributed to her decision to seek medical advice about her lump, despite being told to “go away” by the “breast clinic”. Prior to seeking medical advice, Emma had asked her husband to feel the lump and had sought her mother’s advice. In another part of the interview, Emma said she rang her mother because she didn’t know what to do and her mother suggested she ring the “breast clinic”. Emma’s story illustrates how, for this age group of women, and particularly women who have very young children, potentially assume their “lumps and bumps” are a result of breast feeding.

### *Penelope*

Penelope lived in rural South Australia and had two pubescent daughters at the time of her breast cancer diagnosis, when she was 52 years old in 2006. At the time, she was running a small business with her partner and helping care for her ill mother. Penelope’s account is characteristic of the few women who talked about everyday/everynight life demands delaying diagnosis because of other people’s needs taking precedence over seeking medical advice. In addition, Penelope had thought she was aware of what a breast tumour would feel like, and did not expect her breast change to be breast cancer. Penelope also said that and had started regular mammograms because she had “read somewhere” that she had an elevated risk of breast cancer because of having undergone IVF treatment. Penelope told of her breast being sensitive, then feeling pain and later noticing a thickening.

*I've always done my own self breast examination and thought I was pretty smart at it because I'd been to one of the field days [...] and I'd been to the health clinic and they have the plastic boob - "feel the lump" and I go "oh yep, I've got five "oh good girl, you've got them all" so I thought "oh, I'm pretty good at this", you know. [...] like a little pea. [...] So when I thought, "oh, my breast is really sensitive", [...] and I thought, "that's just me today", so ignored that. Then we went on a lovely family holiday [...] and I'm a swimmer so I love to swim, that's been my physical fitness all my life, so in the water 24/7, swam with the whale sharks. [...] So anyway [...] we went up on top of the roof of the boat and jumped in like I normally do and I thought "holy shit that hurt like hell" and I was holding my breast (Penelope).*

Penelope then discovered what she described as a mass that was not the same as the “pea” she was expecting should it be breast cancer. Penelope went on to describe two occasions that she had made appointments with her doctor to check her breast change, she gave her appointments to her ill mother. Finally her breast cancer was detected through a routine mammogram because she had not managed to get to have her breast change checked by her doctor.

*Because we were doing the extension the postie couldn't get to our letterbox so all the mail from home was going to work [...] and only because I was at work I opened it, I picked up the phone, made my appointment. [...] Normally at home my mail goes on one of those "gunna get to" piles - you have the school papers, the kids stuff, you do everyone else's stuff first - so if that had come to my home I might not have been quite so lucky (Penelope).*

Penelope’s account is representative of the ways in which many of the women talked about putting themselves last within their family contexts, which in Penelope’s case meant delaying following up on her breast change. Again, Penelope talks about “chance” having a great deal to do with taking steps which ensured her early diagnosis. Penelope’s account reveals how competing priorities can mean that a woman’s health is placed on a lower rung than the various needs of those around her. Penelope’s account also highlights differences between the women’s expectations of what a breast tumour will feel like based on their embodied expertise and how breast cancer actually presents. Penelope had recalled that she ought not to “wait til 50” to have her mammograms because of having had IVF treatment, but did not recall health promotion messages about following up *any* breast change.

In summary, “finding the lump” was the first step in the women’s breast cancer journeys. The case studies above illustrate how the women talked about their relationships with their bodies in terms of what they felt about the breast change and what they could feel or see. Like Emma, five of the women asked someone else close to them to look at or feel their breast as a first step, prior to the women’s decisions to seek medical advice. Emma’s account also illustrates how some of the women gave accounts of their



bodies and minds being united with their intuition or “God” and yet others felt it was somehow “good luck” or “by chance” that their breast cancer was detected early. For all of the women, a diagnosis of breast cancer was mediated at some point by their relationships with others, whether this meant that they sought medical advice quickly, or like Penelope, put off seeking medical advice because of competing priorities.

Even at the point of discovering a breast change, we can see that the women’s accounts of their decisions about health are not made in a linear, rational sense where they might 1) note the breast change, 2) recall the literature or campaigns they have seen that tell them to seek medical advice when they notice a breast change and 3) seek medical advice. Rather, they make decisions that are founded on what appears reasonable, based on their full range of knowledge, mediated by their social contexts. This tendency at the outset of the women’s breast cancer journeys sets the scene for their subsequent decisions about health, including their decisions about physical activity.

### **Breast cancer surgery**

All of the women who participated in this study decided to have breast surgery (see table 1) and this section begins with their accounts of surgery decision-making, and where and when physical activity fits in. Twenty-one of the participants underwent a mastectomy (including four women who initially had lumpectomies and partial mastectomies which did not provide clearance of cancer cells). Two women had partial mastectomies and thirteen had lumpectomies (not including the women who then underwent mastectomies). Twenty-eight of the women had lymphatic surgery to remove some or all of their under-arm lymph nodes and four had undergone sentinel node biopsy, which is a more recent surgery that checks the node closest to the affected breast for cancer cells before removing any. Three women had been diagnosed with a recurrence and therefore had further surgery (see table 3 for details).

All of the women said they felt that increasing their chance of survival was far

more important than keeping their breast/s, while at the same time some of the women who had mastectomies said they felt a great deal of grief about losing their breast/s. Some of their particularly poignant accounts, at least for me as a mother myself, were about their children's responses to their breast surgeries, including those women who underwent breast reconstructions which I explore below. In addition, some of the women felt they could no longer allow their children to see them naked because it felt too painful. While this thesis is not the place to include an in-depth discussion of this aspect of their accounts, I would like to note that this appeared to be very important to the women and deserves further attention elsewhere.

In their treatment decisions, most of the women said they felt a particularly strong imperative to do what they could to survive because of the responsibility they felt toward their child/ren. This point is linked to a somewhat contradictory pattern where the women's decisions about competing priorities mean that their own needs are not often top of the list, even after a diagnosis of breast cancer. This pattern is exemplified by the few women who were diagnosed in the Christmas holiday period. The women's decisions to either hold off treatment or to go ahead immediately were based on what they thought was best for their families at the time. This is not to say that men may or may not also make decisions around other priorities, including delaying treatment. This study, however, focuses on the women's experiences in this study sample, and is a pattern that I elaborate on in discussion of the gendered nature of women's health decision-making in Chapter Seven.

The women's accounts below provide some insight into the ways in which they made treatment decisions and what information influenced their decisions in the time immediately following diagnosis. Benefits of participating in physical activity were rarely mentioned as being important at this time of the women's journey, except for some of the women who talked about finding physical activity helpful for "clearing their mind" or "taking time out" or, as described by Sarah below, getting away from the phone. By comparison, the women did talk about other health promoting practices, such

as juicing<sup>2</sup>, taking anti-oxidants, or complementary and/or alternative treatments such as acupuncture, that the women thought may assist them through treatment by boosting their immunity, like Jodie's account below.

*...one of the mums from kinder, who wasn't scared of me, she told me about this naturopath. So I just went and saw him to sort of deal with my immunity a bit, but of course I've since found out you're not meant to take antioxidants and that sort of stuff when you're having chemo. But he was just giving me suggestions to keep my immunity up and vegetable juice, which I still drink now, but not as regularly as I did drink then (Jodie).*

### *Sarah*

Sarah lived in north western rural Victoria and had to travel an hour for her breast cancer surgery. She had 3 children aged 19, 16 and 13 years old at the time of her diagnosis in 2007. Both she and her partner worked at the local large supermarket.

*When I was first diagnosed [my partner] and I would go every night for a walk and we were doing it every night - just get out of the house and get a bit of exercise. It was good and time together and away from the ... the phone rang off the hook so it was really good just to leave...*

*CM Okay, leave it behind?*

*Yeah and we'd go for a walk and we did that up until I had chemo and then I tried to but it just wasn't happening and then I got sore and I just didn't ... and we keep meaning ... we've done a few walks as I've started to get better in the last month, but we're not doing it every night (Sarah).*

Sarah's account is characteristic of the ways in which the women talked about different stages in their breast cancer journeys; when physical activity was possible and when it was not, as well as the purposes for which they would participate.

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<sup>2</sup> Juicing – the practice of juicing (often large amounts) of fresh, usually organically grown, vegetables and/or fruits.

Sarah was one of the women diagnosed near Christmas, but chose to have her initial surgery straight away, which meant that she had three different surgeons, and three operations finally resulting in a mastectomy.

*I had a follow up visit with my surgeon who had come back from holidays the following week and yeah, I went in and he was really quiet and just looked at me and I said "oh no, what?" And he said yeah, "it's got to come off", so he sort of left it up to me but I thought I've got three kids at home; I can't muck around. So I went back in the following week (Sarah).*

Sarah's decision to have surgery sooner rather than later was based on the responsibility she felt toward her children – that is, an imperative to survive.

### *Danielle*

Danielle was 46 years old when she was diagnosed in 2004 and had four children, aged 16, 12, 9 and 7 years old. She was living in a large rural Victorian town and had been working full time as a health professional when she was diagnosed. Danielle's family financial circumstances meant she was able to stop work through her treatment, and had recommenced working a few hours a week at the time of her interview. Danielle decided to hold off treatment because of the Christmas break and her planned family holiday.

*We had to wait for the results which officially came on the 23rd of December and it wasn't very nice. [...] all my relatives live [interstate] and we were meeting them, my husband's family in [town] for Christmas, which was a traditional thing. So we sort of had to, and I said to [the surgeon], "well can I go?" [...] So he said, "look, go and I doubt I will find you", his words weren't "a decent surgeon", but you know what I mean by that [...] so I then rang him after Christmas and he had managed to track down the surgeon that he wanted and he wasn't going to be available until mid-January. So he said, "look, stay there have a holiday, come back and we will have the surgery" (Danielle).*

While Danielle and Sarah made opposite decisions regarding their timing for surgery, they made their decisions based principally on what they considered their priorities in terms of their families.

### *Melissa*

Melissa was 52 years old when she was diagnosed with breast cancer and had 18 and 20 year old daughters. She was not in a relationship and was the sole income earner for her family, working in two part-time casual jobs. Over

the course of her interview, Melissa described how she financially struggled in the time that she was recovering from her surgery. Melissa lived in north-western Victoria and would have had to travel almost 200km to Bendigo to have radiotherapy every day for between four to six weeks if she had a lumpectomy rather than a mastectomy. She would therefore have had to either stay each week in Bendigo or drive back and forth daily, while her daughter was at the end of year 12. Therefore her decision-making about her treatment was based on her location, her younger daughter, being a single mother (no one to look after her daughter during radiotherapy) and her financial situation.

*I had a choice after seeing the surgeon, he said because of the size of it, I could probably have a partial mastectomy, or a full one. Having a partial I would probably need radiotherapy, sort of as a backup. But with a full one, there was a chance I wouldn't need radiotherapy, but not 100%. [...] through this time my daughter here at home was going through Year 12 exams or studying leading up to it (Melissa).*

Melissa went on to say that she had small breasts anyway, so it would not make very much difference, and joked about it being an opportunity to enhance her breasts with reconstruction later. "So yes I thought, 'well hey, I might as well go the lot and then further down the track I will have a full reconstruction done and get both of them enhanced.' [laughs]" (Melissa).

### *Janine*

Janine lived in Adelaide, and at the time of her diagnosis in 2001 she was 40 years old had three children living at home aged 17, eight, and her eldest child was over 18. Janine was the sole income earner for her household. Janine gave an account of putting her work and her children ahead of her own health throughout breast cancer journey. At the time of her diagnosis, Janine convinced her surgeon to agree to wait until she had arranged her work to be up to date and covered by someone else. Janine also worked throughout her chemotherapy treatment, having treatments on Fridays and spending the weekend recovering.

*[After having a partial mastectomy] I went back to work on the Monday and told my boss that I'd had a needle biopsy and that it showed some cancer cells and that I had to have the lump*

*removed. I organised to do that on a Thursday afternoon, so I worked until lunchtime [...] I had the lump removed and it turned out to be a partial mastectomy because the tumour was larger than what they expected. I had the Friday off. I actually stayed overnight and then I came home and it still didn't really sink in what was happening. I went back to work on the Monday and went back to the doctor on the Wednesday and he said that it didn't look good, that the tumour was larger than they expected, more than likely it had probably spread and you will need to have a full mastectomy. I said "I've got a lot to do at work, can it wait two weeks" and he said "I'll give you two weeks - I'll give you to the end of the financial year". So I worked really hard every night at work, until 9-10 o'clock and then I came home. Then I came home and I have three children, all three girls are living at home (Janine).*

Janine also spoke of being abused by her partner who became physically violent towards her after her breast cancer treatment. The police placed a restraining order on him after her uncle saw bruises on Janine's face and contacted them to report his violence. Janine's story shows again, the ways in which, even with the diagnosis of a life-threatening disease, immediate treatment is not necessarily the decision the women made because of competing priorities and their everyday/everynight life circumstances. Her account of her decisions about surgery further illustrates a pattern whereby the women did not consider their own needs the first priority and, put together with her account of her partner's lack of support, dramatically reveals the effects that gender relations can have on women's breast cancer journeys. At this point of Janine's journey, participation in physical activity was not even a consideration. Janine spoke about beginning to walk once she had recovered from all of her treatment, and talked about how walking was the one thing she did for herself. I return to Janine's story in Part Three of my analysis, to describe the meaning that participation in physical activity held for her further along her journey.

### *Nora*

Nora was 50 years old when she was diagnosed with breast cancer in 2000 and she had four children, the youngest being 13 years old, plus the regular care of her two year old grandchild. At the time of her interview, Nora had been widowed for about 10 months, and based on her reported household

income was the poorest of the women in this sample. She lived 50km from the nearest large town in Victoria where she had her surgery and chemotherapy and 110km from Melbourne, where she had travelled daily for her radiotherapy treatments, and often had to take her two year old granddaughter.

Most of the women said they recovered well from the physical side of breast cancer surgery (which was not the case for the women who had reconstruction surgery, in the next section). Nora was the main exception to this, saying she was not given any exercises to do post-surgery and believed that she developed a frozen shoulder as a direct result of being advised to wear a sling.

*No one told me that I had to exercise my arm or you know walk up the wall or that sort of thing. No one mentioned anything like that to me [...]. He just said "Yeah, just leave it in the sling". So that was the one thing, anyone that I've spoken to that has said to me that they've just been diagnosed with breast cancer, they're going to have the operation, one of the main things that I do say to them is "check with your doctor or the nursing staff or someone about your movement for your arm". I mean I'm not going to say to them start doing exercises straight away but I think, as long as they know that they've got to do some sort of exercise to keep it free.*

*[...] When I went down for the second [radiotherapy session] I asked about what exercises and things that they would suggest that I do for the arm, because they actually have physios at Peter Mac, and they sent me to one of the physios [...]. And I seen her and she loosened it and finally it was all, by the time the six weeks was up for having radiotherapy, she'd loosened my arm up. I mean, I still haven't got full movement of it or anything like that and it is full of lymphoedema.*

*CM Has anyone tried to treat the lymphoedema?*

*I've seen the physios here but as soon as the weather gets a bit warm it just all swells up again. It is never the same size as that arm. Sometimes it looks like I've got elephant disease and [...] it will swell up sometimes and it is rock hard (Nora).*

Like Nora, ongoing problems that some of the women said they experienced were mainly due to lymphatic surgery, including numbness and lymphoedema, on which I elaborate below. The women who had problems

with lymphoedema talked about it as being enormously distressing, and all of the women who had lymphatic surgery other than only sentinel node surgery feared lymphoedema developing some time in the future.

All of the women had either a lymph node biopsy or had some or all of their lymph nodes surgically removed. According to the women, the type of lymphatic surgery was dependent on the women's surgeons, and for rural women, the location where they had their surgery. Some of the women said they had full removal of their lymph nodes although they were found to be free of cancer cells. Of these women, those who subsequently felt numbness or developed lymphoedema expressed frustration at later finding out that perhaps they need not have undergone full lymphatic clearance. The women's accounts showed that lymphatic surgery potentially affected their participation in physical activity, whether this was because of fear of lymphoedema or actual lymphoedema, arm weakness or numbness.

### *Justine*

Justine lived in Melbourne and was 51 years old when she was diagnosed in 2001 and her son was five. Justine was working at the time of her diagnosis but changed to part-time freelance work, with some time off in between. Her partner was the higher income earner for the family and she didn't have to work to ensure financial security. Justine's account is analogous with the few women who spoke of having lymph nodes clear of cancer, but had had some or all of their lymph nodes removed (before sentinel node biopsy was viewed as safe) and subsequently had to live with either numbness or lymphoedema. Justine's account exemplifies the frustration that they expressed because of the limitations the (in Justine's view, unnecessary) surgery placed on their everyday/everynight lives, including their participation in physical activity.

*Both arms have lost lymph nodes, but this arm lost more.  
Because I couldn't believe that they were about to take out  
possibly healthy lymph nodes just to look at them.*

*And I still think, I mean now we have sentinel node, it was only  
just coming in, statistics weren't out and my surgeon didn't  
recommend it for me because he was going to be expecting*



*positive nodes. And he wanted to be sure. And I resisted as much as I could. It still felt like a plot against women, you know. They wouldn't do it to blokes. You know, they really would have developed an alternative surgery so fast if it had have been men, but somehow for women it's alright. [...] After I whinged several times, he reduced the number he took out here <pointing under arm> and I've had no trouble at all with this arm. So I think the number of nodes they take is actually significant, for me anyway. They say it's not, but I reckon it is (Justine).*

Justine drew on her prior knowledge regarding lymph nodes, plus her embodied experience of the comparative degree of discomfort she had in each arm, to critique the standard practice of removing lymph nodes that *may* have cancer cells. In Justine's account, her lymph nodes turned out to be clear, and she later talked about a range of problems she experienced in the arm which had the greater number of lymph nodes removed. Several women, like Justine, expressed extreme concern about potentially developing, or exacerbating, lymphoedema as a result of participating in physical activity, and of finding it difficult to find out any definitive answers to this dilemma.

*The nurses, everyone knew I would have to exercise after surgery, but they didn't know what was appropriate for my surgery. And what they had was a little sheet with lymphoedema exercises.*

*[...] When I was well enough I joined the gym for a while and that did do the upper body stuff which is really what was needed to get moving again. But I had to be careful because lymphoedema is the other thing, you can't overdo it. And I had a bit of swelling, it was little bit puffy around here, it's just on that side. I had more lymph nodes removed on the left. So I was very concerned about that as well. [...] on the other hand I think you do need to talk about exercise and keeping moving because this is something that could, with a bit of bad luck, it could just suddenly go up (Justine).*

Soon after the women had recovered from surgery, some gave accounts of beginning to explore other information sources, and discovered that physical activity provided specific benefits for women who have/had breast cancer.

*Isobel*

Isobel lived in a rural Victorian town and was 46 years old when she was

diagnosed with breast cancer in 2004. Her children were five and seven years old. Isobel gave an account of changing her physical activity participation as a direct result of a story in the media after she watched a documentary on the Australian Broadcasting Commission's (ABC) Australian Story about Dragons Abreast soon after her breast surgery.

*It was a timing thing really. The time I was diagnosed was when Dragons Abreast was on Australian Story I think I'd not long got home from hospital and there was going to be a story about these breast cancer people so I thought "I'll have a look at that" and I said "I'm going to do that".*

CM Had it already started...?

*Yes, it started here a couple of years before.*

*[The story was on the] Northern Territory, the original one. But I just looked up the website and found a contact number.*

CM Did you already know it was here?

*No I didn't, no (Isobel).*

Isobel went on to describe the benefits that she gained from participating in dragon boat racing.

*I think it comes back to needing to do something for myself. Like setting your own time aside and not just like a special treat, on a daily basis. Because if you don't do that, it doesn't happen. If you don't make a point of doing it in this world it doesn't happen at all. [...] But the Dragon boat paddling was a conscious decision saying I need to do something, I am going to do something just for me. That was a very conscious decision (Isobel).*

For Isobel, "doing something for herself" was extremely important in her decision to participate in dragon boat paddling. Isobel also talked about feeling concerned about developing lymphoedema and that the dragon boat team helped her to overcome her fears. Isobel's account is also representative of most of the women involved in dragon boat clubs who were not involved in specific support groups and spoke about their dragon boat team as being very much different from a support group.

To summarise, while most of the women spoke about breast cancer treatments with their families, their decisions about surgery were made only

in consultation with their surgeons. While one woman did seek three opinions before deciding on which surgeon to use, she still only referred to the surgeons' advice. The women's decisions about the timing of the surgery, however, were often dependent on how the timing may affect their family or work commitments. The majority of the women were, in spite of their breast cancer, more focused on other priorities, especially their children, meaning that any consideration of participating in physical activity was understandably much further down the list of priorities. As very few surgeons spoke with the women about physical activity except for specific post-surgery exercises to maintain range of movement, the women did not speak of it being important at this time in their journey. The only exception was where physical activity offered them some "time out" during what they described as an extremely stressful time, or like Nora's account, where the necessity for post-surgery exercises was made apparent by its omission.

The only health promoting practices that the women spoke about during this time as being specifically relevant for their health (rather than in terms of "time out", or maintaining post-surgical mobility) were those which the women believed may be helpful in boosting or maintaining their immunity prior to, or once they commenced chemotherapy.

### **Reconstructive surgery and physical activity**

Six participants underwent reconstructive surgery and one woman had a reduction of her unaffected breast. Reconstructive surgery was one topic in interviews that generated discussion about participation in physical activity. This was because the physical activity participation outcome was dependent on whether the woman's usual physical activity practices were taken into account in the decision-making process. The women's decisions about reconstruction were complex, and they gave accounts of medical, physical, emotional and everyday/everynight life influences.

Most of the six women who decided to undergo reconstruction gave accounts of their decisions by explaining ways in which having one breast impacted negatively on their everyday/everynight lives. Women who decided to

undergo immediate reconstruction – that is at the same time as their mastectomy – spoke of feeling better about waking up from surgery still having two breasts. Whereas most of the women who had breast cancer surgery without reconstruction spoke of experiencing a quick recovery, some of the women who had reconstructive surgery said that this surgery was extremely painful and had a long recovery time, sometimes with lasting effects.

The women spoke of decisions about the type of reconstruction being influenced more by their everyday/everynight lives (for example if they were regular swimmers) than aesthetic result. In contrast, the women reported that aesthetic result was of highest importance to the surgeons. While body image was certainly a key reason for undergoing reconstructive surgery, almost all of the women who talked about their decision in terms of pros and cons regarding the potential for bodily interference in their everyday/everynight lives. The main body image issues that the women spoke about included worrying about other people noticing that they only had one breast or seeing the prosthesis, and some of the women explicitly said that they did not view their reconstruction decisions in terms of their sexuality. Further, their accounts of their decisions about reconstruction in relation to body image were related to emotionally moving on from breast cancer or not having the extra work the prosthesis required than about the breast as a sexual object.

### *Vanessa*

Vanessa was living in outer Melbourne and was 33 years old when she was diagnosed with breast cancer in 1998 and her son was four. Vanessa was working full time at the time of the interview. Vanessa's account is illustrative of the ways in which some of the women said reconstructive surgery was promoted by the doctors and nursing staff to the women in terms of sexuality, and how the women felt that the sexual image of breasts was completely incongruous with their own reasons for reconstructive surgery.

*I had just had the mastectomy and the women on the video [about reconstruction] were women in their fifties, older, so*

*again it wasn't really women that I identified with [...] and they talked about not feeling like a woman and so on, and all I kept thinking was "I just want to survive this damn disease and yeah I've got one breast but you know, that's okay". [...] The fact that I only had one breast wasn't my issue at all, it was the fact that I wasn't sure if I was going to survive and watch my son grow up, so I really wanted that support rather than the sexual, the image and so on, because I felt quite comfortable with who I was and I didn't feel I was defined by my breast. So an interesting experience (Vanessa).*

Vanessa decided to undergo reconstructive surgery, and talked about the problems of wearing her prosthesis, in terms of limiting her physical activity participation. Once she had her reconstruction, she found that she was more able to participate in her preferred physical activity pursuits.

*When I had one breast I felt self-conscious about what I could do [...]. I used to enjoy dancing for example and doing programs like [a] kickboxing kind of class, not quite aerobics but something like that. I couldn't bring myself to do [those types of activities] especially when I only had one breast because I felt - well the breast form was huge, but also I felt that it was too obvious to other people. Perhaps it wasn't, it was just to me but I felt really self-conscious and awkward about that so I chose more sedate types of exercises in that intervening time. So yoga [...] I felt really comfortable in that except when I was doing things like you know when you throw your legs arm height because I was kind of choking because [of the prosthesis being pushed up against my throat]. And I have to say I felt I was able to embrace exercise with more vigour once I'd had reconstructive surgery (Vanessa).*

Vanessa's account is typical of the women who felt that reconstruction surgery enabled their participation in physical activity because of previous concerns about their prostheses moving or looking obvious. Her account is also illustrative of the women who spoke about differences between what they thought was important and what they thought their doctors thought was important in relation to breast loss and breast reconstruction.

### *Anna*

Anna was living interstate when she was first diagnosed with breast cancer in 2004 but had moved to Adelaide during chemotherapy after her second diagnosis in 2005 to be close to her parents, who were her main support

people during her treatments. At the time of her first diagnosis she was 34 and her children were six, four and one year old. Her partner travelled interstate for work each week so she had full responsibility for their children's daily needs and she was also developing a small business.

Anna decided to have an immediate latissimus dorsi reconstruction<sup>3</sup> at the time of each of her mastectomies because she felt it would give a more "normal" look than an implant, although it has meant that her shoulders now look "funny". Anna described the procedure, which she said has resulted in restricting her shoulder movement.

*Yeah it's basically they take a whole piece of your back - lat dorsi there <touching shoulder blade area> and they bring it up and they attach it to your rib there <pointing to rib> and then they bring it around and that's why your boob is more normal looking than just having an implant and skin. So my shoulder blades look funny because my shoulder blades attach to the lat dorsi there so it's not normal (Anna).*

Anna went on to talk about being unable to participate in team sport since the surgery. She also said she could no longer do hands-on netball coaching with her daughter's team because she could not reach her arms up like she used to.

*I used to play team sport before I got sick. So I don't think I'll be able to do that ever again. Only because of my reconstructions my arms aren't good. I don't reckon I'd be able to play a team sport again except for a disabled team. I might be able to get in the paras I don't know.*

*CM So have the reconstructions kind of changed – how has that changed?*

*Well the lat dorsi reconstruction, they cut you along your bra line. They actually take a piece of skin out as well, so there's a tightening through the back. It feels tighter than it was before through the back area there.*

For Anna, reconstructive surgery had a detrimental effect on her former

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<sup>3</sup> Breast reconstruction using the latissimus dorsi muscle, which is a muscle that runs from the mid-back through to the chest, under the underarm, and is used in shoulder movement.

preferred physical activity. In addition, Anna talked about the lymph node surgery following her second diagnosis causing numbness in her arm, compounding the limitations that she felt in her body.

*Also my left side, because the lymph nodes were taken out, I've got a numbness through the back of my arm, through there, and because my lymph nodes are out of this arm, I have to watch this arm forever now.*

*[...] Well I probably would have played again. I reckon I would have gone out and had another go in some mums' teams now if I didn't have the worry of my arm and all of that. And also I don't reckon I could play at the level that I'd want to now. I'd have to go down in the low teams and it would be frustrating I reckon. Because I was quite competitive and in quite high teams, so you know if you drop down to lower teams and you've got people that do dumb things, it's annoying (Anna).*

Anna spoke of being disappointed that she could no longer play netball, although at another point in the interview she said that her knees were beginning to limit her netball performance anyway. In Chapter Seven I explore the implications of Anna's inability to participate in her favourite sport, given the medical evidence that women who have had a diagnosis of breast cancer should be encouraged to participate in physical activity.

### *Rebecca*

Rebecca lived in inner Melbourne and was diagnosed in 2001 when she was 39 and her children were nine and four years old. Rebecca said she had a strong history of breast cancer in her family, and that her mother and twin sister had both been diagnosed with breast cancer. She and her partner both worked full time in professional positions and she worked when she could through her treatments. Rebecca had talked about different types of reconstruction with other women and so her decision was made based on her research and the conversations she had with the women. Rebecca had a skin sparing mastectomy<sup>4</sup> after her breast cancer diagnosis and had a

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<sup>4</sup> Skin sparing mastectomy – surgery is performed by cutting out nipple and areola and removing breast tissue from there, thus leaving the skin for subsequent reconstruction.

prophylactic mastectomy<sup>5</sup> and implants inserted a year later, which was her preference although it was distressing during the time when she had one breast and one breast skin flap. Despite having radiotherapy, Rebecca decided on implants because she was a swimmer and did not want her shoulder movement restricted by the latissimus dorsi reconstruction option.

*Usually if you've had radiotherapy [...] they say implants don't work because your muscle is affected. Again, the surgeon I had did a skin sparing mastectomy on me, which is basically just opening the breast up, taking the tissue out, closing it. [...] it is not a nice look and it was really distressing to live like that for me for a year because I do lots of swimming and lots of sport. It was really like a mutilation basically.*

*[...] Because I was having two I didn't actually have enough stomach tissue [for a TRAM<sup>6</sup> flap]. The next option was to use the lat dorsi muscle on the back in conjunction with an implant, and because I do swimming because I've had so much hip surgery I thought I don't want to have a whole lot of surgery up here. So I said to them, "Will you just do implants?" [...] and she was concerned it would be a compromised outcome. And it is slightly compromised but for me, just having the implants is an absolutely easy way [...]. I know people who have had the TRAM flaps and the lat dorsi and I know people who have run into big problems with them [...].*

*CM And how did you find, was it, did you find it painful when you had the reconstruction?*

*No. The initial insertion of the implants, because what they do is they put them in under the muscle, I felt a bit like I had been run over by a truck for a few days but it was nothing, nothing compared to anything else I'd gone through. The rest was just nuisance factor [...]. I was just so excited to be getting some boobs back that I would have gone through hell and high water (Rebecca).*

Rebecca's account of her decision to undergo reconstructive surgery using implants was based entirely on her desire to continue with one of her favourite forms of physical activity: swimming. Rebecca's account illustrates ways in which the women spoke about what they thought was a disjunction

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<sup>5</sup> Prophylactic mastectomy – removal of a healthy breast to prevent breast cancer.

<sup>6</sup> TRAM flap reconstruction – transverse rectus abdominus muscle is used to form a reconstructed breast.



between what they reported was important to surgeons (cosmetic result) and what was important to the women (everyday life, including physical activity). Rebecca spoke about the time in which she had one breast and the other side being loose skin where her breast had been as being extremely distressing, suggesting concern with the aesthetic look of her breasts. Yet, for her, even though the end result would not be cosmetically as good a result as other options, it was still the preferable compromise to potentially restrictive surgery. Thus, Rebecca made a trade-off between cosmetic result and her love of, and desire to continue, swimming.

### *Justine*

Justine decided to have a reconstruction at the time of her breast cancer surgery and felt that had she known how painful it would be, and for how long, she may have made different choices. Justine described in detail her bodily and emotional experiences of making the decision to undergo reconstruction surgery, having inflators inserted at the time of her bilateral mastectomy, the feeling of the inflators inside her chest and their gradual inflation before finally having surgery for silicone implants.

*So I had the reconstruction and that was a much longer and more painful and more invasive process than I had imagined. So I think I also didn't really grasp what the impact of the surgery would be on my medium term physical condition*

*[...] And that process of expansion, they're actually stretching the chest muscles, so you can't breathe properly lying down.*

*[...] it's terribly difficult and challenging to live with having your body changed surgically in that way, but at the same time you do grow and you couldn't revert to who you were.*

*[...] And I found it extremely difficult to look at what they'd done, and I still do. You know, I just avoid looking in the bathroom. My son hasn't actually seen the consequences of the surgery, I just find it too tragic, you know.*

Justine's account includes references to her feelings about her surgically reconstructed body, as well as her son's response to her harder-feeling breasts while they were being inflated.

*What [my son] said to me, we were having a cuddle you know when they had started reinflating these things inside me. I was having a cuddle with [him] one day and my partner was there*

*and [my son] turned to me and said “Mummy why are your breasts so hard?” And I said, “oh, you know, the doctors made a bit of a mess of them when I was in hospital”. But you know, it’s just terribly sad.*

*[...] You know, I’m well supported and you can talk to other women with the disease that there’s still this stuff that they’re not getting to about the body. And particularly because it’s your breasts and [...] for me the breastfeeding thing (Justine).*

Justine’s account is painfully illustrative of how some of the women felt about their relationships with their internal and external bodies including their bodily relationships with those people close to them (in Justine’s account, her son’s response to her hard breasts). Justine also highlighted her struggle with tensions between intellectual and emotional decisions about breast reconstruction and body image.

The accounts above show that when given the opportunity to explore it, an important everyday reason for the women who decided to undergo reconstructive surgery was to enable their continued participation in physical activity. The women who decided to undergo reconstructions after having experienced wearing a prosthesis said they found it easier not to have to worry about the prosthesis slipping while at the gym or playing sport and to be able to wear ordinary swimming costumes. Where the women researched how their everyday/everynight lives could be affected, including their usual participation in physical activity, as part of their decision-making about reconstructive surgery, their accounts of their experience of reconstructive surgery were far more positive than those who did not have the opportunity to consider potential consequences for their everyday/everynight lives and physical activity pursuits. The women who underwent reconstructive surgery typically said they felt that the dominant medical concern was breast loss or change (scarring, reduction in size) and sometimes, what this may mean to their partners.

I have not included accounts of the 30 women who decided against reconstructive surgery (or remained undecided) because they did not talk about their decision being related to their participation in physical activity.

Rather, the women spoke about not wishing to potentially cause more problems for their body, or not being happy with the result. Janine, for example, did talk about her concern that reconstructive surgery could exacerbate her lymphoedema and that for her, losing a breast was not as bad as her experience of lymphoedema.

In summary, reconstruction surgery/ies was incongruent with breast cancer treatment decisions, in that it was the only decision (particularly for the women who decided to have reconstruction surgery/ies) reported as being based entirely on the way they lived their bodies (physically and emotionally) in their everyday/everynight lives and their *own* relationships with their bodies. It was the only decision that they spoke about making outside their social context, for example, they did not talk about including their partners' preferences or what would be best for their children. Rather, the women who decided to have reconstructive surgery talked a great deal about ways in which reconstruction surgery either enabled them to feel more comfortable participating in physical activity, or ways in which it constrained their physical activity participation. The women who found participating in physical activity better after their reconstructive surgery talked about not needing to worry about their prosthesis moving or being seen, or feeling more balanced. In this sense the women's decisions to undergo reconstruction to enable them to resume their usual physical activity participation were very likely based on broader, taken for granted social expectations. The women who found their physical activity participation was constrained by their reconstructive surgery talked about increased pain, or a loss or weakening of muscles that they previously used in their participation of physical activity.

### **Chemotherapy, radiotherapy and physical activity**

Thirty of the women decided to undergo chemotherapy. The women talked about their decision to undergo chemotherapy (or not) in terms of their everyday/everynight lives, particularly their children. The women explained their decisions based on their prognoses plus the age/s and stage/s of their children, like Joanna and Bernadette's typical accounts below:

*I think mine was 90 or 91% of women would be Ok without any*

*further treatment. Then add 1.5% if you have chemotherapy, so I kind of figured that I would run the risk of that [...] and she would have started school being the kid with the sick Mum, or the kid with the bald Mum, or the kid with the funny Mum (Joanna).*

Here, Joanna did not want her daughter to feel stigmatised at what she viewed as an important time in her daughter's life - starting school. She felt that it would cause her daughter distress or embarrassment starting school with a mother who looked different from the other mothers. Her concern for her daughter's sensibilities therefore contributed to her decision not to undergo chemotherapy.

Conversely Bernadette's account, where she decided to have chemotherapy based on her doctors' advice because of her young age and because she had young children:

*When the results came back the lymph was clear [...]. They said chemo was just a mop up because of my age and because I've got little kids they just wanted to make sure that the chemo cleaned everything up so the cycle that we chose was what - [the oncologist] recommended three to us - and we chose the one that was the newest (Bernadette)*

Several of the women's accounts included references to conversations with specialists who reinforced the notion of chemotherapy being particularly important because they were mothers; that is, it was important so they would survive for their children's sake to a greater extent than survival being important regardless of whether or not they had children. The women universally went on to describe their experiences of chemotherapy in the same context.

Some of the women had to work and fitted their chemotherapy in between their work commitments so they could continue to support their families financially. The women included descriptions of their conversations with other people, such as their friends and family, as well as with their doctors, from that period as part of telling their stories, and many talked of trying to keep life as normal as possible for their families.

The women's accounts of participating in physical activity while undergoing chemotherapy and radiotherapy were variable, depending on how they responded to the treatments, both physically and mentally, and what physical activity meant to them before breast cancer. During this time, three of the women gave accounts of their oncologists encouraging or supporting their desire to participate in physical activity.

Twenty-three of the women underwent radiotherapy (one of whom had radiation injections), which involved travelling to a radiotherapy unit daily (except weekends), usually between four to six weeks. For the rural women especially, attending radiotherapy was an enormous burden on their everyday lives. A few of the women who had both chemotherapy and radiotherapy said they found radiotherapy more gruelling than chemotherapy. The women talked about radiotherapy causing fatigue, especially those who had very young children for whom they had responsibility upon their return from treatment each day. Some of the women had severe burns which they found immensely distressing and which limited their range of movement. Thus, the women described a broad range of experiences from very few adverse effects to physically and emotionally traumatic experiences.

The following accounts illustrate the ways in which some of the women described their decisions about physical activity participation once they had reached this part of their journey.

### *Therese*

Therese lived on a farm near a large rural Victorian town. She was 48 years old when she was diagnosed with breast cancer in 2006 and her children were nine and seven years old. Therese decided to keep up doing some physical activity throughout her chemotherapy treatment as a way of pushing the chemicals out of her system more quickly.

*I told [my friend] the other mum that's just been diagnosed. I said, "I truly believe", and my oncologist has said that too. He said before I started, because he knew that I was doing Pilates and all that, and he said that he believed if you could keep pumping that stuff and get it out of your body as quickly as*

*possible that you would feel better and so he said, "Even the day of treatment, if you're able to go home and have a bit of a walk around outside, do it. Just keep moving. Keep that blood flowing" and so I did.*

*[...] And also when I was having my chemo I would savour my energy and I'd think, "okay, right, I need to get up and I need to do the dishes" or "I need to attempt to start cooking dinner" or "I need to do the laundry" or "I need to iron". There's all those domestic, family things that I felt were a higher priority than me going off for a walk and I'd tell my husband that and he'd go, "No, go for a walk. Those can wait" or "We'll get by. Go for a walk", and so I would do what I thought was absolutely necessary to have done in the house and then we've got two dogs and the back of our property is bush and so I'd go, "Come on, let's go for a walk", and I would feel much better when I'd come back and, yeah, it probably did make me a little bit more tired, but I don't know, I think, looking back, it was probably the best thing (Therese).*

Therese's account is of physical activity helping her manage her chemotherapy. Therese's account also demonstrates how partner support was important not only for the women's breast cancer journeys generally, but also for enabling their participation in physical activity, and I follow this up in Part Three of my analysis.

### *Rebecca*

Rebecca continued to work through the first four rounds of chemotherapy but stopped work once she commenced Taxol<sup>7</sup>. In her account, she talked of her partner being extremely supportive, explaining that he took their children away to stay with his brother's family who lived in the country on the weekends after she had had chemotherapy to allow her some time to herself to recover.

*I managed to work through the first four, which was the AC<sup>8</sup>. I would have it Wednesday. I would have Thursday, Friday, Saturday, Sunday pretty unwell. My husband used to take the two girls up to the country so I just had the weekend to myself and I usually got back to work on the Monday. I would work the*

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<sup>7</sup> Taxol is the brand name of a chemotherapy drug called Paclitaxel.

<sup>8</sup> AC – Adriamycin plus Cytosin - a mixture of two chemotherapy drugs.

*next two weeks until the next lot. But then my blood counts got far too low. They had to defer one of them. My work was absolutely fantastic. They completely redesigned my job so I had no client contact. I could do everything by phone. I used to drive to work, not leave the building, never met with anyone because I was just such at risk of infection and stuff and then go home basically. But once I started Taxol, I had the first lot of that and didn't get back to work for four or five months (Rebecca).*

Rebecca spoke of physical activity being her “stress release”, as she does below as a “chill out” and she also spoke of feeling that it was particularly important after her breast cancer diagnosis.

*I feel better doing sports. Always feel much, much better. It is my stress release to go to gym. [...] I think [since my diagnosis] I probably more consciously try and chill out when I exercise. I know that is why I'm exercising. That has been the biggest change. I try and de-stress (Rebecca).*

Rebecca went on to describe the effects of taxol and nutropin<sup>9</sup> on her body and how the drugs limited her capacity for physical activity because she was in a great deal of pain. She also felt fearful of infection should she go to the gym, and then have to extend the period of time over which she had her chemotherapy treatment.

*When I could, I did go for walks. I've always gone walking, but it was more as a chill out than a fitness thing. [...] I was just so exhausted, and you read these things about exercise and breast cancer and treatment. My biggest concern was, because I'd always gone to the gym, I couldn't go to the gym for risk of infection. It was just too significant and I was just so keen to get through those chemos (Rebecca)*

### *Grace*

Grace was diagnosed with breast cancer in 2002 when she was 33 and her children were six and four years old. Grace lived in a rural town in South

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<sup>9</sup> Nutropin is the brand name of Somatropin and is used to replace growth hormone.

Australia and flew to Adelaide for all of her treatments. While she was the main income earner for the family, her partner had received an inheritance which meant they had financial security for the time that she was unable to work. Grace said, however, that she was also able to maintain appointments with her clients around her treatment schedule. Grace's account was of sailing through her radiotherapy treatment. Grace said she felt comfortable leaving her children with her partner and focussing entirely on herself, because it was normal for her partner to care for their children anyway.

*CM And you found radiotherapy alright?*

*Not a problem. Again, [like chemotherapy] I was very lucky. I stayed at Greenhill Lodge<sup>10</sup> for the six weeks and had my little two-minute session every day. In between that I [completed a professional development] course.*

*[...] I had to travel for my treatment, I didn't have my kids in tow, so really it was just all about me and whatever Oprah<sup>11</sup> was doing that day and whatever magazines were out that week and I didn't really have to worry about them too much, well, at all.*

*[...] Maybe in a way, even though I was away from my family, maybe it really gave me a lot of time because I can't really ever remember being tired.*

*[...] but then with the radiotherapy, because I used to [...] walk down to the [institute], and then I used to just go [...] in a taxi to [the hospital] because it took no time to do radio and then just taxi back and then I'd walk back to Greenhill Lodge at the end of the day, like 4 o'clock after the course was finished (Grace).*

Grace was able to walk to and from her radiotherapy sessions and did not have the responsibility of her pre-school aged children upon her return from treatment. Grace pondered whether managing to do some exercise, as well as being responsible only for herself, contributed to managing radiotherapy (and chemotherapy) so well.

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<sup>10</sup> Greenhill Lodge is a motel operated by The Cancer Council South Australia that charges subsidised rates to people who live more than 100kms from Adelaide and are having cancer treatment/s in Adelaide, and their carer/family.

<sup>11</sup> Oprah Winfrey is an USA-based television talk-show program host.



*Sophie*

Sophie was 28 years old when she was diagnosed with breast cancer in 2006 and her baby was 12 months old. She lived in Adelaide, was pregnant at the time of her interview and her partner worked full time. Sophie's account is typical of the women who found radiotherapy extremely difficult, and possibly worse than chemotherapy.

*CM How did you find radiotherapy?*

*Worse than the chemo actually. I found it really gruelling. I think with the chemo you knew that you were going to have those few yucky days, but with the radiotherapy I just found that it was just a daily - fatigue that I couldn't even describe [...] it's almost overwhelming fatigue.*

*And you feel quite - you don't feel yourself, you feel quite blue almost. I found that worse than the chemo. 'Cause I think you kind of rev yourself up for the chemo, you know you're going in there that day, and you just kind of get on with it and deal with the side effects, and then each day you can feel yourself getting better. But six weeks of this kind of black hole where every day was kind of the same, and also with [my baby], having to organise care for her every day was really tough. I could take her in with me, but I needed somebody else to watch her while I went in for treatment (Sophie).*

Sophie talked of being unable to consider doing anything for herself (including physical activity) because she had used up all her support on having her baby looked after while she was having her radiotherapy sessions.

*[My parents-in-law] actually took a holiday saying that it was so she could rest after all of the effort she'd put in, which made me feel just awful [...] and even now if I do, because obviously getting pregnant you have all your appointments and scans and things like that, that I'm asking again, and I just hate it (Sophie).*

I explore the effects of "using up support" on physical activity participation in Part Three of my analysis.

The women's accounts of their decisions about and their experiences of chemotherapy and radiotherapy illustrate the ways in which decisions became increasingly complex over time. While decisions about breast cancer surgery (not including reconstructive surgery) were generally simple (although unpleasant) with relatively quick recovery time, decisions about

chemotherapy and radiotherapy were more complex, and required longer recovery times and therefore had longer lasting effects on the everyday/everynight lives of the women and, by their accounts, their families. The next stage of the women's journeys start at completion of their acute breast cancer treatment. From this point on, decisions about physical activity participation as part of supporting health became more important for some of the women, and this is partly in response to the women learning about exercise mitigating adverse effects of adjuvant drug therapies and induced menopause.

### ***Journey into survivorship***

Most of the women had completed their acute care treatment at the time of their interviews. The women's accounts revealed a distinction between the ways in which they made decisions at the beginning of their breast cancer journeys, and the decisions they made once acute treatment was completed. This second section of the chapter focuses on the women's decisions about their longer-term drug therapy (adjuvant therapy), health effects of treatment and maintaining future health. Many of the women talked in great detail of a range of iatrogenic health problems that they experienced, some of which they felt would be ongoing for the rest of their lives. The women spoke in greatest depth about health benefits of physical activity when it was in terms of mitigating long-term effects of breast cancer treatments. Therefore, during this next stage of the women's journeys, physical activity began to feature more prominently as providing specific health benefits.

Paradoxically, the women who undertook long-term follow-up drug therapy said these drugs are what reduced their capacity to participate in physical activity the most, yet some of these were the drugs which caused bone mineral density loss. The drugs that the women spoke about included

tamoxifen, aromatase inhibitors and herceptin<sup>12</sup>.

### *Jen*

Jen was 42 and her children were 19, 18 and 17 years old at the time of her breast cancer diagnosis in 2004. The women talked about aromatase inhibitors (arimidex and femara) as causing a great deal of discomfort such as painful joints, body aches and burning hands and/or feet, as described here by Jen.

*By the end of every day I am absolutely flat. I can't hardly even think, because I push myself all day and I think, "no, it is not going to stop me – that's it we are just going to keep going". I'm on medication for five years – Arimidex.*

*I just notice that I am very flat and I just hurt – arthritis completely right through every bone. So I try to ignore it and I take something to help me with that of course, but no, I do – I ache a lot. My feet hurt, they just burn all the time.*

*[...] They say it is from the certain chemo that I had – I have no idea what it is called anyway. I had a really big dose of that, so they reckon that's what it is and it will take the five years after I have finished with the Arimidex, they reckon it will stop. But I've got another three and a half to go (Jen).*

Most of the women who had commenced taking aromatase inhibitors explained that they reduce bone density, and that because of this they had to undergo a bone density test prior to their doctors prescribing them. Twelve of the women explained in detail the ways in which physical activity, particularly weight bearing exercises (or resistance exercises), was beneficial in maintaining bone mineral density and therefore slowing or preventing osteoporosis that they said resulted in the drug therapy and/or induced menopause.

### *Manee*

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<sup>12</sup> Tamoxifen and aromatase inhibitors limit the effects of/ reduce oestrogen in the body. Herceptin is used in the treatment of women who have Human Epidermal Growth Receptor 2 positive (HER 2+) tumours.

Manee lived in a rural town near the New South Wales and Victorian state borders and was 48 years old and her daughters were 22 and 18 years old when she was first diagnosed with breast cancer in 2006. Manee's account below is illustrative of the women who spoke about aromatase inhibitors, weight bearing exercises and bone mineral density.

*I walk to town to work so I feel like because I have full bone density [...] arimidex which is the medication I'm just about to change onto is not very good for the bones, it does tend to leech the calcium so that's why [...] if the bone density is not good they won't put women on it, if the bone density results aren't good so because my bone density is quite good I can go onto arimidex but I need to maintain that strength so cycling and swimming aren't really the sports for that so basically it's your walking, it's your weight bearing exercises which is what I get at the gym, the weight bearing stuff so yeah I basically do that for that.*

*[...] so [the oncologist] talks about it as well so she sent me for a bone density scan and that came back good. Cholesterol was the other issue, I had to get my down, I got it down from 6.8, it's just a genetic thing I think but I got it down to 5 so if I can keep it down then I'll stay on the Arimidex. I haven't started on the Arimidex.*

*[...] [The physiotherapist] will always say "well these are the choices, if you're on tamoxifen it's better for bone density but arimidex isn't" so it's actually put into your face all the time, bone density, bone density, bone density depending on which drug so it's something that you cannot not be aware of because what drug you take actually effects your bone density so it's something that comes up all the time, something that we all talk about and then: what is a weight bearing exercise? (Manee).*

Manee's account illustrates the way in which some of the women would explain which drugs were appropriate based on their bone density, and very specifically which types of exercise would assist in maintaining their bone density. Manee suggested that it would be unusual for women who have had a breast cancer diagnosis not to know about weight bearing exercises mitigating the effects of aromatase inhibitors.

Below, I present two case studies to illustrate the ways in which a few of the women made decisions about their longer term breast cancer treatments. The women's decision-making involved negotiating information about their

adjuvant therapy and participation in physical activity.

### *Therese*

Therese's story below of her decision to stop taking tamoxifen begins with accounts of her (physical) embodied experience, conversations with her husband, her oncologist and other women's embodied expertise. Therese said that her doctor insisted her physical discomfort was caused by lasting effects of the chemotherapy rather than the tamoxifen, however as her account illustrates, she was not convinced by his explanation.

*Within a week [of taking tamoxifen] I was having really bad body aches. [...] I called up to oncology and said, "I'm aching really bad", and the nurse said, "That's quite common." [...] and I just remember around Mother's Day we went down to our little dam and we were just yabbing<sup>13</sup> and the kids were mucking around and I sat down on the edge of the dam and I couldn't get back up, like I just ached and [...] I said [to my husband] "I'm so sick of this" and he said, "Is it really worth it taking those tablets?", and the oncologist just - he just went, you know, "It's not the tamoxifen. It's the chemo; it's the chemo [...] sometimes it can be a delayed reaction. It starts affecting your balance months later." So, I had an appointment at the end of May and [...] I didn't take another tablet after that [...]*

*[...] and he said, "The studies aren't really all that conclusive on tamoxifen anyway", and I said, "Well, why did you put me on it?", sort of thing, and he goes, "It's just standard practice, you know. Everybody goes on it."*

*So then I just became obsessed with finding out more on these drugs and so I had my month off. I went and did a lot of reading, talking to a lot of the other ladies who complained about the weight gain and the body aches and a general sense of like depression setting in and I thought, "I'm not having any of that. I'm off this" (Therese).*

Therese stopped taking tamoxifen and searched the internet and talked with other women who had breast cancer about their experiences of tamoxifen and made her decision based on weighing up the effects on her quality of life, her various conversations and her overall medical prognosis. Therese

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<sup>13</sup> A yabby is a fresh water crustacean found in Australian fresh water sources.

also talked about attending a Pilates<sup>14</sup> class immediately after her chemotherapy treatment finished, but being unable to continue once she commenced taking tamoxifen.

*I've always been very active and I was doing an advanced Pilates course once a week and, ride bikes with the kids and do all that sort of stuff at home and go for walks and, we've got a gym at home as well, so always did a bit of weight work, not super, but I've always been fairly fit. [...] I got straight back into the Pilates after chemo and, went fine with that until the body aches started getting too bad. [...] I kept saying to the physio and she said, "Well, I've heard things about tamoxifen. A lot of women have complained about the body aches" and I said, "Well" - and she'd seen me. She'd seen me come from chemo. She'd seen me all through chemo and I wasn't physically complaining. I may get a little tired, but I was still capable of doing everything and still fairly active and then to come back and do several weeks of Pilates and keep up with everyone and keep doing it and then to start gradually going down hill when I started on the medication, she could see it and knew that - well, she felt it was tamoxifen as well (Therese).*

Therese's account is representative of the ways in which some of the women talked about their own or other women's accounts of their bodily experiences (embodied expertise) as knowledge that is interchangeable with or equal to mainstream medical information. Therese used her own, and other women's, embodied expertise as well as conversations with her physiotherapist, to critique medical expert information, to the extent that she insisted on different treatment against her doctor's original advice. Therese finally gained agreement from her oncologist to go off tamoxifen, and also to not take an alternative. Therese took action because she could feel in her body that the tamoxifen was limiting her everyday activities, particularly her participation in physical activity.

### *Jodie*

Jodie was diagnosed with breast cancer in 2003 when she was 39 and her

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<sup>14</sup> Pilates – an exercise regime usually applied for strengthening core muscles, initially designed by Joseph Pilates in Germany.

daughter was four years old. She lived in outer metropolitan Melbourne and was separating from her partner at the time of her interview. Jodie's account illustrates how many of the women had developed in-depth knowledge of breast cancer and breast cancer treatments in the time since their breast cancer diagnosis. Jodie said she instigated a complete change in her treatment after attending a lecture and then checking her own pathology report against the information she gained at the lecture. Jodie also described the types of information that she subsequently gathered from an American website.

Jodie referred to the website on a number of occasions throughout the interview and offered her responses to the different types of information that she obtained from the site. Jodie explained that she started going to the gym because her "heart scan [...] readings were going down" and her knees were painful, and that she knew that these symptoms were adverse effects of herceptin. Jodie's account is characteristic of some of the women's in-depth knowledge of the effects of breast cancer drugs, and one of whom gave details about the effects that particular forms of physical activity has on particular parts of their bodies and biological processes.

*[...] because you have to have a heart scan every three months when you're on Herceptin, and my readings were going down, and I thought "oh my god". And I said "right that's it", and I started to go to the gym. And my knees had been, like walking down the back stairs to the laundry; I was falling apart. So it all sort of happened at once and started taking fish oil and glucosamine and going to the gym. So then my heart scan readings were the same, like they were level. Except for the last one I just had a couple of weeks ago, I'd been a bit slack going to the gym so it had actually gone down to 65, so that was interesting, that was quite a good interesting lesson. So I have since then, going to the gym and that kind of stuff, trying to be more active. Because my body was just; being on the aromatase inhibitors and having had my ovaries out, and just being totally depleted of oestrogen. And maybe the Herceptin too has that effect, according to the website and my American HER-2 website. So I'll be very interested to see how I am six weeks, three months down the track for body aches and stuff.*

*[...] I take the fish oil for my heart function and the exercise to keep my heart up, and also for osteoporosis and all that stuff, weight bearing exercises. But it all sort of comes together as*

*one basically.*

*[...] I have osteopenia, I know that, so I do definitely find the benefit now (Jodie).*

Jodie's account is typical of the very few women who had increased or changed their participation in physical activity because of their breast cancer diagnosis or treatment effects, and because of their own research into breast cancer and health.

The women commonly said that breast cancer treatments caused them to start menopause. All of the women who spoke about starting menopause said they did so after commencing chemotherapy or adjuvant drug therapy (or after having their ovaries removed), with the exception of Blanche.

### *Blanche*

Blanche lived interstate when she was diagnosed with breast cancer in 1986, was 38 years old and her children were thirteen and 20 months old. She was living in Adelaide at the time of her interview. In her account below, Blanche said she started menopause immediately after her mastectomy and about 12 years later was diagnosed with osteoporosis.

*Only my family doctor [talked about health benefits of exercise]. About eight years ago I had general tests, blood tests and I had [osteoporosis] in my spine and at that stage my doctor was suggesting maybe to go on hormone replacement. My doctor looked at that and said "I don't think they have eliminated this factor, and think about it" [...] and I thought no, I don't want this. So I upped my exercise a bit more and I went onto caltrate<sup>15</sup>, took two at night and [the bone density] actually increased slightly so it hasn't degenerated anymore. [...] When we talked about the risk of breast cancer [...] I didn't want to take [hormone replacement therapy]. After I had my mastectomy I went straight through menopause [...] I did swim a lot then and [found out] when I had the diagnosis of osteoporosis that it wasn't a weight bearing exercise (Blanche).*

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<sup>15</sup> Caltrate is a calcium supplement.



Blanche spoke of being concerned about taking hormone replacement therapy and decided to increase her weight bearing exercises and take a calcium supplement. Blanche also talked about swimming and explained that swimming was not weight bearing and so was not a useful exercise for preventing osteoporosis.

### ***Conclusion***

In this part of my analysis I have addressed the women's decision-making about how to support their health, with a focus on physical activity participation. I began by exploring the ways in which the women made decisions following their discovery of a breast change, which sets the scene for subsequent health-related decisions. I described the ways in which their accounts of their everyday/everynight lives, their bodily experiences, their paid work and family financial status, and their relationships with their families, particularly their concern for their children, intersected with their relationships with and information from their health professionals, and information from other sources such as other women who have had a breast cancer diagnosis. It is these intersections over the passage of time, rather than specific information sources as such, which shaped the women's decisions about when and which treatment/s they would undergo. Over the course of their breast cancer journeys, my analysis shows that several of the women gained a great deal of knowledge about specific benefits of participation in physical activity.

In summary, I have described how the women's decisions about their health were not made in isolation as individuals with a disease that requires particular treatments. Rather, with the possible exception of reconstructive surgery, their decisions were made in the context of the responsibility they felt as mothers, daughters, workers, their relationships with their partners and sometimes their parents and/or siblings. Having set the context in which the women made health decisions over the course of their journeys, in the next part of my analysis, I describe the women's responses to health promotion information.



## **Chapter 5: Responding to health promotion after breast cancer**

### ***Introduction***

In the previous part of my analysis I explored the women's responses to and knowledge of information about health benefits of physical activity in the context of their decision-making about their health. I found that the women's decisions were iterative and closely connected to their everyday/everynight lives and stages along their breast cancer journeys. In this part of my analysis I show how the women responded to health promotion messages by reframing and personalising health promotion information as part of their embodiment of breast cancer knowledge.

This chapter is in two sections; the first being an analysis of women's responses to health promotion and second section analyses the women's sources of information. Two key themes emerged from the women's accounts of their responses to health promotion. Firstly, most of the women linked health promotion directly to breast cancer causation. Secondly, and interconnected with ideas about causation, around half of the women spoke about taking health promotion messages "with a grain of salt". In the second section of this chapter, I analyse the information sources and information materials the women said they used.

I begin below by establishing the women's knowledge of specific health benefits of physical activity specifically after a breast cancer diagnosis, as part of their accounts of their responses to information. Most of the women gave accounts of what they knew about physical activity and health, both in general terms and relating to breast cancer. All of the women expressed awareness that participating in regular physical activity provides a range of health benefits, not restricted to women who have had a breast cancer diagnosis. Therefore, none of the women contested the information, although, their accounts varied as to the extent to which they thought physical activity provided health benefits.

## ***Knowledge about health benefits of physical activity***

Twenty-one women talked about physical activity having specific benefits for women who have had a breast cancer diagnosis, with many talking about several benefits. The specific benefits that the women talked about included:

- weight bearing exercises to prevent/treat osteoporosis brought about by cancer drug treatments and/or induced menopause (n=12),
- improving mental/emotional health/ time out (n=10),
- knowing they would feel better (n=7),
- preventing/treating lymphoedema (n=6),
- keeping weight down (n=6),
- getting through chemotherapy better and/or recovering better from treatments (n=5),
- reducing the likelihood of recurrence (n=4),
- reducing stress (and potentially recurrence) (n=3),
- reducing fatigue/increasing energy (n=3),
- increasing oxygen in the body which promotes cell repair (n=1).

Of the women who talked about physical activity being beneficial for women who have had a breast cancer diagnosis, twelve spoke about specific benefits of weight bearing exercises, of whom most described how weight bearing exercises slow bone thinning or improve bone mineral density to counter the effects of adjuvant drug therapies and/or drug or surgically induced menopause. I explore this more thoroughly below. Two women, Emma and Melissa, worked in the fitness industry but did not specifically describe osteoporosis or the effects on bone density of weight bearing exercises. They are not included in the group of 12 women who did, however, because of their workplaces it is extremely likely they did know of these benefits and took it for granted. They spoke about the importance of weight bearing exercises a great deal, without stating why, and went into detail about other physical activity benefits, for example Emma's account of dragon boat paddling to prevent or reduce lymphoedema. Emma referred to Canadian research with dragon boat teams made up of women who have had a breast cancer diagnosis, which led to the establishment of dragon boat teams internationally, including Australia.

*Because you're using your whole paddle - normally you get on the side where you haven't had your surgery. I had my surgery on my right hand side, so I would sit on the left hand side of the boat and by holding the paddle up in the air that supposedly*

*helps lymphatic drainage. So that was originally how dragon boat racing came about (Emma).*

Melissa talked about the types of physical activity she did, with a strong focus on working with weights and resistance.

*Because even my physio she was just saying, “just start off, light ones”, but then again I suppose because of my background I know what I can and can’t do (Melissa).*

Melissa did not specifically mention the benefits of weight bearing exercises on bone mineral density, though she talked about how, being in a small country town, everyone knew about her diagnosis so any women with breast cancer would feel that she would be knowledgeable about what they could do in the gym where she worked.

*...you have an assessment done when you go in and that’s where you fill out your [form] anything you are concerned about, or your aims, what you want to do and medical background [...] everyone knows that I have been through it, you know? So they know there’s someone that’s there (Melissa).*

Here, Melissa is suggesting women diagnosed with breast cancer would be more comfortable going to the gym because of her professional experience plus her embodied experience of having/ had breast cancer.

Six women talked about physical activity being beneficial for women to keep weight down after a breast cancer diagnosis, and one woman talked about this in terms of reducing oestrogen levels. Five women talked about physical activity being helpful in promoting their recovery from treatments and/or from chemotherapy treatments.

Many of the women talked about physical activity being rejuvenating (mentally and/or physically) and potentially increasing overall energy levels or decreasing fatigue, referring to personal experience rather than specific studies that have, for example, found physical activity reduces fatigue or potentially reduces anaemia.

*I think I should [exercise] for health reasons and I know I’ve got to lose some weight before I have a reconstruction. [...] I just*

*get so fatigued. I know the fatigue, once I exercise more, will reduce but it's getting over that hump (Tanya).*

Ten women spoke about specific benefits for mental health, in terms of “clearing the mind”, taking time out, or emotional benefits of team participation in the case of dragon boat paddling. For these women, the benefits were not necessarily limited to physical, biological health, as illustrated by Alana below talking about dragon boat paddling.

*The emotional benefit for women , especially newly diagnosed women, just seeing them, they get so much out of it, it's really good even from that point view, even if there is no improvement in physical fitness, I think it's good just for that.*

*But [dragon boat racing] was not the sort of thing that your specialist would really advocate or you don't hear much about it. So the whole thing about lymphoedema and prevention and that sort of thing in my case, was not really talked about much other than the immediate post operative exercises. I think hopefully now it's changed a little bit. Also because I'd had the area under my arm operated on twice plus severe burns to the area from radiotherapy, I found that the paddling was quite difficult. I wasn't ever a sporty person and it was hard with my arm but it took your mind off it if anything, because it's more the challenge of doing something that's not directly related to breast cancer even though that's the reason it brought the team together to begin with (Alana).*

Again, the women spoke from personal experience rather than information from other sources or evidence from medical intervention studies. Several women talked about *knowing* that they would feel better if they exercised.

Many of the women said that participating in physical activity made them feel good (or better), for a wide range of reasons that applied to them before their diagnosis of breast cancer. In addition to describing scientific medical evidence about benefits of physical activity, the women often spoke of how they felt in their bodies during or after physical activity, drawing on this embodied expertise.

*There were days when I just couldn't but most of the time I know that if I get up and go for a walk or go for a swim or go for a ride I felt better (Bernadette).*

Zoe explained how it is that she felt better after exercise, and how exercising

brought back how she felt prior to her breast cancer diagnosis.

*This morning I did some sit ups. I used to do about nearly 100 sit ups a day and I couldn't do that many this morning but I felt so good. I brought back the feeling how I used to feel [...].*

*CM And the feeling good, can you tell what it was that made you feel good in doing sit ups?*

*You know that feeling that you get, those endorphins that you get? It just felt good because I feel so unfit and lethargic and crappy. It just made me feel like how I used to feel so it was good (Zoe).*

Zoe went on to provide some insight into what contributed to make her feel better, or to feel good. Zoe's account is of feeling good after a range of activities that involve taking time for herself, and physical activity was one of those activities.

*I know what will make me feel good [...]. It is just a feeling that you get. I will know that I feel good to go to the gym. I know that I will feel good if I take time out for myself to read a book or watch a movie or catch up with a friend or just sit in the park. I think it is just life experience. You have been confronted by something like cancer and I think you see the joy in even little things (Zoe).*

Seven of the women talked about physical activity as potentially reducing the likelihood of recurrence, and of these, three women talked about this as possibly a result of reducing stress.

*I was always aware that, I think since I started doing herbal medicine, that there is a component of actually looking after your health in terms of exercise that's actually very good for cancer prevention and that might be to do with the fact that you're taking some of the stress load out of your body so you're doing a lot more relaxation or endorphins or something that it's much better to be healthier (Manee).*

Despite the women's knowledge that physical activity provides health benefits, many of the women were concerned or confused about how much or what types of physical activity were appropriate after their particular treatment/s. The women also spoke of receiving conflicting advice about participating in physical activity.

*Even when I spoke to [doctor], I was telling him about things I was doing, Encore and all this, and he said, “they are just stuff that makes you feel good”. But I think it is a bit more than that.*

*[...] I get conflicting advice. A lot of the women in Encore, their doctors told them “no physical activity”. And one lady who did dragon boats went out for the day and she got lymphoedema so she had to go to a physiotherapist. But I spoke to my oncologist about that and he goes, “there is no evidence to say that it brings on lymphoedema”. So then I would work with weights but then not as much. It is a bit confusing (Zoe).*

Zoe’s account above illustrates how the women used a range of sources of information to make decisions about physical activity participation. In her account, Zoe spoke with her doctors, women participating in the YWCA Encore program and a woman who participated in dragon boat paddling. Two of the women worked in the fitness industry and they also said that there was not a great deal of information for women about how much and/or what types of exercises are appropriate.

*So in my background I knew a fair bit about that sort of thing, but didn’t know a lot about this whole what you are and aren’t allowed to do.*

*[...] We used to ask [the surgeon] a lot, because I was a weight trainer beforehand, one thing that I was told is you can’t really do weights after, because on the side that you’ve had the surgery there is a fear of lymphoedema. So if you lift heavy or there’s constriction. You can’t have blood pressure taken on that arm and whatnot, so they just advised me not to do heavy weight training. They said I could do resistance training, but not heavy training on that particular arm. I used to ask him all about that, but he was good, he said “no you can do this and do that, you’ve got to feel comfortable, but don’t go heavy” (Emma).*

To reiterate, Emma’s account demonstrates knowledge about resistance and weight training but she did not elaborate when questioned about information she has heard about specific health benefits of physical activity for women who have had a breast cancer diagnosis.

In the paragraphs above I have described the women’s knowledge of health benefits of participation in regular physical activity so that it is possible to gain a clear picture of the meaning of physical activity and health after a breast cancer diagnosis (and treatment). I now go on to describe how the women talked about their responses to health promotion, and where physical



activity promotion fits into their more general health promotion stories.

### ***Key responses to health promotion messages***

Almost all of the women spoke of their knowledge about, and sources of, health promotion information broadly, incorporating a range of practices promoted across mainstream, complementary and alternative medical paradigms. Most of the women talked about their views on and/or participation in a range of everyday/everynight practices promoted by mainstream, complementary and alternative medicine, including maintaining a healthy weight, juicing, avoiding dairy products, or practicing meditation (see figure 1). Thus, the women talked holistically about a range of everyday/everynight health promoting practices until I asked the more specific questions about benefits of physical activity, following (usually lengthy) discussions about the range of health promoting practices that the women would initially talk about (see interview guide appendix 7). Based on the women's accounts, and in keeping with reflexive research practice, I therefore refer to "health promotion" as an umbrella for the promotion, by mainstream, complementary and alternative medicine, of everyday/everynight practices that are purported to provide health benefits.

From the moment of diagnosis, virtually all of the women said they were bombarded with information from a broad range of sources. Several women said they put all their information in a box or folder, or just recycled it. Some of the women never looked at it again, or never looked at any of it at all, or just kept it for when they may feel like looking something up, like Grace:

*I stick everything in a box that's in the corner under my bed and that's the breast cancer box and I don't dwell on it. I don't think about it, but I just know if I ever need anything, it's usually in that box (Grace).*

Kate's response below is representative of how many of the women spoke about feeling completely overwhelmed by the enormous amount of advice from a huge range of sources. Kate spoke of dealing with it by doing only what "feels right".

*You're getting advice from everywhere and it just gets too much*

*[...] it was overwhelming and I couldn't take it all in and you beat yourself up because you're not doing the stuff that everyone's telling you that you should be doing, that was really hard. [...] part of what I'm learning now [is that] some stuff you take in and some stuff you let go [...]. Like okay some of the stuff feels right then do it but if it doesn't, don't. Let it go (Kate).*

The women often spoke about information which informed their decisions on ways to support their health in terms of their relationships, recalling conversations they had had with a broad range of people as part of their decision-making processes. The women spoke about helpful and unhelpful advice, advice that they did and did not take, and advice that they were opposed to. Jane's account of conversations with her father and her oncologist is typical of ways in which the women spoke about people giving advice they were opposed to, and how they dealt with it.

*My father was really concerned about me having chemotherapy and had looked into a whole lot of, not necessarily complementary, but new stuff that was out there, particularly selenium and was really quite keen that I take some other stuff which at the time I just wanted to do what was being recommended without thinking what else is possibly out there and doing the research, I just wasn't interested. So that created sort of a tension with me and my father in that he really wanted me to do this and was buying me all these powders and god knows what else and so talking about that with the oncologist, he offered to talk with my Dad. [...] That settled him down and gave him the confidence "well okay there is this evidence". So that was useful in just family dynamics I guess (Jane).*

An important point to reiterate is that it is inappropriate to separate the women's sources of and their responses to information, and their subsequent decisions because in their narratives, like Jane's account above, they typically expressed their responses while talking about their sources and decisions. When it came to thinking about health promotion after breast cancer, the strongest response was that the women talked about health promotion in terms of breast cancer causation.

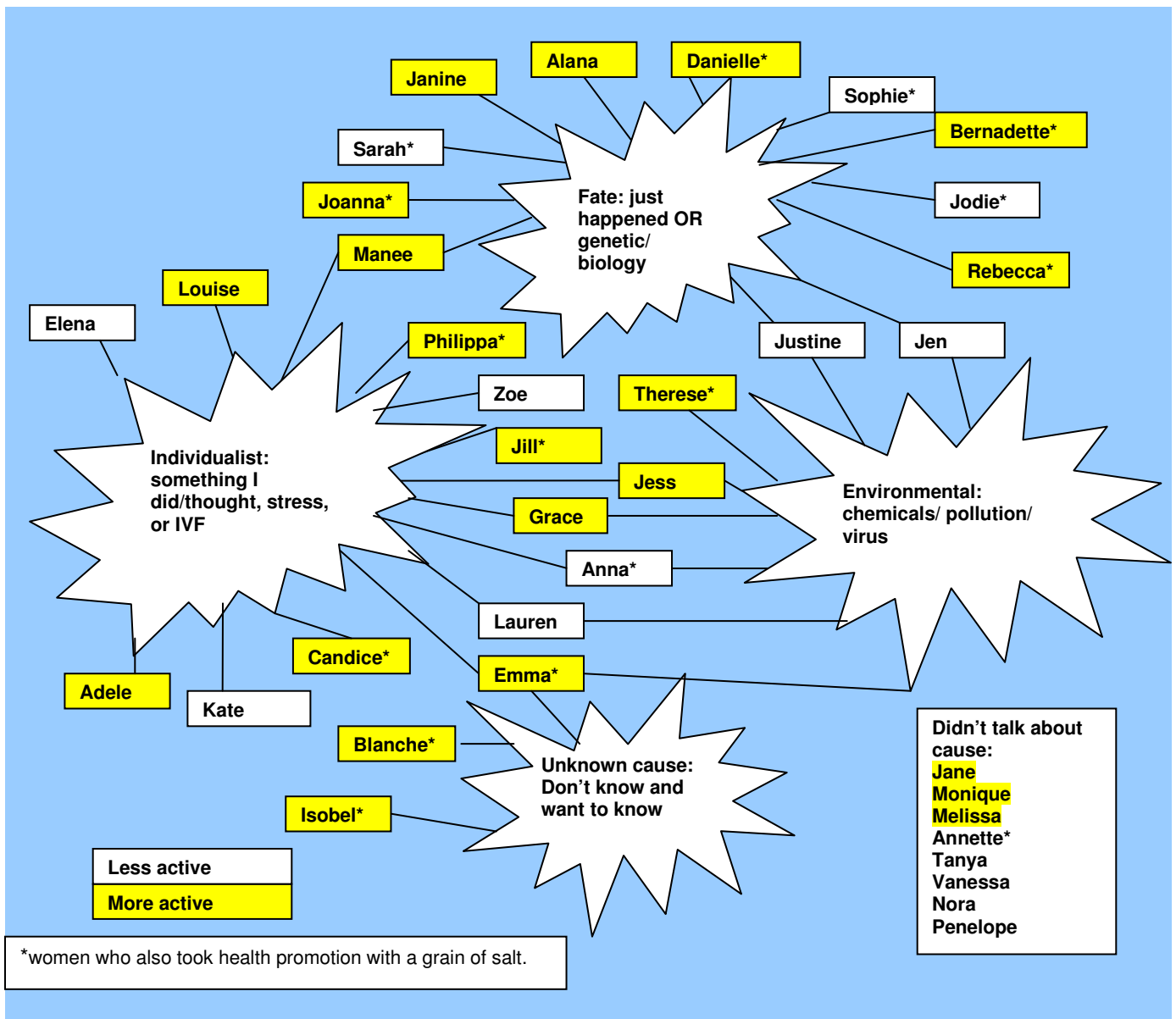


Figure 1: The women's theories of causation

### *Theorising causation and risk*

Over three quarters of the women responded to interview questions about information they had received about how to support their health after breast cancer by talking about possible breast cancer causation. These women weighed up information about benefits of a range of everyday/everynight practices, including physical activity, depending upon what they thought may

have caused their breast cancer in the first place, and thus how they may prevent recurrence.

The women's theories of causation largely influenced their early decisions about everyday life health promotion practices (such as engaging in the practice of juicing or going organic) although the influence on their reported participation in physical activity is less clear. A crucial point to emphasise is that the women who volunteered their theories on causation did so when there were no questions in the interview about causation. For this group of women, there was a direct link between how they viewed health promotion messages and assumptions about breast cancer causation. That is, it appeared the women were interpreting messages about breast cancer risk/protective factors and relating these to their own journeys. Information about health benefits of physical activity did not seem to rate highly in immediate importance if the women did not think physical inactivity caused breast cancer.

The following conversation with Jen shows how the women typically responded to my questions about supporting health by talking about causation.

*CM I was wondering whether anyone talked about stuff that would actually support your health as well, like whether or not they talked about diet, rest, physical activity...?*

*No, nothing.*

*CM Leisure?*

*No, nothing. There was nothing that was given to you in those areas.*

*CM Right.*

*They were just basically, "You've got to have your chemo" – and that's it. Even when I went to Adelaide, I expected them to talk about all this sort of stuff – nothing.*

*CM Okay.*

*I'd say, "What can I do?" – it was just like a blank wall.*

*CM Oh, so you even asked?*

*Yes I would – "do I change my diet? What can I do?" It was*

*just like “**No, it is just one of these things – don’t know why**”. It was a real block off. Then it was other people that would come in and give you information and things like that – it was just other people that have had cancer that would give you other information they had (Jen).*

Jen’s account illustrates how the women typically sought information about what changes they could make in their everyday/everynight practices to support their health with the specific aim of reducing their risk of recurrence - based on what may have caused their breast cancer in the first place. My questions were not directed towards how to prevent recurrence, but were designed to explore whether and how the women received information about health promotion in terms of supporting their health. In early interviews, when the women started talking about causation in response to these questions, I would explain that my questions were not meant to be about what they thought may have caused their breast cancer, but what types of information they had gathered about supporting their general health after breast cancer. Because causation seemed to be a strong response to health promotion messages, and as part of my commitment to reflexive research practice, however, I decided to engage more fully in the topic of causation when it was initiated by the women. I realised that this was an important, although for me unexpected, post-breast cancer diagnosis response to health promotion information.

Jen’s statement in bold above shows that she was seeking to know from her doctors “why” she had breast cancer and “what can I do” to prevent recurrence, rather than simply seeking ways to support her health more generally. Like Jen, many of the women spoke of not finding their mainstream health professionals forthcoming about everyday health promoting practices (for example diet or exercise) which may support their health, and often sought information from other sources, such as other people who had been diagnosed with breast cancer, or from complementary or alternative health professionals.

Four main themes regarding causation emerged, which relate to the literature

on lay/embodied knowledge discussed in Chapter Two and to which I return in Chapter Seven. Firstly, individualist theories, whereby the women wondered what they had personally done to cause the breast cancer, for example, eating something that may have been carcinogenic or the ways in which they have previously responded to stressors. Secondly, environmental theories of causation, for example the women speaking about air pollution or pesticide use in their local area. Thirdly, fatalistic theories of causation, for example talking about whether or not one develops breast cancer as being due to just bad luck or a biological cause such as having lumpy breasts. Fourthly, unproven causation, where women expected that there would be an identifiable cause which is as yet unknown. Some of the women spoke about more than one theory of causation, and some said their views about causation changed over the course of their breast cancer journey (see figure 1). In relation to the research question for this study, individualist theories of causation were most germane, whether the women agreed with or contested them.

### **Individualist theories of causation**

Over one third of all of the women spoke about something they did in their everyday/everynight life practices that they believed may have contributed to causing their breast cancer.

Only one of the women spoke of reports that being overweight or sedentary may cause breast cancer, in response to a media campaign at the time of her interview. Jill gave an account of feeling victimised by the media's take on research on links between breast cancer and physical inactivity and obesity. She expressed feeling that the media was stating that women caused their own breast cancer.

*Well, I must admit, a few weeks when they were saying you know it's because they're obese and women aren't exercising, I felt a bit hurt. I felt like saying "well why doesn't every fat lazy woman, and I'm not lazy, get breast cancer?" I initially felt a bit... "oh, they're making it sound like you're fat and lazy" (Jill).*

Jill's account goes on to be critical of individual risk factors being portrayed as causing individuals to develop breast cancer and refutes the evidence in

terms of knowing individuals who did not fit the risk factors. Jill referred to Australian marathon runner Kerry McCann who was diagnosed with breast cancer around the time of her interview.

*And then when that young, that 40-year-old runner got breast cancer, well there goes that theory [...] when I was having chemo I met a Greek girl who was a little bit younger than me, we had exactly the same, grade 3, one node. And she was a gym junkie, she was thin, completely different diet (Jill).*

Jill distanced herself from evidence that physical inactivity and /or obesity causes breast cancer, based on her own observations of other women she knew, or knew of, who were extremely fit and lean and still developed breast cancer. Although she spoke about physical inactivity and obesity in terms of causation, she did so by rejecting the theory.

*Was it something I ate?*

Eight of the women expressed concern that perhaps something in their diet caused their breast cancer, most of whom took up the practice of juicing at least in the early days following their breast cancer diagnosis. Fifteen women in the study said they juiced at some stage, even though not all of the women who took up juicing said they thought their breast cancer was caused by their diet. Some of the women also spoke about juicing as a practical way of being able to consume fruits and vegetables while undergoing chemotherapy. Several women also spoke about the importance of maintaining or “boosting” their immune system and viewed the practice of juicing as contributing to this, especially during chemotherapy. Of this group of women, three “went organic” meaning that they changed from eating regular fruits and vegetables and sometimes other food products to only eating fruits and vegetables and other food products that have been grown organically.

Some of the women spoke about fearing food altogether, especially in the early part of their breast cancer journey, as illustrated by Anna.

*After the second operation I lost a lot of weight and then I had eating issues where I was worried about what to eat, because I felt like it had contributed - eating something wrong (Anna).*

The women in this group gave accounts of having similar feelings to Anna in

an initial period following diagnosis. They typically said they simply needed “time” to get through an extreme fear of food, although most of them maintained some changes to their diet, as illustrated by Manee.

*[...] something that did happen to me just after I was diagnosed was I didn't know what caused this lump, I didn't know where it came from and I just became paranoid about everything, about what I ate, what I drank, going out in the sun, I didn't know, I just didn't know where it had come from so I didn't know where to protect myself, how to protect, I just didn't drink, didn't eat sugar, I didn't eat meat so that contributed to everything kind of falling apart physically because I was too afraid to breathe so it's nice to be through that and come out the other end.*

CM What helped you get through that, that sort of fear of food?

*I think it was just time. I'm still quite careful (Manee).*

Some of the women found that over time, juicing and keeping up with only eating organic food became too difficult to fit into their everyday/everynight lives, or too expensive. While some of the women talked about reducing chemicals, a few women also felt that it was not helpful to tell women to “go organic”.

*It's really people doing what it is that seems the right thing to do. For some it really is feeling that by going organic or changing diet in some way they're helping themselves and if that makes them feel better for doing that, that's what they need to do but it's that fine line of them doing that if they want to do it, not because there's some expectation that this is what they should be doing otherwise the cancer will come back because that's mean, it's holding them to ransom (Jane).*

Most of the women who spoke about juicing and/or going organic just in the early part of their breast cancer journeys did so in response to concerns that they had caused their breast cancer. Those who continued with these practices typically said they did so because they had done so prior to their breast cancer diagnoses, while a few of the women continued because of their theory of causation. By comparison, none of the women reported deciding to take up physical activity in the early days of their breast cancer journeys because of fears that physical inactivity may cause breast cancer,



or that physical activity may prevent recurrence.

*Something in me*

Three of the women said they believed their breast cancer was “given” to them “for a reason”, or caused by the ways in which they had previously dealt with life circumstances, for example by not following their path, or by being too “nice”. All three proponents of this theory took up juicing and one went organic, while none increased their participation in physical activity. Lauren’s account pinpoints the cause of her breast cancer as being at a particular time in her life that, in the following account, she revealed in a session with her psychotherapist.

*And so I wanted to find out how I created cancer. So I went and had a session with [psychotherapist] and we talked about it and we worked through that session and I felt like I had found how it had happened and how it occurred and I came out of there feeling fantastic and I actually felt really in control of what was happening. [...] So for me it was not only taking out this physical lump, it was removing a lot of emotional stuff as well (Lauren).*

Lauren talked about feeling she had been foregoing her own and her children’s needs in order to look after her mother following her father’s death and at the same time was having difficulties in her relationship with her partner. Lauren’s account is typical of the way in which a few of the women spoke about coping better if they feel they have some degree of control, that is, feeling that they have some control by knowing the cause of their breast cancer. In other words, first of all knowing the cause, and then viewing the cause as something that can be modified, means to this group of women that some sense of control can be achieved. Lauren went on to talk about her views on Ian Gawler’s<sup>16</sup> theories of causation, and how his theories felt right for her.

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<sup>16</sup> Ian Gawler established The Gawler Foundation, which promotes an holistic approach to living with cancer and more recently other chronic disease. The Gawler Foundation is based in Victoria, Australia. For more information see:

[http://www.gawler.org/html/s01\\_home/home.asp](http://www.gawler.org/html/s01_home/home.asp)

*But at Gawler's they said there's a cancer personality, because they were saying it's a nice people's disease and it's people who can't express themselves and who can't say no [...] would put other people first, not themselves [...]. Yeah it was interesting to change those attitudes, so I thought "oho I've got to change that" (Lauren).*

For Lauren, being able to change her attitude, that is, to stop putting others first, meant regaining control over her future. Similarly Louise talked about her cancer being caused by living her life based on what she thought everyone wanted her to be. Louise spoke with certainty about how and why she developed breast cancer.

*[...] but the reason that I got this is that I was pushing myself too hard, and I was not being myself. I was being what my mother wasn't and I was trying to be this person that everyone else wanted me to be [...] and I now know that if people do expect too much of themselves and have this egotistical view of what their life should be like, that they're going to get cancer (Louise).*

Two of the women gave detailed accounts of using self help literature, citing books written by Louise Hay<sup>17</sup> that they felt assisted them in changing the way they thought about themselves and the way they lived their lives.

*I think probably I'd say a lot of breast cancer women probably put other people ahead of themselves. I've just read this Louise Hay book "You Can Heal Your Life" and just reading her stuff is quite amazing and it just sort of makes sense to me and I think if you learn to appreciate your body and your health and yourself as a person then you'll want to take care of it. Rather than thinking "I should take care of it" it's more of a "you want to care of it" so that's where I want to head in learning to actually care rather than just feel pressured. You feel a little bit like that, like "oh, I have to do this, this and this to be healthy, I don't want the cancer to come back so I have to", it puts pressure on yourself (Kate).*

Again, Kate talked about identifying breast cancer as being caused by putting

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<sup>17</sup> Louise Hay's website describes Louise Hay as one of the founders of the self-help movement. She promotes positive thinking and self-love as key to healing the body. See <http://www.louisehay.com/>

others first. In Kate's account, the self-help literature has assisted her to avoid placing pressure on herself about what she "should" do. Rather, in her account, it assists her to feel like caring for herself, and she felt that if she cared more for herself she would be more likely to engage in health promoting practices. So for Kate, the sense of control was to avoid being over-controlling, and to care for herself first, then all else would follow. Zoe talked about drawing on self help literature prior to her diagnosis and then going back to it after her diagnosis. She expressed frustration at feeling unable to live the way she wanted to because of her financial necessity to work full time. Elsewhere in her interview, Zoe talked about wanting to reduce her paid work hours in part to enable her to participate in physical activity and I follow up her account of this in Part Three of this analysis.

*[...] like Louise Hay. In different parts of your body your illness means different things so with breasts - you don't love yourself, you've got to nurture yourself. So I thought, "Yeah, I've got to do that". I believe it all but I just kind of lost track. I have. I have just lost track of everything because of working. I haven't been living the way I want to live and I think that is crazy (Zoe).*

The women who found self help literature useful talked in terms of the ideas in the books assisting them to take control over their lives and making decisions that felt right to them. These four women, Lauren, Louise, Kate and Zoe, as well as seeing a future that they could potentially control, were able to draw on particular meanings of their breast cancer journeys and self help philosophies of causation, ultimately resisting gendered expectations to continue putting others first.

Conversely, two other women expressed feeling extremely hurt when people suggested that they somehow created the cancer themselves; Justine (below) through something (as yet not revealed) in her life and Jane through unresolved grief following the loss of her first child.

*I mean one of the most devastating things that happened to me was that this very nice mum from the school [...] She said, [...] "oh, you're really going to have to look at yourself now". I said "what do you mean?" And she said "it comes for a reason you know, there's something in your life that makes this happen". And I just, I didn't actually burst into tears on the spot, I sort of*

*said “I don’t think I need a kick up the bum on quite this scale”, and sort of stormed off (Justine).*

Justine went on to express her extreme outrage about Ian Gawler’s philosophies which she felt promoted ideas about causation that lead people into believing that they caused their own (breast) cancer.

*I was in BreastScreen<sup>18</sup>, the day of my diagnosis, and we were shunted past all these different people including the chief counsellor and she said “you might like to read Ian Gawler, he is really inspiring”, and I knew nothing about Ian Gawler. I went and got his autobiography out of the library, it’s called You Can Cure Your Cancer, and started flicking through and there was an account of a woman who’d been doing very well on his alfalfa sprout diet, but then she lost faith and got depressed and got sick and died very quickly. And I was completely outraged. [...] And you know, it’s dangerous nonsense. And yet somehow it’s just allowed to go through [...]. Great, have a cancer centre where you can meditate and do massage and think about the future and where you want to go with your life. You know, great. But if you claim to be able to cure, that is a completely different ball game (Justine).*

The accounts above demonstrate the ways in which the women differed enormously in their views about mainstream and complementary or self-help or alternative philosophies, where a few of the women found Ian Gawler’s philosophies helpful, whereas others, like Justine, found them offensive and dangerous.

Like Jill’s earlier account, Justine’s is typical of the way in which the women would tell me stories about other people they know who do not fit a particular discourse, from “risk factors” to “think positive”. She spoke about her views on “thinking positive”, expressing anger at the ways in which, in her view, thinking positive is promoted as offering a cure.

*Well I think it basically is dishonest. You know, to say that people can survive because they’re positive is absolute bullshit.*

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<sup>18</sup> BreastScreen is an Australian Government funded national mammography screening program, 2 yearly free screening for women aged 50-69 (also for women from 40 years old and women over 70, but these women are not actively recruited or reminded).

*One of the most positive, creative, lovely people I ever knew got breast cancer and died within a year, even younger [than me]. She was a much better human being than I am, and I'm alive and she isn't, and there is nothing to do with being positive. It's to do with the genes and the tumour. It's written in the genes. [...] And it's people, other people who are going to do all that and say "well I saved my own life", and it's bullshit. They had slow moving tumours and they're going to live til they're 95 anyway (Justine).*

Justine spoke with certainty about what she thought contributed to which people developed cancer and which people survived, talking about causation as being "written in the genes" and survivorship as being dependent on the type of tumour rather than whether or not one thinks positive.

### *Stress*

While stress could be viewed in an environmental or structural context (e.g. paid workforce practices, gendered division of labour), the six women in this study who talked about stress as a possible cause of breast cancer talked about either needing to deal with stress better or reducing their levels of stress, thus framing it as an individualist theory of causation. Typically, the women explained exactly which period of their lives they believe contributed. Above I included Lauren's account of attributing her breast cancer to being partly due to the way she responded to a stressful period in her life; she also spoke of the stress itself as a cause.

*Yes so I had a whole lot of stuff going on that for me I believe the cancer was created because of all that stress. [...] So for me I was diagnosed at the end of 2003, [...] dad died in September of 2002 [...]. So then I had to go look for retirement homes for [my mother] we put her into a retirement village, had to do all of that (Lauren).*

The women who theorised about stress being a cause of breast cancer, like Lauren, typically framed stress as meaning "doing too much". Candice talked about trying to "de-stress" in order to support her health in terms of preventing recurrence because she said she believed that stress contributed to her breast cancer.

*I think I was trying to do too much probably at that stage and once you've had a cancer diagnosis I think you think "well if I get an opportunity I'll take it but if I don't want to do something, maybe I won't" and [...] de-stress a little bit that way [...]. Always have that feeling that stress can have a lot to do with it*

*So I actually probably get more worried when I'm stressed than any other times or if I think "oh no...[laughs]" (Candice).*

Candice was trying to ensure that she did not take on too much paid work and was working part-time at the time of her interview. Three of the women talked in terms of either wanting to reduce their hours of paid work or wishing that they could, to assist in reducing their stress.

*...they do say that with cancer, stress can cause things to change so I'm aware of that and that's why I'd be looking to try and reduce my hours (Elena).*

Elena said she couldn't name any specific information sources regarding stress as a cause of cancer, but talked about a number of probable sources, including books that she had read and Occupational Health and Safety lectures. Elena also referred to biological explanations for stress being unhealthy for the body and how physical activity can reduce stress by increasing endorphins.

*I feel like I'm always catching up so it's all not good mentally for the body and I think the cancer sometimes has a lot to do with how stressed you feel so that's why I know that I need to change what I'm doing now in terms of reducing my hours because it's critical to me to give myself the time. Because of all this, it is causing internal feelings of anger, well not so much anger but just frustration, unhappiness, I feel like I'm not moving forward. [...] you should be out there enjoying the sunshine, doing some sport because again physical activity makes you happy I find and I know it does scientifically because of the endorphins that it creates in your body and all that (Elena).*

Elena therefore linked her mental, emotional and physical health by explaining how physical activity makes people happy, which reduces stress, which prevents physical ill-health.

*Stress is I suppose a major cause of a lot of illnesses, when people are stressed they actually get sick more, headaches, migraines, and cancer was part of it.*

*So it's a belief that I've taken on myself and to me it's something that I think "yeah that's good because it's something*

*I can control". If it is something that has occurred, if it's a cancer that's occurred beyond your control well you can't do anything about it it's just your bad luck but if it is something that you can control like you know what they're saying now is the food that you eat can prevent some cancers. So I think it's pretty silly if you know, if you have that kind of information and you just ignore it, it's like smoking causes lung cancer so if you smoke, well what do you expect (Elena).*

Elena's account shows that for her, like the women's accounts above, cause is identifiable and individually modifiable. Elena was certain about cause and for her, being able to control possible causes of cancer was helpful.

Paradoxically, at the time of Elena's interview, she was unable to fit participation in physical activity into her life because of multiple demands including full-time paid work, unpaid work such as cooking and ferrying children to their extra-curricular activities. She expressed concern about this because she had been diagnosed with breast cancer twice and yet had not changed her life to reduce stress.

A few of the women who said they simply could not make the time to participate in physical activity gave accounts of physical activity promotion affecting them negatively because trying to fit it in to their daily lives added to their stress levels.

*I was beginning to get to a point where I think it was, whilst I knew that I should be doing it and it was going to be good for me, that I figured that by getting so stressed out about trying to do it, would have been more harmful than anything. [...] And I had to, yes make that conscious decision to just let it go until we weren't quite so hectic [...]. It did make me feel better when I just decided, "well look, this is ridiculous, you are just putting too much pressure on yourself" and [physical activity] was unfortunately the first thing to get dropped off (Joanna).*

While Joanna did not say explicitly that stress is a cause of breast cancer, in her account she was weighing up the detrimental effects on health caused by stress with the positive effects on health produced by participation in physical activity.

While some of the women who spoke about stress as a cause of breast cancer spoke about participation in physical activity as potentially reducing

stress and thus reducing the risk of recurrence, this was not necessarily translated into actually being more active. Therefore, holding theories of causation relating to physical activity were not enough in themselves to bring about an increase in participation in physical activity.

*I want to know the cause*

Finally, three of the women talked about causation in terms of wanting to know why they developed breast cancer – they felt that they would just like an answer.

*[...] basically I want there to be an answer. I want there to be a cure, but I want to know why in the first place. And so if no one can do either there are lots of theories about lifestyle. But you look at even just at Dragons Abreast which is only 30, 40 people and there are people in it who have lived perfect lives doing nothing wrong, you know, never had a drink, never had a cigarette, you know, done everything by the book and there are the opposite as well. I'd be somewhere in the middle, probably on the bad side [laughs]. And then you look at all the theories about, you know, if you have more than one glass of wine a day you're going to get breast cancer, and it's not the case (Isobel).*

Isobel's account gives examples of people she knows to show how health promotion messages about risk factors do not offer answers, and her account ties in with the next theme; women's accounts of taking health promotion with a grain of salt.

### ***Taking health promotion with a grain of salt***

Thus far, I have described ways in which most of the women responded to interview questions about supporting their health by talking about their ideas about breast cancer causation. For some of the women, theorising causation was an attempt to regain control in the hope of preventing recurrence in the face of dissatisfaction with health promotion messages. The women's theories of causation framed the ways in which they responded to health promotion messages and helps explain why many of the women also responded to health promotion messages "with a grain of salt".

Almost half of the women said they respond to health promotion messages



with some degree of scepticism or cynicism; some stating they “take it with a grain of salt”. The New Shorter Oxford Dictionary defines “to take with a grain of salt” as: “accept with a certain amount of reserve, regard as incredible or exaggerated” (1993 p2674). Several women gave accounts of thinking this way because in their view, scientific research results often at one time show that a particular food/activity prevents cancer and then later research results suggest the opposite. Many of the women referred to research on specific foods, in addition to everyday life risk factors that they cited having seen in health promotion literature. Annette’s account below is typical of this response.

*I think you've got to take it with a grain of salt, to be honest. I think like all the things you read about, if you do this or you don't do this, you know? One thing that I think is real funny is when they say if you eat lots of broccoli you won't get breast cancer. We have broccoli every night in our meal. Probably we eat too much of it. I just think, as far as telling you what to eat and what not to eat, how often do they tell you, “don't eat potatoes” because it's not good for you or something and then 2 years down the track they're telling you to eat potatoes? So I think you've got to just eat sensibly. Have a balanced diet (Annette).*

Like Annette, many of the women interpreted health promotion information as suggesting that if they behave in particular ways, for example by consuming a lot of broccoli, they *will not* develop breast cancer. Several women expressed exasperation at the promotion of healthy lifestyles to reduce breast cancer risk factors because they felt that they did everything right in the first place and still got breast cancer. Thus, they were interpreting messages about reducing personal lifestyle-related risk as leading to personally avoiding breast cancer. Using this interpretation, many of the women questioned the veracity of individual risk factor claims, listing health promotion messages and the most commonly cited evidence about breast cancer specific risk factors, illustrated by Sophie, below. Sophie had read the recommendations from, she recalled, the Cancer Council, and said that she felt “cynical” about reading that type of health promotion literature because she had done “all of that”. In her account below, Sophie lists lifestyle factors in terms of “do” and “don’t” imperatives.

*From the Cancer Council I think, I did some reading on things that you can do to look at preventing breast cancer, and other cancers, which I tend to view a bit - everything I seem to read on what you can do to avoid breast cancer, I think "well I was doing all of that at the time". You know, "breast feed your children for at least 12 months", well I'd done that. "Eat healthy", which I'm a healthy eater. "Don't smoke", I don't smoke. "Don't be over weight", I wasn't over weight. "Exercise", I was exercising. So I kind of look at all that stuff and think "You know what? For some people it's still going to happen even though you do all those things." So I know at the back of my mind that all those things do help, and I wouldn't stop doing those things and think "I'll just go and eat McDonalds every day, it doesn't matter," but I'm a bit cynical when I read that because I think - well you know, it didn't apply to me. So yeah, I'm aware of the Cancer Council's views on steps you can take to reduce - yeah (Sophie).*

Sophie's account above was typical of many of the women who struggled with what they viewed as contradictions between information about risk/protective factors and their own diagnoses of breast cancer. Where the women felt that they had avoided breast cancer risk factors (such as alcohol) and had engaged in protective practices (such as breast feeding their babies), they typically spoke in terms of their own or other women's diagnoses being proof that the evidence purported by health promotion organisations that specific practices prevent breast cancer were incorrect or incomplete. Here, the women's talk about causation intersected with taking health promotion messages with a grain of salt, because the women who contested the veracity of health promotion messages based on their own, and other women's experiences. Strikingly, the women who responded to health promotion messages with a grain of salt in many ways were speaking about it in the same way that Justine did in relation to "think positive" in the previous section. That is, both gave examples where it did not apply either from their own experience or that of other women.

Bernadette's account, on the other hand, differentiates between health promotion messages from major mainstream medical health promotion organisations (such as the Cancer Council) and how it is reported by the media. She talked first of all about taking media representations of health-

related research “with a grain of salt”.

*I've read a lot and I was saying to [my surgeon] just before - in the media lately and comments my mother had made in relation to the “are you buying organic? Are you changing your lifestyle?” She read an article to me yesterday about drinking, that two glasses of wine increases your risk quite significantly according to yesterday's newspaper and I've said to her “that's fine Mum but you can't live on spring water” which it just seems that if you believe everything that you read. Life in general is going to give you cancer is the bottom line, if you're going to get it [...]*

*Yeah or just have the ability to read it and take it with a grain of salt and say well yes sure but you have to live life, you can't tiptoe around and live on organic carrots and water. Balance it all. Balance your exercise, don't let yourself get obese but you don't have to constantly diet (Bernadette).*

However, Bernadette said she liked mainstream medical evidence-based health promotion campaigns as reminders of what is or is not healthy. Bernadette talked about health promotion organisations as being more credible sources of information than the media because they do not “sensationalise” the promotion of healthy behaviours. Typical of many of the women, she also talked about disease awareness raising campaigns while on the topic of health promotion. Bernadette said that she liked them particularly because they are only once a year.

While the women talked about health promotion messages in the media, most said they felt they already did what they could to keep themselves healthy, so they didn't take a great deal of notice.

*I don't really read magazines. I'm not a magazine person. I just flick through the Sunday Mail<sup>19</sup>, so I don't take any notice of that. I suppose I do notice it on TV, you know when they have these [health and lifestyle shows]. I don't watch them religiously. I will look at them and when they promote eating healthy and things like that, I don't pay a lot of attention to that. I just try and do for myself, make sure I have my fruit every day*

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<sup>19</sup> The Sunday Mail is a local Adelaide, South Australia newspaper, owned by News Ltd.

*and my vegetables and try and maintain my weight (Janine).*

Typically, the women who took health promotion with a grain of salt said that unless there was some absolutely irrefutable evidence about what they should or should not do, they would not make any radical changes, as illustrated by Joanna.

*I'm the kind of person that if they said, Ok that 100% organic, pesticide free diet is going to cure you and it will not make your breast cancer come back, then I would go on to the 100% organic diet. But because they don't know what causes it, I kind of figure, I don't do anything incredibly bad. [...] I might as well enjoy my life. [...] I would probably have taken it all with a grain of salt anyway [...]. I kind of consider that I do the right things, food and nutrition-wise anyway (Joanna).*

Nevertheless, a few of the women talked about making some minor changes following new research results, but not putting too much weight in it as it could just be “the problem of the month” as illustrated by Candice.

*[...] we always just say everything in moderation. So if they say “this is good for you or that's bad for you” we might cut down a bit on it, increase a bit of that but we're not going to say “well none of that and everything of that”. So that's basically the way I take it, with a grain of salt and you think “well yes there might be something in that” and it's just whether you want to live your life with no dairy or whatever else happens to be the problem of the month (Candice).*

The women's responses to health promotion were complex, and were tied up with their everyday/everynight lives, their embodied knowledge prior to their breast cancer diagnoses and their beliefs about breast cancer causation. While none of the women disputed that physical activity was beneficial for their health generally, their ideas about what may have caused their breast cancer, or whether they took health promotion with a grain of salt, were more influential on their decisions about everyday/everynight health promoting practices (whether they managed to engage in them or not) than information that they received about any specific benefits. Women's accounts of their responses to health promotion lead us to consider how and why it is that they respond in the way they do. Below I explore the women's sources of health

promotion information after their breast cancer diagnoses.

### ***Health promotion information sources***

In this section, I explore the women's main sources of advice about supporting their health, as described in their accounts. I describe the health promoting organisations to which the women referred according to the types of organisations: mainstream medical health promotion, complementary and alternative health promotion, and breast cancer advocacy. I analysed the organisations' websites and their content relating to physical activity participation against the women's responses to them and contemporary health promotion debates that I reviewed in Chapter Two.

Besides the Breast Cancer Network Australia's *My Journey Kit*, very few of the women were able to recall specific information materials. Rather, they typically referred to information as coming from particular organisations. Therefore, I analysed organisations' websites and the resources that they have linked to them (which are usually also available as hard-copy booklets or pamphlets). Internet sources are in the public domain and thus were available to the women. Thus, I could document the organisations that the women referred to, the overarching discourses the organisations use to describe themselves as well as the discourses in their information materials, whether or not the women used their internet sites.

A number of the materials available at the time of this study were not being produced when some of the women were diagnosed. The women further along their breast cancer journeys, however, typically spoke about currently available information. My analysis of the journey concept suggests the information was still of interest because the women were still in their breast cancer journeys. Moreover, as demonstrated in Chapter Two physical activity promotion is important for the health of all women who have/ had breast cancer irrespective of when they were diagnosed. While some women were diagnosed more than 10 years before the study when the internet was a new phenomenon, most were accessing the internet and demonstrated

awareness of major health promotion messages at the time of their interview. It is therefore possible to draw some conclusions about some likely connections between the women's responses and the content and framing of information about health benefits of physical activity, and other health promotion messages.

### **Mainstream cancer-related organisations**

The main sources of mainstream medical information to which the women referred were the state and national Cancer Councils, and in Victoria, the Peter MacCallum Cancer Centre. While there is a national Cancer Council, called Cancer Council Australia, each state and territory Cancer Council defines its own strategic directions and has its own Board which governs the direction of the individual organisations' work. The women spoke about the Cancer Council Australia, the Cancer Council South Australia (SA) and the Cancer Council Victoria. All three organisations provide information about health benefits of physical activity, particularly in terms of cancer prevention, but also in terms of recovery and future prevention for people who have had a cancer diagnosis. Yet, there are differences between the ways in which they present the information and the discourses they use.

Also included in this section are my analyses of the Peter MacCallum Cancer Centre and the National Breast and Ovarian Cancer Centre (NBOCC) websites. Several of the Victorian women spoke about using the Peter MacCallum Cancer Centre for information and services, and some of the women spoke about information which, based on the content, I surmised would have been accessed from the NBOCC.

Earlier in this chapter I described some of the women's responses to health promotion information from mainstream medical organisations that focuses on risk, whereby the women spoke about avoiding the risks and participating in protective health practices and getting breast cancer anyway. Below, I examine the sites to which the women referred, with a focus on physical activity-related information and the ways in which the information is presented.

### *The Cancer Council Australia*

The Cancer Council Australia *home page* includes links to a range of topics, sorted beneath two headings, one for professionals and one for “seeking information about cancer” (Cancer Council Australia, 2007, accessed 2-07-09). Top of the list for people seeking information is *Cancer smart lifestyle*. This link takes you to a list of eight links to “cancer smart lifestyle fact sheets”, and these include *stay in shape*, *move your body*, and *look after number one – women* (which is last on the list; *look after number one – men* is two up from this fact sheet).

All three fact sheets state:

We know that by maintaining a healthy body weight, being physically active every day and enjoying a healthy diet, you can lower your risk of developing cancer. We know that these factors account for at least 30 per cent of all cancers (Cancer Council Australia, 2009).

Framed in this way, there is a suggestion that people can lower their individual risk of cancer by 30 per cent, rather than accounting for the statistic being derived from population data which actually means that if all individuals changed their behaviour in the ways being promoted, 30 per cent fewer would develop cancer.

There are nine *After a diagnosis* factsheets. Four of the fact sheets, providing information on bowel, ovarian, breast and prostate cancer, state:

Exercise therapy can improve your cancer recovery. Research has shown that regular physical activity is beneficial and can reduce side-effects such as fatigue. Talk to your physiotherapist or exercise physiologist and doctor (Cancer Council Australia, 2009).

The *After a diagnosis of breast cancer* fact sheet includes the above-quoted “exercise therapy” in the second column, after descriptions of surgery, radiation therapy chemotherapy, hormone treatment and diet therapy.

### *The Cancer Council SA*

The Cancer Council SA *home page* (as accessed on 8-03-09 and 2-07-09) includes the statement “reduce your risk: Did you know that if we changed the way we lived, we could reduce our risk of cancer”. The Cancer Council

SA *home page* also states, beneath its “welcome” heading, that it is “the state’s leading non-government cancer control organisation, dedicated to ensuring that South Australians are reducing their cancer risk and receiving the best cancer care”. Top of the *home page* is the Cancer Helpline phone number, and an orange (everything else is in blue and yellow) *Donate* tab and a site search box. Below the top tabs is the yellow daffodil Cancer Council SA logo, below which is a banner of tabs across the page; *About us*, *Info and support*, *News*, *Prevention and early detection*, *How to help*, *Fundraising events*, *Shop*, *Research*, and *Health professionals*.

The tab *Info and support* leads to a drop down list that includes *Coping with cancer*, which has another drop down list including *Lifestyle changes*. The *Lifestyle changes* page begins with the statement; “a cancer diagnosis can make you think about how you live”, and goes on to say:

Research is suggesting that a healthy lifestyle may reduce the risk of your cancer returning. Good nutrition, physical activity and relaxation techniques will all help you take control and get the most out of your life (Cancer Council SA).

In this view, there is a link between people making changes to their lifestyles as part of taking control of their lives, and therefore reducing their chance of recurrence. Somehow, the lifestyle techniques are what helps “you” to take control. Here, the fateful moment of a cancer diagnosis, when people potentially think about how they live their lives, is taken up by the Cancer Council as a teachable moment. The page goes on to state:

A healthy lifestyle after cancer means

- maintaining a healthy body weight
- being physically active
- eating more fruit and vegetables (having a healthy diet)
- handling food safely
- limiting or avoiding alcohol
- not smoking
- being SunSmart (Cancer Council SA).

Most of the dot points have links attached, and the *being physically active* link leads to specific information about physical activity participation after a cancer diagnosis:



Physical activity is really important for your physical and emotional health. It strengthens cardiovascular and pulmonary systems, reduces risk of heart disease, osteoporosis, obesity, high blood pressure, fatigue, and improves emotional well-being (Cancer Council SA).

The *Lifestyle after cancer - physical activity* page offers readers ways to become more active, and describes different types of exercise. There is no information about breast cancer specific exercise, or how to juggle exercise and family responsibilities, but the webpage suggests the reader “talk with your doctor first to check that what you want to do is OK for you” (Cancer Council SA).

The drop down list from the *Prevention and early detection* tab includes *Reducing your risk* which leads to a page that states “at least half of all cancers can be prevented with a healthy lifestyle. There are some simple steps you can take to minimise your cancer risk” (Cancer Council SA) followed by an online copy of a booklet called *LiveSmart – Your lifestyle guide* which was launched in June 2006. *Your Lifestyle guide* states:

How do I reduce my risk of cancer?

By deciding to. If you want to reduce your risk of cancer you can. This is how.

- Eat well – lots of veggies and fruit.
- Get some exercise.
- Stay at a healthy weight. If you are overweight, try to lose weight.
- Protect yourself from the sun
- If you smoke, quit (The Cancer Council South Australia, 2006 p3).

*Your Lifestyle guide* goes on to say “if you do all this, you’ll cut your risk of getting cancer in half. And you’ll feel better straight away” (2006 p3) and the rest of the guide describes tips on how to go about making behavioural changes, the following being for physical activity:

I know I should do some exercise, but how much?

Probably more than you do now.

So if you do nothing, do something! Or lots of little somethings. Even a walk around the block helps.

If you don’t do much, do more! Leave the car at home when you can. Walk the dog – borrow one if you have to. Walk up stairs, rather than catch the lift. Go for a swim. Have a walk at lunchtime.

If you do half an hour a day of something that makes you puff, or an hour a day of brisk walking – then good on you. You're reducing your chances of getting cancer.

You don't have to do that half an hour in one go.

You can do it in blocks of 10 minutes or more.

Visit [www.beactive.com.au](http://www.beactive.com.au)

Remember – 30 minutes a day of activity that makes you puff, or an hour a day of something gentler, reduces your risk of cancer. So be as active as you can (The Cancer Council South Australia, 2006 p3).

Again, there is no mention of how to manage competing priorities. The Cancer Council Australia and the Cancer Council SA both promote physical activity using rationalist, individualist approaches to behaviour change that rely on population-based risk factors to promote individuals' health. Using the word "smart" in relation to lifestyle suggests that people who adopt health promoting activities that they suggest are "smart". Also common to both websites is the use of the imperative; "look after number one", "get some exercise" when they are directing the information at the reader, yet use passive language when describing benefits of health promoting practices. When put together with the women's responses to these types of health promotion messages, it seems reasonable that the women may have responded by either rejecting risk factors based on their own experience, or feeling responsible for their cancer.

Neither of the sites provides names on their web pages to let the reader know who has reviewed the information, or what evidence it is based on, and the Cancer Council SA does not provide last updated dates on their pages.

#### *The Cancer Council Victoria*

The Cancer Council Victoria home page (as accessed 3-07-09 and 6-07-09), beneath "welcome" states: "The Cancer Council Victoria is a non-profit organization. Most of our funding comes from caring Victorians" (Cancer Council Victoria). There is no obvious suggestion personal responsibility is key to prevention of cancer on the *home page*, and the message that is emphasised is that the Victorian community is "caring" and that the Cancer Council Victoria acknowledges that the organisation is indebted to the assistance of Victorian citizens.

There is a range of tabs on the home page, one of which is *About cancer*, which has a drop down list including *Living with Cancer* and *Survivor's guide*. *Living with Cancer* leads to a link to a comprehensive booklet called *Life with Cancer* as well as seven links to specific topics, one of which is *Nutrition and exercise* (Cancer Council Victoria, 2008). Again, there is a link to a comprehensive booklet that describes the evidence about physical activity health benefits (Cancer Council Victoria, 2007c), plus tabs to specific links, including: *Can good nutrition and exercise prevent cancer?* and *Can certain foods or exercise cure cancer?* At the top of the page there is a list of reviewers, including an oncologist and two dieticians. The answers to the questions cited above are clear and do not suggest that a person may cause their own cancer; that is, the language used avoids blaming the victim. For example:

There are many different types of cancers, with many different causes. Only some of these are understood. The development of cancer is the result of complex processes in which diet and exercise can sometimes play a part (Cancer Council Victoria, 2008).

The text indicates that there is more that is uncertain than there is known about causes of cancer, and that individual behaviour plays only a small part. Similarly, there is a link *Cancers A-Z*, with a specific section on breast cancer, including a link to a booklet on breast cancer (also accessible from the Peter MacCallum Cancer Centre website, accessed 6-07-09). While again the site includes information about risk factors, (and also the name of the reviewer) the language does not blame the victim. Indeed, the text highlights that at an individual level, risk factors alone are unhelpful in understanding why some people get cancer while others do not:

Having some of these risk factors does not mean that you will get breast cancer. Most women with breast cancer have no known risk factors (Cancer Council Victoria, 2007a).

In relation to physical activity, the site states that:

Regular physical exercise appears to decrease the risk of colon cancer and breast cancer. Exercise may help reduce the chance of cancer coming back. People with cancer, or who are recovering after cancer treatment, need to discuss with their doctor or physiotherapist

what level of exercise is safe for them to do (Cancer Council Victoria, 2008).

The *Breast Cancer* booklet includes a brief paragraph regarding exercise after a breast cancer diagnosis:

You will probably find it helpful to stay active and to exercise regularly if you can. Exercise can help with fatigue. The amount and type of exercise you do will depend upon what you are used to and how well you feel. Talk with your doctor about what is likely to be best for you (Cancer Council Victoria, 2007b).

The language used by the Cancer Council Victoria avoids the use of the imperative in *Living with Cancer*, and *Breast Cancer* although does use it under another tab accessible from the home page: "Prevent cancer" with a drop down link to *Be physically active*.

Overall, the Cancer Council Victoria site avoids the language of individualist lifestyle approaches and provides complex information, presented in an easy to read style. Naming the reviewers up front ensures the reader knows who has reviewed, if not written, the information.

#### *National Breast and Ovarian Cancer Centre (NBOCC)*

None of the women specifically mentioned The National Breast and Ovarian Cancer Centre, however some of the women referred to the breast cancer risk calculator which is described below. Also, the NBOCC is linked to the Cancer Council websites. The NBOCC *home page* (accessed 28-07-09) welcome heading states; "Leadership in cancer care and control through the application of evidence", followed by:

National Breast and Ovarian Cancer Centre (NBOCC) is Australia's national authority and information source on breast cancer and ovarian cancer (National Breast and Ovarian Cancer Centre).

Having established its authority, the NBOCC website has tabs to *breasthealth*, *Clinical best practice* and *Ovarian cancer program* at the top of the *Home page*, plus links to *About NBOCC*, *Resources*, *Media* and *Contact us*. *About us* outlines the work of the NBOCC, with one of its main roles being to translate international research into:

meaningful and evidence-based information to guide the work of Australian health professionals, improve health service delivery, inform people with breast or ovarian cancer about all aspects of their diagnosis and treatment, and raise community awareness about the diseases (National Breast and Ovarian Cancer Centre, 2008)

The *home page* has an information heading under which there is a breast cancer heading with links to a range of topics. One of the links is *risk factors*. *Risk factors* includes a range of tabs, including *lifestyle & health* and *protective factors*. Under *protective factors* is the following statement about physical activity:

The exact amount of physical activity needed to reduce your risk is not yet clear. However, studies have shown that one and a half to four hours per week of brisk walking (or equivalent) reduces the risk of breast cancer in post-menopausal women. And the more exercise you do, the bigger the benefits in lowering your risk (National Breast and Ovarian Cancer Centre, 2009b).

Also linked to *risk factors*, is an online risk calculator which takes individual women through a range of tick-box risk/protective factors based on population-based evidence, including alcohol intake, number of pregnancies, length of time breast feeding, height and weight, finally coming up with a particular women's individual risk estimation – my calculation on 28-07-09 was:

Compared to another woman of your age group, your risk level has been assessed as moderately increased. This means that you have some risk factors for breast cancer. However this does not mean that you necessarily will develop breast cancer (National Breast and Ovarian Cancer Centre, 2009a).

In the discussion chapter, I critique the extent to which the risk calculator is useful for women who have or have not had a diagnosis of breast cancer, in terms of population based risk factors translating into individual risk.

The NBOCC website has a search box, which produces a large range of information range of information, from research evidence and personal accounts, on health benefits of physical activity

*The Peter MacCallum Cancer Centre*

Several of the metropolitan Victorian women had their treatment through the Peter MacCallum Cancer Centre (Peter Mac), which is a dedicated cancer-related public hospital, and some of the rural women used some of their services (particularly radiotherapy). The *Home Page* (as accessed 6-07-09) states that it is “Australia’s only public hospital dedicated to cancer treatment, research and education” and that the website is designed to introduce people to the Centre; “our services, our people and our commitment to Excellence, Innovation and Compassion” (Peter MacCallum Cancer Centre, 2009a). The purpose of the Peter Mac website, therefore, is to provide information about the Centre’s services, and contact numbers for potential patients to call, rather than to provide in-depth information about cancer and cancer-related topics. Nevertheless, it does provide information, or links to other sources of information. The Peter Mac website has several links to Cancer Council Victoria resources for people diagnosed with cancer, including those cited above.

The Peter Mac *Treatment* link includes *Allied Health*, which has a link to the Peter Mac physiotherapy department. The link includes information about general benefits of exercise after cancer, and offers exercise programs with various goals, from regaining function, through to promoting general wellbeing (Peter MacCallum Cancer Centre, 2009b).

To summarise the section above, while the women gave accounts of receiving limited advice regarding health benefits of participating in physical activity after a breast cancer diagnosis, the main cancer-related organisations to which they referred in their interviews do provide information with often similar content. Also, the women cited much of the information that the organisations provided suggesting that while they did not necessarily receive information from their medical professionals, they did access the information elsewhere. Notably, the organisations present the information using different approaches, using different language styles and different discourses. In Chapter Seven I follow up on this analysis to draw some conclusions regarding the women’s responses, the ways in which everyday

health promotion practices are promoted by mainstream medical organisations and the literature on risk factors and health.

### **Complementary and alternative cancer-related organisations**

#### *Defining complementary and alternative medicine*

The National Centre for Complementary and Alternative Medicine, a USA Federal Government funded agency, defines complementary and alternative medicine as:

a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine (National Centre for Complementary Health and Alternative Medicine, 2009).

The Cancer Councils and the Peter Mac use and cite the above definition in their explanations of complementary and alternative medicine, for example, the Cancer Council Australia defines complementary and alternative therapies as “a diverse group of practices and products not considered part of evidence based, conventional medicine” (Cancer Council Australia, 2005, accessed 6-07-09). Mainstream cancer-related medical organisations define complementary therapies as literally being complementary to mainstream medicine – that is, they can be used in addition to mainstream medicine and are not intended to stand alone, or to be curative. Examples include massage, acupuncture, art therapy and mind-body techniques to alleviate or manage cancer symptoms and cancer-treatment adverse effects, and to improve quality of life. Alternative health practices are defined by the Cancer Council Australia as being used instead of mainstream medicine, and usually refers to naturopaths, homoeopaths, New Age self-help or other non-mainstream medical professionals that claim to provide cancer cures. The Cancer Councils advise that people should be wary of such claims and to seek further clarification, either through their own research, or from their mainstream medical health professionals (Cancer Council Australia, 2005; Cancer Council SA).

Organisations defined as above to which the women referred, define complementary or alternative medicine services and practices somewhat

differently, and are more in line with how the women spoke about them. The Cancer Care Centre, for example states that the organisation bases its work on a philosophy of an “Integrative Medicine approach” to cancer care which means:

By integrating complementary care with hospital-based treatments, we are actively seeking to help the entire person with cancer and support them as they work towards healing (Cancer Care Centre Inc., 2009c).

The Australasian Integrative Medicine Association seeks, in its mission statement, to promote “the integration of holistic and complementary medicine with current mainstream medical practice, in pursuit of a complete whole person care” (Australasian Integrative Medicine Association, 2009).

*The Cancer Care Centre Incorporated (South Australia)*

The Cancer Care Centre website home page simply says “Embrace Hope – Enhance Healing”, which heads the Centre’s vision statement, detailed in their Annual Report, which can be found via the *About Us* link (Cancer Care Centre Inc., 2009b). There are fifteen tabs on the home page, including *About Us, Services, Newly Diagnosed, Give To Cancer, Healthy Living* and *Clinic*. The About Us tab leads to other links, including *Our Philosophy*, which is an “integrated approach to cancer” (Cancer Care Centre Inc., 2009a). The purpose of the website, like the Peter Mac website, is to inform people of the services that the Centre offer, and the philosophy from which they offer them, rather than a site for information about cancer-related topics. The website includes links to a range of cancer-related organisations, including the Cancer Councils, the major South Australian Public hospitals and Dragons Abreast. Neither the Cancer Councils, nor the Peter Mac websites include links to Dragons Abreast, or to the Cancer Care Centre.

The Cancer Care Centre produces a quarterly magazine called *Healthy Living* which is accessible by the internet as well as in hard copy. While the site states that the most recent edition is available electronically, the most recent edition is January-March 2008 (accessed on 27 July 2009). The site has a quarterly *Syllabus of Programmes*, three editions of which are posted from the remainder of 2008, which outlines all services, programs, support



group sessions and events available at the Centre. In both magazines, the Centre advertises that it holds public lectures which include talks on topics such as exercise and cancer, toxins in food and the environment, lymphoedema and supporting well-being after mainstream medical cancer treatments. Talks are made available on the website as podcasts. Complementary and Alternative health practitioners include a resident naturopath and visiting practitioners (for example, massage, reiki, shamanic healing) as well as counsellors. The Centre also states that it provides courses such as organic gardening, juicing, meditation, art therapy, writing and cooking, and ongoing classes, such as yoga and meditation, and support groups (Cancer Care Centre Inc.). Yoga and Wu Tao<sup>20</sup> are promoted as ways to reduce stress levels and promote general health and wellbeing through connection of mind and body.

The website does not have a search function, which makes it difficult to search a specific topic, such as exercise or physical activity. However, it is possible to search through the individual online versions of the *Healthy Living* magazine, or to look up articles based on each magazines' table of contents. There are five editions over 2007 and 2008 of *Healthy Living* available on the website. The summer 2007 edition includes three articles which cite mainstream medical research evidence about benefits of physical activity. One article cites evidence from a yoga intervention self report study, which found that the women who undertook yoga during radiation therapy for breast cancer experienced better quality of life and less fatigue than the control group (Cancer Care Centre Inc., 2007b). The second article describes activities to regain and maintain range of movement after breast surgery (Bray & Godfrey, 2007). The third article cites evidence that moderate intensity aerobic exercise improves erythrocyte levels (especially haemoglobin) during radiation treatment (Cancer Care Centre Inc., 2007a).

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<sup>20</sup> A type of stretching/dance, based on the philosophy of Traditional Chinese Medicine. See <http://www.wutaodance.com/>

The Autumn edition 2007 includes an in-depth article that systematically describes specific precautions that people who are going through cancer treatment ought to heed when they are considering an exercise program, as well as describing evidence of health benefits of moderate-intensity exercise (Atkinson, 2007). Other articles include; exercise as one way to reduce the effects of stress, yoga practice improving quality of life and wellbeing in women with secondary breast cancer, and participating in physical activity as part of a range of everyday/everynight health promoting practices to prevent/heal depression from an Ayurvedic medicine perspective (Cancer Care Centre Inc., 2007a; Cancer Care Centre Inc., 2007d; Marshall, 2007).

There is no single place where all physical activity evidence is compiled. Rather, information about health benefits of physical activity is found either as individual articles citing recent research findings, or included in articles that cover a range of health promoting practices. While there is an emphasis on living “healthily”, as per the Centre philosophy, there is no use of the imperative to participate in physical activity in the magazine or the website more generally. Most articles either name the writer or cite the author of the article from which the information was sourced.

*The Gawler Foundation (Victoria) and Tayen Park (South Australia)*

The Gawler Foundation *Home Page* opens with the message “Profound Healing – Sustainable Wellbeing” above slowly changing tranquil garden-scapes. There are a range of tabs on the left; *About Us, Programs, Services, Events and Media, Ian’s Lectures, Membership, Donations, Health Professionals, Employment, Research & Articles, and Shopping*. On the right is a search box, a “please donate” link, and quick links to cancer programs, MS [multiple sclerosis] Programs and Shopping Cart, and a contact telephone number. The main purpose of the Gawler Foundation website is to advertise the programs and services that the Foundation offers. However, the website also advocates for the relevance of body-mind techniques in cancer care in particular, and integrative medicine more generally, evident in some of the articles that are attached (Gawler, 2007).

The *About Us* page includes links to; *Welcome, A Place for Everyone, Our Staff, Our Structure, Getting There* and *Testimonials*. The Gawler Foundation website advertises a range of programs for people who have had a cancer diagnosis. The focus of the programs is on participants developing “full confidence in “establishing a healthy, healing lifestyle” (Gawler Foundation). The approach is to teach participants self-help strategies, with which they can work towards finding inner peace and strength that leads them to being able to confidently seek and gain support from others, and to take care of themselves by living healthy lifestyles (defined as practising regular meditation, positive thinking and eating an organic, vegetarian diet). The text strongly encourages participants to have a support person (usually their main carer) join them, so that their main carer can understand and support what they have learnt, and for them to have the opportunity to voice their own concerns or issues.

While the focus of the website is entirely about changing one’s lifestyle, it does not use imperatives. There is very little advice regarding physical activity participation, and most advice about other everyday/everynight practices lead to other references, especially books by Ian Gawler, the organisation founder.

The Tayen Park Healing Retreat, near Clare, South Australia, was set up by Stephen Taylor (and his partner Edeltraud Ennich) who had a cancer diagnosis several years previously and was inspired by a range of proponents of mind-body healing techniques, including Ian Gawler, to set up a retreat for people who have/ have had cancer in South Australia. To of the South Australian women had either attended a retreat or were planning to. There is very little information regarding health promoting practices on the website (accessed 27-07-09) as it is really a marketing tool for people to read about Stephen Taylor and his services and to make bookings for a retreat. However, the retreat is based on similar principles to the Gawler Foundation of self-care, meditation, vegetarian diet and positive thinking.

*Self help - Louise Hay*

Louise Hay is an author of self-help books that promote positive thinking and self-love. While she is not really a cancer-related organisation, a few of the women in this study drew on her books to help make changes in their own lives. Louise Hay's *Home Page* contains a photograph of Louise Hay, and her most recent books and DVDs for purchase. The tab *About Louise* offers a biography, which begins by stating; "recently dubbed 'the closest thing to a living saint' by the Australian media, Louise L. Hay is also known as one of the founders of the self-help movement."(Hay). Louise Hay has authored several books which espouse positive thinking, with the use of affirmations, to heal ill-health (including cancer) and to produce and maintain health. Louise Hay's biography states that she has had a cancer diagnosis and claims that her work on her self is what cured her cancer. The site is a marketing tool for selling books and videos by Louise Hay and other authors published by Hay House, her publishing company, rather than an information site. Besides espousing the benefits of positive thinking, there is very little freely accessible information or advice regarding health promoting practices.

A common thread between the complementary and alternative medicine organisations is that they rely on individuals to make changes in their lives that require an initial process of deep reflection. These changes are promoted in a way that suggests the ways in which people previously led their lives may have contributed to their cancer. It is this point, apparently made more directly by these fields than by mainstream medical organisations, that led to the polarised responses from the women that I described in the previous section of this chapter, whereby the women either found them helpful or harmful.

### **Breast cancer advocacy and action organisations**

In Australia, women who have had a diagnosis of breast cancer are well represented in breast cancer organisations as a result of twenty years of intense lobbying. The three peak organisations are the Breast Cancer Network Australia (BCNA), the National Breast Cancer Foundation (NBCF), both of which are charities, and the National Breast and Ovarian Cancer Centre of Australia (NBOCC) which is a commonwealth government

organisation rather than an advocacy organisation, and so included above in the mainstream section of this analysis. Each organisation plays a distinct role and all three collaborate closely (National Breast and Ovarian Cancer Centre, 2009d). The women spoke a great deal about the BCNA (in particular, gathering information from the newsletter the Beacon, and the My Journey Kit). This is understandable as it is the peak advocacy body for women who have been diagnosed with breast cancer. It was established by a woman who had been diagnosed with breast cancer and serves as an information filter for women and also gathers information from women upon which it bases its advocacy work (Breast Cancer Network Australia). I also include in this analysis the advocacy groups The Young Ones and Breast Cancer Action Group, which were mentioned by some of the younger women.

#### *Breast Cancer Network Australia*

The BCNA *home page* (as accessed 28-07-09) is strikingly pink, and the pink lady which is the BCNA logo is top left of the page, with photographs of women's faces to the top right. There are eleven tabs in a banner beneath the pink lady and the photographs, including *About BCNA*, *Newly diagnosed*, *Secondary breast cancer*, *Stories*, *Information*, *Policy and advocacy* and *Supporting BCNA*.

Below the banner, to the right is a photograph of "field of women –live" on the Melbourne Cricket Ground, taken in 2005, representing the number of women diagnosed in Australia each year (in pink rain ponchos) and men (in blue rain ponchos). On the left is a welcoming paragraph which states:

We are the peak national organisation for Australians personally affected by breast cancer. We work to ensure that Australians diagnosed with breast cancer and their families receive the very best information, treatment, care and support possible, no matter who they are or where they live.

We are represented by the Pink Lady silhouette, which depicts our focus; the women diagnosed with breast cancer (Breast Cancer Network Australia)

The BCNA uses the third person plural throughout the *home page*, giving a

sense of the organisation being a collective. Directly below the welcome note, the home page has links to the *My Journey Kit* (for newly diagnosed women), *E-Bulletins* (for updates on breast cancer research and news) and *Hope and Hurdles* (for women with secondary breast cancer). Beneath these are links to the BCNA newsletter, *The Beacon*, *The Inside Story* (a supplement to the newsletter specifically for women who have secondary breast cancer) and the BCNA Annual Report.

The *Information* tab has an A-Z tab, under which there is a link to information about exercise (under “E”) after breast cancer.

Exercise has been shown to improve both physical and mental well-being. Mild to moderate exercise, such as walking, can improve your energy and fitness levels, your body image, give you time to yourself and help to reduce stress (Breast Cancer Network Australia).

The *Exercise* page encourages women to take up whatever form of physical activity they participated in before their breast cancer diagnosis, in consultation with their doctor. There are links to Dragons Abreast and the YWCA Encore program, with descriptions of each of these organisations, plus how to access an exercise video called *Stretch*, that has been designed for women who have had breast cancer treatment. The BCNA provides information about exercise, similar to that quoted above, in various places throughout the website.

The BCNA website has a search box, which facilitates negotiating through the large amount of information on, or attached to, the website. A range of information about participation in physical activity can be found, in personal accounts of women who have/ have had breast cancer, and in citing evidence from research. Part of the reason for large number of personal accounts of participation is that “Member Groups” include exercise groups, as well as support groups and advocacy across Australia. The BCNA website does not use the imperative in relation to participation in physical activity although it promotes participation at whatever levels are appropriate for individual women, based on medical evidence of benefits to mental and physical health (BCNA, 2009).

### *The Young Ones*

In recent years, younger women diagnosed with breast cancer have been mobilising in response to the ways in which they have felt marginalised by mainstream breast cancer services. Some of the Victorian women were involved in an advocacy group specifically for young women (The Young Ones, accessed 28-07-09). The Young Ones began as a support group in 1999, and later formed an advocacy group in 2004 (Young Action on Breast Cancer) which raised concerns in response to feeling their treatment is based on breast cancer being an older woman's disease. They raised young women's concerns about fertility, sexuality, forming and maintaining intimate relationships, survival, workforce/career and child care, that make their experiences different from those of older women. There is no information about participation in physical activity after a breast cancer diagnosis on the website, however there are links to other organisations such as the YWCA Encore Program and the Cancer Council Victoria, which do. At the time of writing, the Young Ones had announced in *the Breast Cancer Action Group Newsletter* that it would cease operating, in part because of

...the explosion of social networking which young women have embraced as a preferred method of connecting across the globe. Chat rooms dedicated to young women affected by breast cancer, as well as more general sites such as face book, allow women to share experiences and stories with those in similar circumstances without having to leave their homes (Marigliani, 2009 p12).

The Breast Cancer Action Group (BCAG) operates in Victoria and in New South Wales. The Victorian group publishes an online and hard copy newsletter (accessed 28-07-09), which contains in-depth information on advocacy work and new research. Newsletters include information on new and current research on physical activity and breast cancer, including information about a study on osteoporosis and adjuvant therapy (Sawkins, 2009).

What is striking about all of the breast cancer advocacy groups is that they both advocate on behalf of women who have/ had breast cancer and also encourage women to participate in research. Crucially for this study, they

provide detailed and often complex information about ways in which physical activity provides health benefits to women who have/had breast cancer. Notably, in stark contrast to both mainstream and complementary/alternative medicine information, none of the women spoke about the information provided by breast cancer advocacy groups as suggesting that something they did caused their breast cancer.

### ***Conclusion***

In this chapter, I have described how the women responded to health promotion, concluding that they typically re-interpreted health promotion in terms of causation and risk in the context of their own and other people's cancer journeys. I have also described and analysed the types of information available from the organisations that the women spoke about during their interviews, suggesting links between the framing and content of the information and the women's responses to it. In Chapter Seven I draw on the health promotion, lay and feminist literature to elaborate on these ideas.

In the next part of my analysis, I explore how the women responded to information about health benefits of physical activity in terms of their accounts of their participation in physical activity.



## **Chapter 6: Mothers, breast cancer and physical activity participation**

### ***Introduction***

In the previous chapters I explored how the women developed breast cancer related knowledge over the course of their journeys. I described the women's health related decision making as changing over time. I showed how their responses to messages about physical activity, and health promotion more generally, were interconnected with their embodied experiences of breast cancer at different stages of the journey, in the context of their everyday/everynight lives. While the previous chapters examined the women's accounts of their views on health promotion messages generally, this chapter explores their accounts of their physical activity participation specifically.

In Chapter Three, I provided details of how I arrived at my qualitative categorising of the levels physical activity in which the women participated at the time of their interviews, to establish which women were *more* or *less* active. In this chapter I explore factors that, based on the literature, would be expected to influence the women's participation such as social or structural factors including social support, socioeconomic status, location and individual factors such as pleasure, pain and fatigue. The women tended to speak about their levels of participation in the context of social and individual factors which affected their participation. My analysis of data from the interviews enabled me to tease out factors that influence participation by comparing the women's levels of participation with how they spoke about their experience of participation, as well as by examining the women's responses to the demographic form for factors such as household income and education attainment (appendix 5).

### **Levels of participation**

Applying my analysis of participation, 21 women were *more active* and 15 women were *less active*. I expected a reasonable number of *more active* women, because my purposive sample included women involved in dragon

boat clubs and the YWCA Encore program. While the literature suggests that women who have/had breast cancer are likely to participate at lower than women's average population levels, the study sample has provided a means to explore in depth what factors enable women with a breast cancer diagnosis to participate in regular physical activity, as well as which factors constrain their participation.

In this chapter, I begin by describing the key socially structured and individual factors which influenced the women's participation in physical activity. While there is a great deal of interconnectedness between the factors, it is helpful to identify them separately before going on to describe the ways in which they work together as enabling or constraining participation. The women talked about constraints and enablers together, so after separating out key enablers and constraints, I go on to provide typical cases of accounts from women who were *more active* and *less active* to show how the range of factors together enable and/or constrain the women's participation.

### ***Factors influencing physical activity participation***

There were many ways in which the women's participation in physical activity was influenced by the social contexts of their daily lives. While for those women who had always participated in physical activity, breast cancer treatment interrupted their participation for a period of time, in their accounts breast cancer did not feature as the most important enabling or constraining factor over the longer term, with the exception of reconstruction surgery described in Chapter Two. Analysis of the interviews shows that the key factors that enabled or constrained the women's participation in physical activity largely reflect the literature reviewed in Chapter Two; specifically the sections that refer to social constraints and enablers to physical activity participation. My findings show that level of partner support, expectations of the paid workforce, demographic factors and embodied gendered identity had the strongest influences on participation. At an individual level, constraining or enabling factors include the extent to which the women enjoyed physical activity, treatment-related fatigue and/or pain, time since

treatment completion and preferences for use of available time<sup>21</sup>. Most of the women experienced degrees of both enabling and constraining factors contributing to their level of participation and there was a great deal of interconnection between social and individual factors. Prioritising others over oneself, for example, was explained by some of the women as being their individual personal preference, however, a critical analysis of such accounts reveals ways in which socially constructed expectations influence people's preferences, and I explore this more fully in Chapter Seven. Below, I outline the key factors that I identified in the women's accounts as contributing to enabling or constraining their participation in physical activity.

## ***Social influences***

### **Social support**

The women spoke of obtaining various levels of support from various people and networks over the course of their breast cancer journeys; some people and networks were supportive in some areas and not in others. The women talked about obtaining support from their partners, mothers, mother-in-laws, fathers, sisters, sister-in-laws, older children, friends, social networks and support groups – both formal and informal. Despite wide-ranging potential sources of support, all of the women who were in relationships emphasised the importance to them of the level of support they received from their partners above all other sources of support. Support from their partners that mattered to the women included practical (help with children and/or household chores), emotional (listening) and physical (opportunity to rest and/or take time out). Of all the types of social support, for those women with partners, partner support was the most important source of support contributing to the maintenance of regular and ongoing participation in physical activity. The importance of partner support to the women's

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<sup>21</sup> I acknowledge that enjoyment of physical activity (or taste) and preferences for use of available time are largely socially defined and embodied as part of a gendered identity (Bourdieu, 1984; McNay, 1999; Young, 1990).

participation was, however, compounded by the women's gendered identities – that is, the women's expectations of themselves as women and as mothers, and this is explored further below. Furthermore, most of the women who were not in relationships were *more active*, which I describe in greater depth below.

### *Family support*

Most of the women talked about receiving support from family and/or friends, however only a few women spoke about obtaining support beyond the acute treatment stage of their journey, and only two women spoke specifically about support to participate in physical activity. Anna, for example, spoke about her parents supporting her to participate in the YWCA Encore Program, and Qigong (or ch'i kung)<sup>22</sup>. Anna's partner worked interstate, so her parents supported her throughout her breast cancer treatment and beyond.

*So like to do the Qigong thing, Mum and Dad would come up here to have dinner with me every Wednesday night and they'd help me with the kids. Mum and I would go and do the Qigong and then we'd come back and Dad would have dinner cooked, or I would have made something beforehand, and they'd eat with me (Anna).*

At the time of her interview, Anna was *less active* because by her account, it was difficult to maintain a regular date with her parents and managing three young children and their activities left little time for her to participate in regular physical activity.

Zoe's account below is typical of the ways in which most of the women talked about obtaining support from their parents and/or friends. Like Zoe, many of the women described a tension between accepting support for child care and feeling an obligation to forego their own separate needs to ensure time with their children. Zoe's account is characteristic of how several women talked

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<sup>22</sup> Qigong (or ch'i kung) is a Chinese healing practice which combines movement, meditation and breathing exercises, see [http://www.qigonginstitute.org/main\\_page/main\\_page.php](http://www.qigonginstitute.org/main_page/main_page.php).

about not being able to obtain the support they would have liked from their partners and finding support elsewhere. However, their other sources of support did not extend to acting as enablers for regular physical activity participation.

*I didn't really get much support. From my parents definitely because they live next door and my mum would cook for me, she makes me juice now every morning. Even before when I was going through it she did everything. They looked after [my daughter]. So definitely my parents were great support (Zoe).*

Zoe talked about how her parents looked after her daughter while she was undergoing treatment, but when it came to looking after her so that Zoe could participate in physical activity, Zoe said “my parents live next door so they could, but that is not fair on her. [My husband] thinks it is fine but I don't”. So for Zoe, one of the factors contributing to being less active was not so much that she was unable to seek child care, rather that she did not believe it was “fair” for her daughter. I explore Zoe's account further below, as she was typical of most of the women who had a number of intersecting factors which meant that they were *less active* at the time of their interviews.

#### *Partner support*

Thirty women were in relationships at the time of their interview, one of whom had divorced after her second breast cancer diagnosis and had since re-partnered. Of the women who were not in relationships at the time of their interview, two women were divorced, two were widowed, one woman was separated and one was in the process of separating. Three of the women who had separated/divorced or were in the process of separating gave lack of support from their partners during their breast cancer journeys as a major reason for the end of the relationship (see table 3). The literature I reviewed in Chapter Two suggests that women with dependent children who are in unsupportive relationships are less likely to participate in regular physical activity than those who do not have partners, and this study supports that pattern.

The women's accounts showed that the level of support that they were able to obtain from their partners throughout their treatment and physical recovery

was extremely important to their overall experience of breast cancer, and also to the ways in which they felt about their partners beyond treatment. The level of support also affected the degree to which the women were able to take action to support their own ongoing health and wellbeing. In this study sample, there is a clear pattern whereby more women with supportive partners were *more active* than women with less supportive partners.

Based on my categorising of levels of partner support outlined in Chapter Three, 13 of the 17 *more active* women who had partners at the time of the interview talked about their partners as being “supportive”. Most of these women were in relationships that had always been supportive, while a few women found that they were more able to expect and receive support after their diagnosis of breast cancer, illustrated by Isobel:

*I said, “I’m going out to do this and this is going to be something that I’m going to do for me”, which I had never really done before. So that changed at home as well. And that all worked out fine.*

*[...] “it’s Wednesday so I’m not here”. Yes, and that’s just how I fit it in. Probably actually not only with paddling. If I actually do something myself, that’s probably easier to accept it now (Isobel).*

Three of the *more active* women talked about obtaining “variable support” from their partners while only one of the *more active* women talked about her partner as being “unsupportive”. Joanna, who was *more active*, spoke about her husband as being variably supportive; extremely supportive emotionally throughout her breast cancer journey, but not being supportive in practical ways.

*...whilst [my husband] is fantastic and everything, he doesn’t think of things to do himself. He will still be sitting, or trying to attempt to watch the news when there are 3 screaming children that need to be bathed and you know? He would be one of these guys that you need to ask, and he will do it, but he doesn’t think to do it. If someone was telling him that that’s what he should have been doing, he probably would help because I don’t think he’s a strange male. I think he’s like a regular male (Joanna).*

Joanna's account is characteristic of ways in which some of the women talked in terms of believing that mothers putting themselves last is "normal" and also that unsupportive men are "normal men". Indeed, although Joanna was *more active*, her account was typical of several of the *less active* women, in that she viewed mothers as being "bottom of the pile" (one of the terms she used) in the family hierarchy.

*There are other responsibilities that are happening within the household that still have to happen regardless. So, I think with women, well, most women put themselves last, bottom of the list, and we'll deal with ourselves last. Our kids come and our husband comes before us. So that was the way it was for me. So if I had any time at the end of all of that, well then I might have gone on the treadmill. No I wouldn't have! [laughs] (Joanna).*

Four of the *more active* women were separated, divorced or widowed; one had divorced and re-partnered since her second breast cancer diagnosis. Of the five women who were not in relationships, plus the one woman who was in the process of separating, at the time of their interview, four were *more active* (see table 3), suggesting that an unsupportive partner appears to be a greater constraint to participation in physical activity than no partner.

By comparison, only four of the 14 partnered *less active* women talked about their partners as being "supportive" and described their reasons for being less active as being because of lasting treatment effects such as fatigue, or because they had never enjoyed exercise before breast cancer, or it simply was not a priority for them. Sarah's account is typical of these four women, describing how her partner had been extremely supportive throughout her treatment. He had to continue working to support the family financially, and arranged his work-days to fit in all of the extra household and caring work.

*[My husband] did the whole lot. Like I've got a small group of friends who have been fantastic and supportive, but they all work. We had a few meals that other people would make at the very beginning, which was good, but other than that [my husband] just cooked like the whole way through. I barely cooked a meal (Sarah).*

Sarah spoke about friends and family telling her that she should participate in

some kind of exercise, because they believed it would make her feel better. Sarah described feeling like she was “failing” because she could not exercise, and how she felt in her body when she tried to exercise, particularly during chemotherapy.

*People are telling me that I should be walking and I should be doing this and I should be doing that [...] well, I wasn't doing [exercise] before, so to start up to do it now would take huge motivation which I haven't got (Sarah)*

For Sarah, being *less active* was directly related to her relatively recent treatment completion and not being particularly interested in exercising before her breast cancer diagnosis.

Six of the *less active* women talked about their partners providing “variable support” and three talked about their partners as being “unsupportive”. The women who were *less active* with variably or unsupportive partners talked about their partners as unsupportive in a number of ways, and explained what they thought contributed to their partners being unable or unwilling to provide the support they would have liked. They commonly said that their partners were unable to cope, for example with taking them for treatment, looking after the children, or taking care of domestic work. Kate's account is characteristic of how the women would describe the reasons for their partner's lack of support.

*I think he really wanted to be supportive but it was just too much for him, like when I really wanted to talk, we actually had a really rough time like our relationship was really bad. We fought a lot during that time, like if I got upset he actually got angry with me but I think that was a lot to do with, well he was under so much pressure at work and then he'd come home and I'm on the couch and it was like "oh man, I've got to..." he's under the same sort of pressure at home and we had [our child] to look after so for him I guess he was trying to juggle a lot of things (Kate).*

Thus, variable support for this group of women includes two main types. Firstly, some women explained that their partners did not always have the capacity to offer the support that the women would have liked because of circumstances beyond their partners' control, but did provide support when



they could. Secondly, some of the women gave accounts of their partners having the capacity to provide specific types of support (for example practical support) but not other types (for example emotional support). In this way, the women spoke about their partners being unable (rather than unwilling) to provide the support the women would have liked.

Women who reported having unsupportive partners commonly talked about their partners placing their needs and wishes above the women's, to the extent that their own wishes were barely a consideration.

*My husband [...] says, "Well if you want to exercise, just go and do it." And I find it really hard to just do that. For example when we got back from Queensland he spent Saturday going for a half hour walk and then working out in the gym. I did all the unpacking and the washing and all of that. Like I find it really hard to just go, "oh well I'm not going to do everything" (Anna).*

Following this theme, at the same time, most of the women talked about feeling responsible for their children and general household chores, and feeling that it was not the right thing to do to put themselves first, as described in Joanna's account above.

Some of the women who described their partners as unsupportive or variably supportive sought, or were offered support, from other family members and friends as described above. Some talked of feeling at a loss, either emotionally or practically, until they found support from formal support networks or other avenues such as dragon boat clubs. While support other than partner support increased a few of the women's short term participation in physical activity (for example participation in the YWCA Encore program), it did not lead to regular, ongoing, physical activity for this sample of women.

**Table 3: Physical activity and potential influencing factors - more active and less active women**

Pseudonym	R^	M^	Age at 1 <sup>st</sup> diagnosis	Yr/s diagnosed	Age of children at 1 <sup>st</sup> diagnosis	Treatment/s	Partner support: S, U, V, N/P*	Physical activity participation	Support group- includes formal, internet, informal Y/N	Household income	Education	Private health insurance Y/N
<b>More active women</b>												
Adele	✓		40	2002	17, 14, 10, 6	Mastectomy 10 lymph nodes removed; 1 had cancer cells. Chemotherapy Tamoxifen Fosamax Oophorectomy	S	Pre-children: netball. While very young children: aerobics and gym, Pre-diagnosis: netball, basket ball. During treatment: walking. Post-diagnosis: Dragon boats, Encore program, Tai Chi, netball. Occasional swim. More active	Y	\$60,001-\$80,000	Year 12/ enrolled nurse	Y
Alana		✓	28	1991, 1993	3, 2	1 <sup>st</sup> diagnosis: lumpectomy then mastectomy Axillary clearance (1/22 nodes positive) Chemotherapy. 2yrs later, TRAM flap reconstruction. 1 yr later recurrence in scar line – lumpectomy & Radiotherapy	S	Lifetime: not sporty but always walked. Post breast cancer: Dragon boats for 2 years, walking. More active	N	\$60,000-\$80,000	U/G Degree	Y
Bernadette	✓		39	2007	4, 2	Mastectomy, axillary clearance (none +ve) chemotherapy Considering reconstruction.	S	School: club & school tennis and hockey + athletics. Also snow skiing and waterskiing. University + shift work: social netball, walking, swimming. Later, touch football. Met partner: more touch football, golf, tennis. Children & moved to rural city: walking, swimming, bike riding with family. Later back into touch football until diagnosis. Post breast cancer swimming, cycling	N	>\$80,000	U/G degree	Y

								with family, core work with smart ball. More active				
Blanche		✓	38	1986	13, 20 months (still born baby between 2 children)	Radical mastectomy	S	Pre-children: squash, aerobics. Post children: swimming, aerobics. Post breast cancer: Dragon boats, walking – walks to work and in evenings with partner & dog. More active	N	\$40,000- \$60,000	TAFE	Y
Candice		✓	44	1997	16, 14	Lumpectomy Radiotherapy 2 x needle biopsies since	S	Lifetime: always walked. Before children: social tennis, squash, volleyball. After children: social tennis, netball (intermittently). Post breast cancer: dragon boats, social tennis, walking. More active	Y	>\$80,000	U/G Degree	Y
Danielle	✓		46	2004	16, 12, 9, 7	Lumpectomy Chemotherapy Radiotherapy Herceptin	S	Lifetime: “fits & starts” Until 20yrs: athlete – sprinting & long jump, then sporadic activity. Post children: social tennis, own fitness program @ home. Post breast cancer: own fitness program @ home (past 2 months), occasional walks, just joined Dragon’s Abreast (2x wk). More active	N	>\$80,000	P/G diploma	Y
Emma		✓	40	2002	3, 10months	Partial mastectomy Chemotherapy Radiotherapy	U	Pre-children: water sports – water polo, competitive swimming, iron woman, surf-lifesaving, scuba diving, water skiing. Post-children: Social netball, gym (heavy weight training, fitness etc). Post breast cancer: swimming difficult, started dragon boat racing – initially socially, at the time of the interview – in the state team. Back into gym (aerobic & fitness, not	N	N/A	U/G degree	Y

								weights). More active				
Grace	✓		33	2002	6, 4	Lumpectomy Chemotherapy Radiotherapy Tamoxifen	S	Before children: swimming. Babies: aqua aerobics. Post breast cancer: Gym (treadmill) most weekdays @ lunch time. More active	N	>\$80,000	Yr 12/ TAFE	Y
Isobel	✓		46	2004	5, 7	Mastectomy Chemotherapy Tamoxifen Arimidex	S	Child: netball Adult: sedentary until 7 years prior to diagnosis: walking most days. Post breast cancer: Dragon boats straight after chemo finished, recently joined a gym. More active	N		Yr 12	Y
Jane		✓	38	1998	11, 8, (stillborn baby before other children)	Mastectomy Chemotherapy Reconstruction	S	Teens/young adult: bushwalking. Post children: gym between children then after 2 <sup>nd</sup> baby, very little for about 8yrs. Post breast cancer: Nepal trek, walks about 4x week, bike ride 1x week. Recreational canoeing/camping bushwalking. More active	N	>\$80,000	P/G diploma	Y
Janine		✓	40	2001	3 children, youngest 8 years old	Mastectomy Chemotherapy Radiotherapy Tamoxifen	N/P	Pre-marriage: netball. Post-marriage & children: stopped all sport – walking only. Post breast cancer: Walking 3x week 45 mins. More active	N	\$60,001- \$80,000	Yr 9	Y
Jess	✓		40	1992	7, 5, 2	1) Lumpectomy 2) Partial mastectomy + lymph nodes radiotherapy	V	Tennis throughout life. During treatment: walking. Post breast cancer: tennis 1 x wk & walking,- past year prefer bike riding to walking since knee injury - about 3 x week More active	N – tried, didn't like it	\$40,001- \$60,000	Yr 12	N
Jill	✓		46	2005	16, 14, 12	Lumpectomy + axillary clearance	N/P	Pre-relationship: occasional netball, walking (fits and starts).	N	\$20,001- \$40,000	Yr 11/ Nursing	Y

						Chemotherapy Radiotherapy Tamoxifen Breast reduction		During treatment: walk every few days. Post breast cancer: walks 3x week, gym x2 week More active			training	
Joanna		✓	35	2004	4, 2, 3 months	Lumpectomy + sentinel node biopsy Radiotherapy Tamoxifen	V	Always fits & starts. Pre-relationship: aerobics classes, gym equipment. Post-relationship & children: walking with partner & home gym. Aerobics/yoga/ running hurts breast and underarm. Post breast cancer: Home gym equipment –treadmill in fits and starts More active	N	>\$80,000	Yr 12	Y
Louise		✓	44	2005	16, 13, 11	Lumpectomy Chemotherapy Herceptin Hysterectomy	S	Pre breast cancer: Netball, tennis, marching (except during 6 yrs while children were young). Post breast cancer Encore program, gym, walking, gardening. More active	N	\$20,0001-\$40,000	Yr 11	N
Manee	✓		48	1) 2006 2) 2007	18	Lumpectomy + sentinel node biopsy Radiotherapy Tamoxifen Oophorectomy	S	Lifetime: gardening, Tai Chi (on & off). With 1 <sup>st</sup> partner & post children: farming – physical labour, tennis, golf. With current partner: period of very little exercise, then started gym, swimming, cycling, walking. Post breast cancer: dragon boats, Tai Chi, walking, swimming, cycling, gym. More active	Y	>\$80,000	Certificate	N
Melissa	✓		52	2007	18, 20	Mastectomy Tamoxifen	N/P	Gym, takes fitness classes (started back 5 wks post surgery) bike riding (with squad, training for long distance rides) More active	Y	\$20,001-\$40,000	Yr 12	N
Monique	✓		51	2006	18, 12	Mastectomy Radiotherapy Hormone therapy (check interview)	V	Pre-breast cancer diagnosis: walking. Post diabetes diagnosis: strength training 3x wk, aerobics 1x wk, ½ hr 4x wk with TV, walk the dog with	Y	\$40,001-\$60,000	Yr 11	N

								partner each evening plus Sundays. More active				
Philippa		✓	41	1992	9, 8	Mastectomy	N/P	Childhood: tennis University: nothing Post-university: bike riding, swimming (living next to beach). Working in country: tennis, Post children: tennis until separated from partner. Post breast cancer: initially daily life activities as single mother of young children, e.g. housework. Later: Dragon boats, walking. More active	N	\$60,001-\$80,000	P/G diploma	Y
Rebecca		✓	39	2001	9, 4	Lumpectomy then mastectomy + axillary clearance Chemotherapy Radiotherapy Adjuvant therapy Prophylactic mastectomy and bilateral reconstruction – implants and nipple reconstruction	S	Child, teens: netball until 20s, stopped due to hip problems, competitive swimming Post 2 <sup>nd</sup> child: break from gym a few years, just walking with pram. Post breast cancer: nothing 3 yrs then dragon boats, walking, gym, pilates/yoga 1-2x wk. More active	N	>\$80,000	P/G diploma	Y
Therese	✓		48	2006	9, 7	Mastectomy Chemotherapy Reconstruction	S	Post breast cancer: Pilates 1x wk (stopped when started tamoxifen because of body aches), then gym 2 x wk (participating in post breast cancer exercise trial), Pilates 1 x wk, home gym, walks, cycles with family. More active	Y	>\$80,000	U/G degree	Y
<b>Less active women</b>												
Anna		✓	35	2004, 2005	6, 4, 14 months	Each diagnosis: mastectomy + latissimus dorsi reconstruction. 2 <sup>nd</sup> diagnosis only: lymph nodes dissection + chemotherapy Tamoxifen	U	Netball until working shift-work then moved interstate with partner and back to netball. Post-breast cancer, lateral dorsi reconstruction plus lymph node removal weakened arms – stopped netball. Encore program, tai chi, chi gong (Now stopped). Walking and wants to start running.	Y	>\$80,000	Yr 12	Y

								Less active				
Annette	✓		40	2002	9, 5	Lumpectomy + lymph nodes – 11/13 positive Chemotherapy Radiotherapy	S	Pre-children: netball, tennis and intermittent aerobics, gym. Post breast cancer: intermittent walking and gym. Less active	Y	>\$80,000	Yr 10	Y
Elena	✓		40	2002, 2005	11, 6, 4	Lumpectomy Mastectomy Axillary clearance Chemotherapy Radiotherapy	V	Child: cycled, played netball & table tennis, Guides until form 5 (Malaysia). Adult: fits and starts Less active	Y	>\$80,000	P/G diploma	N
Jen	✓		42	2004	19, 18, 17	1) Lumpectomy 2) Mastectomy Chemotherapy Radiotherapy Tamoxifen	S	Pre-marriage: netball. Post-marriage: occasional table tennis, regular sailing x 10 yrs, built 3 x houses with partner, bike riding. During treatment: built a house. Post breast cancer Sometimes walks, bike rides, swimming. Anti-hormone drug therapy- very sore feet & ankles – peddling bike hurts, walking in water soothes. Less active	N		Yr 11	N
Jodie		✓	39	2003	4	Mastectomy (4 operations) Oophorectomy Tamoxifen, Arimidex, Femara, Herceptin (2 years on trial) (had “cording”)	N/P	Child: athletics Lifetime: generally active, busy life e.g. mother, gardening, housework. Post breast cancer: 2yrs afterwards did Encore, 18 months ago started gym because heart function had “gone down” possibly due to herceptin. Doesn’t like exercise – “a drag”. Less active	Y	\$40,001- \$60,000	Yr 11	N
Justine		✓	51	2001	5	Bilateral mastectomy + immediate reconstruction (implants) Tamoxifen, Zoladex, Femara (had “cording”)	V	Teens: running Post child: “five years running after a toddler” Lifetime: generally active life e.g. cycling, bushwalking, gym on and off, pre- & post-natal yoga. Current: walking, cycling - irregular, pilates 1x wk.	Y- online	>\$80,000	U/G degree	Y

								Less active				
Kate		✓	32	2003	17months	Mastectomy Chemotherapy Radiotherapy Tamoxifen Oophorectomy	V	Child: calisthenics, tennis. Pre-relationship: tennis (until working FT) Post-relationship: tennis, social netball. Post Child: very little except walking. Post breast cancer: Encore program, walking (arm too sore for tennis) Less active	Y	\$60,000- \$80,000	Yr 11	Y
Lauren		✓	40	2003	6, 4	Needle biopsies x2 Lumpectomy Sentinel node biopsy Removal of lymph nodes Radiation injections	V	Says never been very active. Post children: walking, family bike rides. Post breast cancer: Chi gong for 1 yr. Less active	N	>\$80,000	Diploma	Y
Nora	✓		50	2000	31, 29, 23, 13 grand- children: 2 to 8yrs	Lumpectomy Radiotherapy Chemotherapy	N/P	Pre-breast cancer: tennis, walking, occupational. Post breast cancer: Encore program, occasional walking, occupational Less active	Y	<\$20,000	Yr 10	N
Penelope	✓		52	2006	11, 14	Lumpectomy Chemotherapy Radiotherapy Tamoxifen	U	Pre-children: competitive swimming, windsurfing, scuba diving, squash (until squash courts closed). Post breast cancer: Occasional walking, yoga Less active	N	\$60,001- \$80,000	Yr 10/hair- dresser/ beautician/	Y
Sarah	✓		37	2007	19, 16, 13	Mastectomy Chemotherapy (had "cording")	S	Teens: aerobics, cycling Adult: not into sport. Pre- working longer hours, walked most evenings. Current: Occasional slow walk Less active	N	\$40,001- \$60,000	Yr 11	N
Sophie		✓	28	2006	12months pregnant at time of interview	Lumpectomy Chemotherapy Radiotherapy	U	School: rowing. Pre-relationship: long walks on beach most days, swimming. Pre first child: walking most evenings, gym for short time. Post breast cancer: exercise program (until current pregnancy), irregular walks with toddler and walks with family on weekends.	N	>\$80,000	U/G diplomas	Y



								Less active				
Tanya		✓	45	2005	14, 12, 8, 6	Mastectomy Lymph nodes removed Chemotherapy Radiotherapy Herceptin Treatment for depression	S	Lifetime: not sporty. Teens/20s: liked going out dancing. Post children: intermittently attends belly dancing classes. Post breast cancer: occasional walks. Less active	N	\$20,001-\$40,000	U/G degree	Y
Vanessa		✓	33	1998	4	Lumpectomy then mastectomy Chemotherapy Radiotherapy Reconstruction (diagnosed with thyroid cancer 29yrs)	V	Pre breast cancer: usually did some exercise – walking, yoga/aerobic programs. Post breast cancer: Encore, back into more aerobic styles of exercise post-reconstruction. Been “slack” last 6 months. Less active	Y	N/A	N/A	N/A
Zoe		✓	37	2004	3	Lumpectomy Chemotherapy Radiotherapy Tamoxifen Zoladex	V	Most of life: own exercise routine & gym. Post breast cancer: aqua aerobics until started work, Encore program for a while. Gym when can. Less active	Y	N/A	U/G degree	Y

\*S=supportive, V=variably supportive, U=unsupportive, N/P= no partner (divorced/separated-ing/widowed)

^ R=rural, M=metropolitan

### *Support groups*

Support group criteria for this thesis include any formal or informal group or network of women who have had a breast cancer diagnosis, including internet support groups. Around 40% of the women were involved in support groups (see table 3). Several of the women were involved in online support groups or chat groups. The women gave accounts of the friendships that they had made as being one of the most important aspects of their involvement in a group. The women emphasised that the support group was not a place for dwelling on cancer. Rather, it was a social event which also included information and experience sharing at times.

*We don't tend to talk about our experiences as much or our diagnosis or what we're doing to achieve it because it's like a get together, social get together, so you don't want to talk on the negative things that have happened in your life and it is a friendship type support group (Elena).*

Some of the women found online support groups extremely helpful in relation to information sharing and also to feel part of a group when there were not any women diagnosed with breast cancer around their age locally.

Some of the women who were involved in dragon boat racing talked about the group as being supportive but did not talk about the group as a “support group” as such. Indeed, several of the women defined their dragon boat group as being *not* a support group.

*I'm not a big support group person [...]. [The dragon boat team] is a group of women and it is not a support group. We're always really clear about that. We're not a great support group, however we've all formed our own networks. It is very rare we talk about exactly what is going on. You know, you might discuss with one or another. Our primary thing is the actual sport of it. It is just darn good fun! (Rebecca)*

I included Isobel's account of participating in dragon boat racing in Chapter Four and include here her account of the difference between a formal support group and the benefits that she gained from participating in dragon boat racing.

*I'm not a support group person because I don't like the idea of*

*going along with a group of people and just reliving everything over and over again, which is my impression of what a support group might be. Whereas Dragons Abreast, okay we're all there with the same reason in the first place, but we don't dwell on it. We get on and we're doing something else. But if we need to talk to somebody about something we're there for each other. But we don't sort of get bogged down with it.*

*It's more an attitude of moving on and saying all right we've been through this, but this is what we can do now (Isobel).*

Thus, while the women described differences between support groups and dragon boat teams, the types of support that their dragon boat teams provide are very similar. Three of the nine women involved in dragon boat paddling were also participating in support groups.

Most of the women who were not involved in support groups were not at all interested in joining one, stating that they were “not for them”. Women who rejected support groups either did so because they did not find the idea of a group of strangers discussing details of their experience attractive, or they had been to one and felt worse afterwards because of the stage they were at in their breast cancer journey or because all the other women were much older than them; *I found it quite confronting...there was a woman... diagnosed with secondaries, ... I didn't want to hear (Sophie)/ I went there and oh it was the worst day of my life...they thought I was dying (Jess).*

Of the 15 women who reported being involved in support groups, six were *more active*, three of whom were involved in dragon boat paddling. The remaining two thirds were *less active*. Eight of the women who participated in support groups were living in rural locations and of these, five were *more active* and three *less active*. The remaining seven women were living in metropolitan locations, and of these, only one woman was *more active*.

All nine of the women who reported being in a dragon boat team were in the *more active* group, because most of the dragon boaters participated in dragon boat training or racing at least once and usually twice a week, so only required one more activity per week to reach the “at least three” criterion. All

except one woman (Emma) who was involved in dragon boat paddling reported having supportive partners. An important note to make is that dragon boat racing is seasonal, so the nine women who were *more active* at the time of this study may not have been in this group at another time. The same can be said for most team sport activities and similar caution must be taken in respect to any self report study that refers to the “previous week” or “previous two weeks” where respondents’ participation includes seasonal team sport.

Whereas the majority of the women said they were not enamoured with formal support groups, their accounts show that talking with other women who have had a breast cancer diagnosis has a strong influence on their decisions about supporting their health. However, support group participation did not translate into physical activity participation, except for women involved in dragon boat teams.

### **Paid work**

Some of the women who spoke about working, particularly full-time, spoke of not finding time for themselves, or being too tired to participate in physical activity in addition to their paid and unpaid work. In Chapter Five, in the theorising causation section, I described Elena’s account of “always catching up”, wanting to reduce her paid work hours and feeling frustrated at being unable to participate in regular physical activity:

*I know that I need to change what I'm doing now in terms of reducing my hours because it's critical to me to give myself the time (Elena).*

Nevertheless, half of the women who worked full-time participated in regular physical activity. Women who were able to participate in physical activity when they worked full time talked about individual and social factors that enabled them to do so, such as wanting to do some physical activity during their lunch break at work, or their partner looking after their children while they go to the gym or for a walk at night, early in the morning or during the weekend. Grace, for example, spoke about going to the gym during her lunch

break: “I love going to the gym when I go in the middle of the day”. Blanche walked to work, plus during her lunch break and in the evenings with her partner: “I might get three lunch time half hours and about three nights in the week we go for a walk [...] I don’t have to walk too far to work”.

For most of the women who participated in paid work, particularly those who were in full time paid work, the level of physical activity in which they participated was dependent on other factors, such as the degree of partner support they could obtain and the extent to which their identity as mothers constrained them from taking time in addition to their paid work hours.

### **Gendered identity**

Almost all of the women spoke about mothers/women putting themselves last, despite having had a diagnosis of breast cancer: “I just think it is hard for mums to put themselves first” (Zoe), “the traditional thing is: Mum always comes last, you know, whether you’re dishing up the tea and you have the burnt chop” (Tanya), “I didn’t play any sport at all then for ages – but I took the kids to all of their sport” (Philippa), “I guess it’s that putting yourself at the bottom on the pile again” (Joanna).

The women who gave accounts of women putting themselves last typically spoke about feeling that taking time out for themselves would be selfish. Being a [good] mother did not fit with taking time out for physical activity, even in the light of a breast cancer diagnosis.

*I would look at it as being more selfish with my time. Say if I wanted to go to gym, I’d have to go of a night because I work through the day, and that’s not going to change now. And I’d feel I wouldn’t want to be away from [my daughter] as I’m at work all day, so I wouldn’t do it (Janine).*

Yet, a few of the women spoke about regular participation in physical activity as being part of being a good role model, although in Zoe’s account, which I explore further below, she was unable to act on her wishes at the time of her interview:

*...physical activity definitely is so important and I’m going to teach [my daughter] that as well, to look after herself and eat*

*healthy so I've got to be a good example for her as well (Zoe).*

A tension between motherhood and physical activity participation, whereby on the one hand mothers feel they are being selfish, but on the other feel they are being a good role model, if they take the time to participate in physical activity, has been found in previous studies, as reviewed in chapter Two. Also in agreement with previous studies, as the women's children became older and more independent, they typically began (or resumed) to participate in regular physical activity, as illustrated by Rebecca's account.

*I had always, all my life I've done sport, competitive sport [...] I had a few breaks, with the second one particularly, when she was born. She was just so busy and very clingy that I had a break for a while, but I've always had sport in my background (Rebecca).*

Several of the women spoke about wishing to spend any available time with their children and/or partners. A few of the women spoke about a sense of time with their families being more precious after having a diagnosis of breast cancer. While for some of the women this time included physical activity, for others it did not, or was not regular enough to mean being *more active*, like Sophie's account of walking with her family being inadequate in terms of providing the benefits she would like: "so with my walking now it's never complete".

### **Class**

To explore class influences, I examined patterns between the women's reported participation level, their responses in the demographic form which included education attainment, occupation, household income, partner's education attainment and occupation (see appendix 5) and the ways in which the women spoke about the resources available to them for participation. The majority of the women in this study came from what would commonly be called middle-class, based on the measures of income (the majority reported living in households with annual incomes over \$60,000, with almost half over \$80,000) education attainment (two thirds had some kind of tertiary education) and working in the range of occupations generally considered middle class (see tables 2 and 4). The ways in which the women spoke about resources available to them, however, suggested gender-based social

stratification within the household operated as a stronger factor in their participation.

Looking at income, of the nine *more active* women who stated their annual household income was more than \$80,001, eight said they had supportive partners and one had a variably supportive partner. By comparison, of the six *less active* women who responded that their household income was more than \$80,001, one had a supportive partner, three received variable support and two spoke of their partners as being unsupportive (see tables 2 and 4). While it is hard to draw conclusions from a small sample, the direction of the data certainly supported the idea that class was a factor in physical activity participation, and that it operated in conjunction with partner support. This was shown by illustrative accounts of the women from some of the wealthiest households below; Grace's account as one of the *more active* women, and Anna's as one of the *less active* women.

Higher education attainment also seemed to be associated with women being *more active* if examined in isolation, reflecting national physical activity participation survey findings described in Chapter Two. Two thirds of the women who responded that they had completed either a degree or a trade certificate or diploma were *more active*. Four of the five women who had completed year 12 and one third of the women who had not completed year 12 were also *more active*. Again, this association appeared to be tempered by level of partner support and the women's gendered identities. Sophie's account illustrates this point; according to her response in the demographic form she has more than one post graduate diploma, yet in her account below, she describes in detail how she is unable to participate in regular physical activity because she was unable to obtain support from her partner and she felt it was her role to take the lead in caring for her toddler. Emma, the one woman who was *more active* and had a degree and an unsupportive partner worked in the fitness industry, which was what contributed most to her being *more active*.

For this sample of women, income and education attainment featured as influencing their participation in physical activity. Yet the influence was moderated when accompanied by other factors explored in this section to varying degrees, with a combination of gendered identity and partner support being the strongest of these influences on the participation of women in relationships. It appears that class and gender as social stratifiers influencing physical activity participation, at least for these women, cannot be examined separately. I explore how the range of social/structural influences work together, along with individual influences, in the women's accounts below and go on to examine these features further in the theoretical implications in Chapter Seven.

### ***Individual influences***

#### **Stage in the breast cancer journey - pain/fatigue**

While the women's level of pain or fatigue was usually associated with their stage in the breast cancer journey, some of the women experienced and/or expected pain, discomfort, arm weakness and/or fatigue to be ongoing; for months, years or for the remainder of their lives. Several of the women spoke about this, including post-surgical breast (particularly reconstruction-related) pain or post-radiotherapy underarm pain from scar tissue, arm numbness or lymphoedema from lymph node removal and/or radiotherapy. I described some of the women's accounts of effects of cancer treatments that constrained their participation in physical activity in Chapter Four, for example Anna's account of being unable to resume playing netball because of her reconstructive surgery:

*I used to play team sport before I got sick. So I don't think I'll be able to do that ever again. Only because of my reconstructions my arms aren't good (Anna).*

The women experienced breast cancer treatments differently, with some women feeling able to participate in physical activity throughout their treatment journey, while others said they felt physically unable to participate in any physical activity during their treatments and sometimes for a lengthy time post-treatments, as described in Chapter Four.



*My feet burn to the stage that it feels like – you know when you have ripped your foot raw from an itch and it burns, that's how they feel all the time. They just burn all the time. So I have to force myself to do things, really (Jen).*

Tanya reported experiencing extreme fatigue which would hit very suddenly. She said she did not like to walk to the shops because while she may manage getting to the shops, she feared being unable to return home because of the potential for a sudden onset of fatigue.

*The fatigue bit is a real – a real pain. It doesn't seem to go in increments like, you know and you've got a gradual progression [...]. So in a word I'm not actually doing very much at all (Tanya).*

Though many of the women talked about ongoing effects of treatment, more of the women who were at least five years along their journey were *more active* (see table 3). Whereas one reason for this was their physical recovery, for some of the women their increase in participation was also because their children were older and therefore less dependent on them.

### **Pre-breast cancer physical activity participation and “being competitive”**

Most of the women who reported being *more active* at the time of their interview also spoke of being active and/or enjoying physical activity prior to their breast cancer diagnoses.

*I think it was very much an environmental thing set up by my parents in the first instance just to always play sport. And I always, I feel better doing sports. Always feel much, much better. It is my stress release to go to gym (Rebecca).*

Similarly, Adele said she had always played sport when she was younger, then with young children she participated in activities that provided child care services:

*So through that time there I probably didn't play netball or basketball but did like gym classes, aerobics (Adele).*

Several of the *more active* women described themselves as being competitive people; “I'm an athlete by nature so quite competitive” (Emma). Some of the women who participated in dragon boat racing spoke of ways in which dragon boat teams negotiate between women being involved in the

teams at any stage of their breast cancer journey, and at the same time being competitive.

*Some people are more competitive than others [...] and that's where it can be a little bit difficult [...] there needs to be an awareness that not everybody wants to be as competitive as some of the others. So it's striking a balance for everybody really. And the people who are not so competitive tend not to come along to races (Isobel).*

Danielle described how dragon boat teams managed to find a balance between those able to be more competitive and yet including those who may be feeling too unwell to participate at a more competitive level.

*...it's a slightly different attitude towards exercise I suppose from that point of view, which I assume has grown out of the fact that obviously from time to time, not necessarily well people are there exercising. [...] Like there's one lady who goes who is still having chemo and she rows for a little while some days, and then she swaps and sits at the front of the boat (Danielle).*

In spite of this, there was also a sense that there were some tensions between dragon boat teams in the ways in which they defined themselves, as illustrated by Philippa:

*I think some of the girls who paddle do it because they are competitive and some do it for the camaraderie and the support. Our team is actually quite strong. There are several dragon boating groups of women cancer teams or supporters, but there is one group who are just like fluffy feathers and stuff like that and all about 'pity me'. Then we are more competitive – like get on with it, let's have a good time. So when we have race days we are winning races against other able-bodied teams. You know we have been interstate and overseas and won medals and things at an average age of God knows what – but in their 50s. We are still up there and in amongst it! (Philippa)*

On the other hand, some of the women described themselves as not being competitive, or not sporty, and of these, some were *more active* and some *less active*: “I was allergic to sport” (Tanya), who was *less active* and Alana, below, who was *more active*.

*I'm not really sporty or competitive. It doesn't bother me doing stuff on my own sort of thing. And you can just do your own*

*pace, I guess I like that too (Alana).*

Only two of the women spoke about not liking exercise, but doing it anyway for health benefits (albeit in “fits and starts”), one of whom was *less active* and the other *more active* at the time of their interview. Several of the *less active* women reported being active when they were younger, or before their child/ren were born, and would have liked to be active again but found that the factors mentioned in this section: gendered constraints, lack of partner support and/or work or pain from their breast cancer treatment, meant they had not managed to return to regular participation in physical activity.

### **Knowledge of health benefits of physical activity**

Only two women who spoke about being relatively inactive prior to their breast cancer diagnosis commenced physical activity because of their knowledge of specific health benefits (Jill and Jodie) although Jodie was *less active* at the time of her interview.

*CM So you were saying that you just started doing some walking - is that because, I mean, were you doing stuff beforehand, or was it because of...*

*Mainly because of the breast cancer. I used to exercise up until I got married, and once I started having the kids, virtually that was it (Jill).*

Grace, one of the *more active* women spoke about using her knowledge of specific health benefits for women who have had a breast cancer diagnosis to justify her participation (see Grace’s account below). Knowledge of health benefits alone, however, provided insufficient impetus for most of the *less active* women to become *more active* and the remainder of this chapter teases out how the factors above interweave to constrain or enable women to participate.

### **Participation in context**

The levels of participation in which the women engaged were dependent on all of the factors described above, with partner support being the most critical factor in the partnered women’s participation. In the following pages I describe the interrelations between social and individual influences on the women’s physical activity participation in the daily lives of the women.

## More active women

### *Bernadette*

Bernadette spoke of growing up in “a sports mad family” and described herself as competitive. She had played a range of sports throughout her childhood, stopped team sport while at university then recommenced after she started work. She met her partner through playing sport and they were both tertiary educated and worked in health and education respectively. Bernadette and her partner moved from Adelaide to a rural South Australian town soon after the birth of their first child. She found that her participation in physical activity drastically reduced because the move meant she no longer had child care support from her family and friends and talked about feeling extremely unhappy during that period of time.

*[After the move] we didn't have family support for babysitting - we didn't play a lot of sport for a long time because it was hard taking a baby with us.*

*[...] We were playing touch football while he was little enough to just lie in the pram but once he got mobile that wasn't really an option. We tried tennis but again it was late at night and that was too hard with the kids. So then I did a bit of mixed netball. We did mixed netball together but again it was all just a season here and a season there because of babysitting (Bernadette).*

Bernadette spoke of participation in physical activity being extremely important to her and once she had made friends she started walking with a group of friends two or three mornings a week, which she continued as much as she possibly could during her treatment and once she had returned to work.

*I'm still doing it, I don't always get there three days a week because I'm back at work. I generally try and get there two days a week and I would have a swim on the odd occasion now if we take the kids to the pool. [My husband] will play with them and I'll do some laps so certainly not as active as I was but I still enjoy it.*

*[...] we take the kids [bike] riding so yeah I do it because I enjoy it. I've always been a very slim person so I've never done it for weight reasons other than the fact that if I don't do it I lose muscle tone and I get skinnier but I do it more just because I enjoy it and it makes me feel good and I'm competitive. (Bernadette).*

Along with Bernadette's personal enjoyment of physical activity being an enabler, her account is representative of the women who talked about being more likely to negotiate with their partner to take time out following their breast cancer diagnosis. In Bernadette's account, this was in the context of an already supportive relationship. The few women who experienced this typically talked about changes in themselves, where they have become more assertive in their relationships since their breast cancer diagnosis.

*CM if you felt like going for a walk at a different time, would you just say to [your husband] "look I didn't get to have my walk at six o'clock, I really want to go now"?*

*Yeah I would. I think I have a few times. I know when I went swimming I did. I said to him "yes we can go to the pool but you've got the kids, I'm doing laps". [He] would always say to me "you do what you want to do, don't worry about everybody else" and I used to worry about everybody else and now I think well no, I know everyone else is fine, this is what I want to do (Bernadette).*

Previously in my analysis, I presented Bernadette's account of knowing she would feel good if she did some sort of exercise. She also spoke of how she felt when she did not manage to do some exercise:

*I want to go walking and it would be six o'clock in the morning and my alarm would go off and I'd think I just can't do it this morning but then at ten or eleven o'clock I'd be really cranky with myself because I hadn't got up and gone (Bernadette).*

Bernadette was adamant that she wanted to remain active through her treatment:

*I guess I knew that I wanted to keep active. I've always been sports mad to a point. The thought of actually sitting doing nothing for four months was just like no, that's not going to happen (Bernadette).*

Bernadette's account of her participation in physical activity includes individual and social factors which together enable her to be *more active*. Individual factors include her preference to participate with others (team sports or walking with friends – also meaning that this became a constraint when she moved away from social networks), and feeling better when she participates and not liking how she feels when she does not participate.

Bernadette also spoke about herself as being “competitive”, which is how several of the *more active* women defined themselves. Bernadette’s account of her personal change following her breast cancer diagnosis meant that she was more likely to negotiate time for herself. Such a change featured in a few of the *more active* women’s accounts. Social enablers for Bernadette’s participation include a supportive partner and child care availability. Bernadette’s paid work did not stop her from participating in regular physical activity, although it reduced the frequency.

Bernadette did not speak about information about health benefits of participating in physical activity (or any other health promotion campaign) as influencing her decision to participate. Rather, she spoke about how, based on her embodied experience, she knew she felt better if she exercised.

#### *Grace*

Like Bernadette, and most of the *more active* women, Grace had individual and social factors enabling her regular participation in physical activity. Grace owned her own business, having gained further education, and was the main income earner in her family. At the time of her breast cancer diagnosis, however, she was working for another employer in the same field and her family was not financially reliant on her being at work and her partner did not have to gain work to support the family financially. In addition to her family’s financial security, her partner contributed substantially to their unpaid labour responsibilities. Grace’s partner was familiar with looking after their children (and their children with him).

*In hindsight, [my husband] really wore a lot of the stress and life changes more than me. I just slipped out of our life on the side and had the treatment and then came back done. [My husband] wasn’t a full-time worker. [He] used to work and still does work for me and supports me with my [business] [...] but he kind of already was the number one parent [...]. He doesn’t have to work 9 to 5. He doesn’t [have to] be answerable to someone else, so I think it made us very lucky and the kids are really good with [him] as well. So I think we’re pretty fortunate to have that as well. They’re equally comfortable. You know how people just ask mum for stuff, like they’ll ask [dad], because it’s that role, I suppose, where he’s often been that number one*

parent.

*[...] [My husband's inheritance] gave us the lifestyle we're allowed to have, which has been really fabulous. So I think that's helped a lot because otherwise you have to work to pay your mortgage and you do have to work to pay your bills, whereas we work because we love what we do. We still have bills, don't get me wrong, but we've got choices (Grace).*

At an individual level, Grace spoke of having very few adverse effects during her radiotherapy or chemotherapy. In Chapter Four, I included Grace's account of walking to and from her radiotherapy treatment and wondering whether walking improved her treatment experience. At the time of her interview, Grace was working full time and regularly went to the gym during her lunch break. She talked about her exercise as "my medicine". For Grace, knowledge about health benefits of physical activity after having a breast cancer diagnosis helped her to justify taking the time to go to the gym. She also spoke of going with family and friends which she found encouraged her to keep going.

*I go to the gym in my lunch break usually and mum has just started coming with me and my sister goes as well, so normally about 1 to 2[pm] I drive and we do an hour's workout. [...] So I definitely have an awareness that's it's a good thing to do, especially now for me and sometimes I feel guilty about going to the gym. I feel very self indulgent and I feel like I almost have to justify it to my staff. Like it doesn't seem to be a valid thing to be doing when things are busy, but then I tell myself that it's actually like my medicine. It's actually a good thing for good thing for me to do and not only do I feel better from it, but long term it's what I should be doing (Grace).*

Grace's decision to go to the gym during her lunch break was in the context of structural factors including having a secure household income, owning her own business, being in a supportive relationship, plus having the support of her mother. When I interviewed Grace at her office, her mother looked after the shop-front.

*Alana*

Alana was 28 years old at the time of her first breast cancer diagnosis in 1991 and her children were two and three years old and she had a second diagnosis in 1993. Since her second diagnosis, she had attained a university

degree and was working in a university. Unlike most of the *more active* women, but representative of a few, Alana spoke about herself as being “not really sporty”. Alana had felt unsupported emotionally during her breast cancer journey, which led to her reassessment of her relationship. At the time of her interview, her children were no longer dependent, she was in a supportive relationship and was *more active*. At an individual level, Alana had never played sport before her breast cancer diagnoses, but several years after her second breast cancer diagnosis she took up dragon boat paddling which she said surprised “everyone”.

*I wasn't ever a sporty person and friends were really surprised when they heard I was doing dragon boating, it just wasn't me to be involved in a team sport and I didn't even like deep water. I've always walked for exercise (Alana).*

While having had a breast cancer diagnosis is what led Alana to participate in dragon boating, she had stopped at the time of the interview, because she no longer wanted breast cancer to feature so highly in her life.

*Some people do make breast cancer their lives and I just don't feel that I have the energy and the passion that some of the women do, they are just wonderful. They speak at events and it's their life focus to raise awareness and these are sometimes women with advanced breast cancer. You still have breast cancer in the back of your mind no matter how long ago the diagnosis was but for me personally, it's good to get my mind onto other things. I had found myself battling depression on and off over recent years and needed to focus on myself on an emotional level (Alana).*

Individual enablers for Alana included incidental activity such as walking her dogs and walking to and from the train stations to commute to work. Alana said she had studied health when she returned to university in the time between her recovery from breast cancer treatments and the interview, and learned that regular exercise was beneficial to health, particularly after a breast cancer diagnosis. She said she gained her knowledge about health benefits of participating in regular physical activity at university, not during her breast cancer treatment journey.

*My diagnosis was many years ago when there was not a lot of information available regarding breast cancer and exercise. At one point I remember joining a local gym and having to explain*



*to the young fellow who was doing my fitness assessment about the restrictions related to my various areas of surgery. It was quite embarrassing doing this and also coupled with having to arrange for childcare for my youngest child, it was just all too hard. Today there are group exercises specifically tailored for women following their breast surgery. Years later, during my return to study, I learned a little about exercise behaviour and incidental exercise; such as getting in 20 mins of exercise by taking the stairs instead of the lift or walking to the shop, train station and that sort of thing over the course of the day (Alana).*

Alana's feelings about going to the gym and having to explain about her surgeries, plus problems with arranging child care, were typical of several of the women; particularly the women who were less active at the time of their interview.

### *Emma*

As described in the previous chapter, Emma worked in the fitness industry so being regularly physically active was her job. Similar to other women who did not feel they received support from their partners, Emma described her sources of alternative support, particularly her friends. Typically, the women who spoke of their partners as being unsupportive usually offered accounts as to why their partners were unable to provide the support they would have liked.

Emma's account describes the hardship of having to continue working throughout her treatment in order to support her family financially. She found that her partner was unable to emotionally or financially support her and illustrates ways in which a few of the women talked about men in terms of being less able to cope with sudden changes in domestic circumstances than women. She also described how she made decisions that meant her partner could continue with his plans, despite meaning that her life would be more difficult, because such decisions were preferable to the possible alternative of feeling resentment from her partner.

*I did work through it, because I had to. My husband couldn't work full time [...] so I had to keep work up, because you can't get any compensation whatsoever [...]. It was dreadfully hard, but I think the hardest thing for me was my husband's*

*personality [...] he's quite highly strung, so it was very hard for him to cope with trying to train, trying to keep the house in order, looking after two little children and having me. [...] I think [my husband] actually had trouble dealing with it as well. He probably should have gone through some counselling at the time. I think he had trouble, all of a sudden his very fit wife, physically very, very fit and [...] here she is laying in bed [...]. And all of a sudden he's got to become head of the house, which if they're not in that role it's probably hard. I think males have more trouble with that than women. Us women we do six things at once.*

*[...] thank goodness for friends is all I can say. Yeah my girlfriends were awesome (Emma).*

Later in her interview, Emma illustrated the way in which many of the women described the meaning of “being a mother”, where in relation to physical activity, mothers’ needs come last; after the needs of their children, partners and paid work. Nevertheless, Emma also spoke about an added imperative to fit in exercise because she encourages others to do so.

*As a mother I think we tend to fit the kids and husbands in and working in before we fit ourselves in. I always find time to exercise, but I think it's the industry I'm in, I'm preaching that all the time. I'm the one always suggesting to people how they could find time to exercise, so I will always find time to do something. And I just think that's so important as a stress relief and mental cop out (Emma).*

### *Janine*

Janine was not in a relationship at the time of her interview, having separated from her husband. She was working full-time in an administrative position and had completed year nine at secondary school. She reported that she was active as a child, and played netball until she married. Since her marriage, she said that she had always walked, except in the time during her breast cancer treatments, and through to around five years after her treatment. In Janine’s account, the main structural factor enabling her to participate in physical activity at the time of her interview was that her youngest child was old enough to be left home alone while she walked. Individual enabling factors included her feeling of wanting to do something for herself and the length of time since her breast cancer diagnosis. Her structural constraints to participation were her ex-partner and her work.

*As a child I was always very active, rode my bike to school, played netball. [...] I got married when I was 18 and I stopped playing netball because my husband didn't want me to play anymore. So physically I did no sport at all. Then I had [my first child] when I was 22 and the only sort of physical activity I did was housework or going for a walk with the baby in the pusher. I didn't do any extra. I never went to a gym or anything like that and over the years that is the only sort of exercise I have done. It's only ever been walking, if its walking to the shops, or walking the baby in the pusher or walking over to my grandmother's or my mother's [...] and once I got sick with the cancer I just basically didn't do anything, just went to work and came home, did what I had to do and that was it for that length of time. As I said it has taken a very long time for me to get back the strength to walk three times a week (Janine).*

Janine also talked about the influence her feeling of responsibility towards her children had on the type of activities in which she would participate.

*If [I] wanted to do more I would have to, I would look at it as being more selfish with my time. Say if I wanted to go to gym, I'd have to go of a night because I work through the day, and that's not going to change now. And I'd feel I wouldn't want to be away from [my youngest child] as I'm at work all day, so I wouldn't do it. And I don't think I'd go to a gym anyway and [...] I can't swim. That's why I made sure the [children] learned to swim [...]. And the only thing is, in time as [my youngest daughter] gets older and a bit more independent, if she doesn't mind me spending time away from her, the only thing I would do probably during the summer months is walk maybe five nights a week and that's the only exercise I would do. I wouldn't do anything else (Janine).*

In Chapter Four I included Janine's account of the ways in which she spoke about prioritising her children's needs and her paid work above her own needs throughout her breast cancer journey, in the context of living with a violent partner. Here, Janine explains in her account below that her partner's emotional and physical abuse and his inability to provide practical, emotional or financial support was because he did not cope with her breast cancer diagnosis, or with her treatments. As mentioned previously, Janine said she had to continue paid work through her chemotherapy treatment and arrange alternative care, usually her mother, for her children at times when she could not cook for them.

*That morning when I was meant to go to hospital, my husband*

*was supposed to take me and he didn't. He couldn't handle it. So I had to ring up at the last minute and get my mother to drop me off and I was very nervous.*

*[...] I took part in a trial [...] where they bandage your arm and I said that I could only do it if I could come after work and they agreed that I could do that. That went for four weeks, four nights a week of going out [...] every night and having my arm heavily bandaged and my fingers. So basically when I got home my arm was out here and I couldn't do anything. So he never liked that and he actually came out and slept in the lounge room. But the bandages would come off of a morning and then I'd go to work and then you'd go back and they'd bandage – and you'd have it bandaged over night and I had to organise and paid for my Mum to have the girls go over there to eat so that they would be fed (Janine).*

Janine went on to talk about how her partner verbally abused her because of her mastectomy because “he didn't like that my body had changed”. For Janine, participation in physical activity was part of her emotional healing from her relationship. During the early days following her diagnosis and the time of her acute treatment, physical activity participation did not feature at all. Janine talked about walking regularly once she had recovered from treatment, as being a way of coping with everything that had happened since her breast cancer diagnosis, going on to talk about the details of her partner's arrest and subsequent restraining order.

*When I go for my walk – rushing home to go for my walk I find very stressful because as I said I have to make sure I leave work on time, rush in the door and quickly get changed and quickly say Hello to the girls and you know, [my youngest daughter] will ring me at work once she gets in from school and so I talk to her then about homework and things like that. I quickly get changed and then I go off on that walk and I once I start walking I feel better. I feel: "Yes, I'm doing this for me". And then sometimes I think: "Oh my God why am I doing this, I'm too tired but keep going." I feel better that I've done it and if I don't do it three times a week I feel guilty that I've let myself down. So I really want to stick to doing the three times a week. Just for the exercise and to have some quiet time to myself to think. Because obviously lots of things are happening in my life that I don't want to happen and I suppose it is time away from the house and everything to think, you know, to think "why is this happening?" Go through a lot of negative thoughts, why did this turn out this way? Why did he not cope?*

*CM It sounds like for you as if it's a time out thing as much*

*as anything.*

*Time for me to think, think. Especially with what's going on at the moment. I will walk and think about it all. [...] Sometimes I need to remind myself of what he's said and done to me and how he's treated me since I've had cancer, because he definitely changed once I got diagnosed (Janine).*

In Janine's account, her walks were something that she could do for herself, and provided time to think about everything that had happened. Janine was struggling with the ways in which her partner had been abusive after her breast cancer diagnosis. Janine's account shows how participation in physical activity can provide benefits other than biological health, because for her, her walks were an empowering time, where she was doing something for herself and building resolve to maintain separation from an abusive ex-partner. Janine did not talk about specific health benefits of physical activity for women who had had a breast cancer diagnosis, but clearly experienced other benefits. Janine's account is typical of ways in which the women spoke about physical activity as providing benefits other than biological health, for example, time out for oneself or time to think.

The women's accounts above demonstrate the range of social and individual features in their lives that worked together to enable the women to be *more active*. Social factors such as partner support and class (household income, occupation, education), along with being able to draw on these resources featured highly, as well as individual enablers such as a history of participation in, and enjoyment of, physical activity participation and time since diagnosis. Other types of social support such as friends and family or support groups did not appear to be strong influences on the women's participation, except for example in Bernadette's account, when it was in the context of having a supportive partner. Emma was the only partnered *more active* woman to have an unsupportive partner. Paradoxically, like Janine, four of the five women who were not in relationships were *more active*. Thus to reiterate, for the women in this study, having an unsupportive partner was more of a constraining factor than not having a partner at all. This supports existing literature, which I reviewed in Chapter Two and to which I return in

Chapter Seven, that has found that being in an unsupportive relationship is more constraining for physical activity participation than being un-partnered. Below I explore case study illustrations of the *less active* women's accounts, which highlight the range of social and individual factors which contributed to the women being *less active*.

### **Less active women**

#### *Tanya*

Tanya was diagnosed with breast cancer two years prior to the interview when she was 45 years old and her children were 14, 12, 8 and 6 years old. She lived in a suburb of Adelaide and her partner was the main income earner for her family, working in a blue-collar position. While she had recently completed a university degree, based on her response to the demographic form, Tanya was among the poorest women in this sample. Tanya said that she was "allergic to sport" as a child but enjoyed dancing from her late teens on. She said that after her youngest child was born she started belly dancing classes and had continued them on and off over the years, and was contemplating returning to classes at the time of her interview.

Tanya said that if she was to do anything at all, it would be belly dancing, for the following reasons:

*And especially in a class session because the beauty about belly dancing, is you don't have to be beautiful. You can be any shape at all. Because my arm gets very sore and heavy I can just hold it and just do the foot work and it's quite fun and it is a fairly reasonable work out. So it's surprising really for something that usually looks so controlled and it's the controlled movements that keep you all together. [...] it's only in school terms and it's during school hours so I just arrange around it (Tanya).*

While none of the other women spoke specifically about participating in belly dancing, several shared Tanya's preference for activities that did not focus on body image; dragon boat paddling and women-only gyms being two examples. Tanya also talked about gyms being prohibitively expensive and that she did not like the environment. This too was a sentiment shared by several of the women, with a few women giving accounts of paying gym

membership and then only using the gym a few times. She also felt concerned about starting belly dancing classes because if she paid and then missed some classes, she would be wasting the money.

Tanya expressed surprise and gratitude at the extent of support that she gained from her partner and wondered whether it was in part because of her oncologist's advice. Tanya's oncologist described to her partner how Tanya may be feeling through chemotherapy, in particular that he may have to take over the household cooking. She also talked about how supportive her partner continued to be after her treatment, as at the time of the interview, she was still experiencing extreme fatigue.

*But he's really good and he was cooking and he arranged to take the time off while I was in the hospital so he was taking, getting kids organised for school and getting things there. And even though I still had to go shopping every week. I mean he went, came with me and pushed the trolley and that but he's not a very good grocery shopper, so we probably saved a fortune by me crawling out every week, whether I felt awful or not, just to get it done. But he did everything else. And yes, he's performed above and beyond what I ever expected (Tanya).*

Tanya's account is typical of the four *less active* women who spoke about their partners as being very supportive. These women's participation was influenced by individual factors such as fatigue and/or pain following their breast cancer treatments, and also by preferring to use the time they had to themselves in other ways. None of this group of women spoke about participating in physical activity as being a priority in their everyday/everynight lives, either before or after their breast cancer diagnoses. Though, all of the women in this group talked about participating in some form of physical activity at different times in their lives, and also about enjoying it at the time.

### *Zoe*

Zoe lived in a suburb of Adelaide and was diagnosed with breast cancer in 2004 when she was 37 years old and her daughter was three. She had a university degree and was working full-time in a professional position. Her partner worked in three customer service jobs over the course of a week.

Earlier in my analysis, I included Zoe's account of how she enjoyed physical activity because it made her "feel good". She said that she had always participated in some type of exercise, but at the time of the interview was unable to participate in any regular physical activity. Zoe talked about financial constraints, whereby both she and her partner were working a great deal, meaning that she was unable to have time for herself in times that would not further reduce her time with her daughter.

*I need to get part-time work. I am finding five days a week, and I'm probably a bit angry about that, about why I am working full-time? I need time for me. I haven't had time for me and I get angry because like on the weekend of course I want to spend with my daughter. She hardly sees me. My husband takes her to school and picks her up. I don't do that. And then sometimes I just need time for myself. So I just can't fit it all in so I want to eventually go part-time so I can have time for me, go to the gym. [My husband] works a lot. He works at night. He works on the weekend. We want to be able to look after her (Zoe).*

Zoe spoke about the practical support that her partner provided, including taking their daughter to and from school and doing the housework.

*[My husband] does the housework now. Not the way I like it though. He does the housework and he takes her to school and picks her up and he does the grocery shopping, but I just can't because I am working full-time (Zoe).*

Zoe's account, however, is also characteristic of how several women talked about not being able to obtain the emotional support they would have liked from their partners.

*Like [my husband] is emotionally not someone you can talk to really, so I didn't feel like I got that, someone to talk to. Sometimes I was really frustrated because I just needed to talk but I didn't really get that. I remember the nurse telling me that a lot of marriages don't survive breast cancer because of things like that (Zoe).*

Zoe went on to explain that it is difficult for mothers to put themselves first, and how she felt that husbands do not understand that.

*I just think it is hard for mums to put themselves first. It is just really hard just fitting it in after that. Sometimes it is still hard. The husband doesn't get it but it is still hard (Zoe).*

Zoe spoke about her knowledge of ways in which physical activity was beneficial for everyone's health and for women's health after a breast cancer



diagnosis, particularly for women who start menopause as a result of treatment.

*They did something [at the gym] that was specially for your bones like weight bearing exercises are very good. [Talking with child]. Because one of the things about not having your periods is osteoporosis, no oestrogen in your body, so that is one of the drawbacks of everything. So weight bearing exercises are good.*

*[...] I remember seeing something that there was a study done and you get The Beacon, which is the Breast Cancer Network Australia newsletter. I remember there was a study being done [about benefits of physical activity]. There was also something in the Sunday Mail. Something about the importance of women's recovery and exercise and just the whole picture. I have always believed that. I think everything combined is really important for people's recovery. I have always felt it, thought it (Zoe).*

Zoe's account represents the ways in which social and individual factors combine to enable or constrain participation in physical activity. Zoe's account illustrates structural constraints to her participation, including variable partner support, her gendered identity as a mother, and full time paid work. In addition, Zoe's account highlights a gendered assumption that it is "normal" for men to be unable to talk about emotional issues, and this assumption was shared by many of the women.

Zoe's account illustrates the ways in which the level of partner support can be constrained by financial pressures and women feeling an imperative to prioritise others (especially their children) above themselves. At the same time, Zoe wanted to be a good role model for her daughter, which was a driver for Zoe to keep looking toward changing her situation. In this respect, she was typical of several women who spoke about a future which they hoped would include regular participation in physical activity; for Zoe this would be achieved by working part time.

Zoe's account also exemplifies typical individual constraints including long term fatigue after breast cancer treatments. While Zoe spoke of enjoying

physical activity (previous chapter), and about her knowledge of benefits of physical activity, at the time of her interview she was unable to be *more active*.

### *Elena*

Elena was 40 years old when she was first diagnosed with breast cancer in 2002. Her children were 11, 6 and 4 years old. She had a second diagnosis in 2005. Elena lived in a large rural Victorian town and worked full time in a professional position, having attained a post-graduate diploma. She had taken substantial sick leave while she had her breast cancer treatments and her partner was in paid work intermittently. In the previous part of my analysis I described Elena's detailed knowledge of health benefits of physical activity, particularly for women who have had a breast cancer diagnosis. I also described Elena's concern for her health because at the time of her interview she was still working long hours and that because she felt that stress caused her breast cancer, and that her concern was heightened by having had two diagnoses.

Elena had mostly social constraints to her participation in physical activity; her paid work, her parental responsibilities, her household chores and her variably supportive partner. At an individual level, she spoke about effects of chemotherapy which contributed to discomfort when she exercised.

*And also one thing that happened to me like over summer I find that I can't really go out for a walk because my whole back becomes very prickly and I've never had this until after the chemo.*

*CM Like prickly heat?*

*Yes like a prickly heat, like little you know [...] it was very uncomfortable and very prickly and you just couldn't be outside because it was causing a problem and I still have it now, it's not so bad but you know at that time it was really bad. So that sort of stopped me going out during summer like I would do it spring time and all that but the main thing with me is the working full time, coming home, kids, having to cook and by the time they settle down it's like eight something, nine and then you're up again the next morning (Elena).*

I return to Elena's typical account in the next chapter to unpick further the tension between her knowledge about benefits of physical activity and the constraints she identified that meant she was *less active*.

### *Sophie*

Sophie had attained undergraduate diplomas and was not in paid work at the time of her interview as she had a toddler at home and was pregnant. Her partner worked full-time in a management position and had attained year 12. She had rowed at school, but had always walked as her main form of physical activity since she left school. Sophie said that when she was diagnosed with breast cancer she was "really quite fit" because she had been going to the gym to look good for her wedding which was to be two weeks after her diagnosis. Sophie spoke of trying to maintain her fitness throughout her treatment, but found it difficult to keep up.

*I tried to exercise as much as I could [through chemotherapy]. I stopped the gym, but just walked - but it was during the heat of summer as well, so recovering from chemo and feeling vile anyway, everything was hard, it was hard to kind of keep up a regular exercise pattern. But I still probably at least three times a week went for an hour walk. But I found the further along I went with the chemo, my fitness levels just declined rapidly (Sophie).*

After her treatments, Sophie looked into programs she could undertake because she was concerned that people working at an ordinary gym may not understand specific requirements for women who have had breast cancer treatments.

*I was worried about going to a normal gym thinking I'd have some personal trainer going "Yeah, you'll be right, you've had breast cancer, but just do this." I really wanted someone that knew something about recovery from cancer.*

*[...] I called The Cancer Council and found out about a program at the Hampstead Rehabilitation Centre<sup>23</sup> and it's with an*

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<sup>23</sup> The Hampstead Rehabilitation Centre is operated by the Royal Adelaide Hospital, which is one of the major South Australian public hospitals, for further information, visit:

<http://www.rah.sa.gov.au/hampstead/hampsted.php>

*exercise physiologist in a group situation, but you're not all doing the same thing. So there's a program, and they monitor you I think monthly. So I actually started that until being pregnant, and since not kept that up. But I found it quite good, limiting though on the times you could go. [...] I was managing Saturday mornings, so I was thinking it's probably not enough, I could have done with some more times to be able to go (Sophie).*

At the time of her interview, Sophie expressed frustration at being unable to participate in any regular physical activity, besides going for a family walk on Sundays. Sophie also said she struggled with information about health benefits of physical activity – trying to work out how much is enough for health benefit.

*[My partner] works on Saturdays, so we have Sunday as a family, that's our only one day. We generally, we'll all go for a walk on a Sunday [...]. So with my walking now it's never complete. Whereas I used to start at a certain time, walk for an hour, start getting faster at the end, it's more about just short bursts of exercise now. So again I find that confusing with all of the information that is that enough? Two 15 minute bursts of exercise, or really is the 45 minute duration better? You know, things like that. But you just do what you can do to fit in with your family (Sophie).*

Sophie spoke specifically about not being supported in the organisation of domestic work, including housework, shopping, cooking and child care. In the previous chapter I described previously how Sophie said she felt she could not ask friends or family to assist in her doing something enjoyable for herself because she had relied heavily on their support during her acute cancer treatments. She talked about ways in which the organisation of labour is gendered, even when the woman has a breast cancer diagnosis, making comparisons with what would likely happen if a man were diagnosed with cancer.

*Even if a male had cancer, I mean it's just a given that the woman would be looking after the children, keeping the house, cooking all the meals. Whereas the woman gets cancer and she has to organise care for that child, and of course he has to go to work to provide money because you're down to one income, but it's still left up to you to organise all these days,*

*and the care, and how we're going to eat, and who's going to do the shopping, and that's still left up to the person that really should be focusing on getting well.*

*Because there were some days that I just thought "I can't deal with having to pick up the phone to ring someone to say 'I'm really bad, can you please help today,'" having to explain everything. I just thought I just want people to offer so that you don't have to, because it took enough energy just to get up (Sophie).*

While Sophie acknowledged that her partner was the sole income earner, because of her breast cancer diagnosis, she talked of feeling unsupported because he had the capacity to help in other ways, such as ringing other people to arrange help but did not. This was typical of the women who shared the view that their partner did not do the smaller tasks that would have helped enormously, like taking the initiative to arrange child care on bad days. Sophie also expressed disappointed in the level of support offered by friends and family. Below, Sophie's account is of her partner taking time for his own physical activity participation, while she was unable to do so herself. Sophie talked of struggling with her feelings of responsibility toward her daughter and her frustration at being unable to negotiate time for participation in physical activity. Typical of most of the *less active* women who wanted to be more active, it was particularly frustrating for Sophie that her partner fitted in his regular exercise no matter what was happening in the household, whereas she was unable to do the same.

*CM So does [your partner] help with having you go for a walk or something?*

*No. Well this is the thing, he is very into his fitness, so he runs at 6:30 in the morning three mornings a week with some friends, and so that's his time. He gets home at 7 at night. So he leaves for his runs at 6:30, comes home for a quick shower at 8:30, goes off to work and comes home at 7. So I could possibly say then "I'm going for a walk" [but] I'm exhausted 'cause I've run after her most of the day, it's her bedtime, so she - like that's a bonding time for her when she has her cup of milk and we read a couple of books, and by that time I'm sitting here. And some nights, like last night she's really not going off until 9 at night. So I don't feel comfortable in saying "I'm going for a walk." I probably should, [...] I've got to detach and think "Well he's capable, he can put her to bed." But I think as mothers, we tend to... (Sophie).*

Sophie went on to talk about how her neighbours managed to both participate in their preferred physical activity, reflecting on the structures that do not always support gender equality.

*We've got neighbours here who have three kids, and they both always get their exercise, but they're just smart with it, and I just think why - like when he gets home, she goes out for her run and he just has to deal with whatever's going on at the time, whether it's in the middle of dinner, or bath time, or bed time, and she just thinks "No, I'm going for my run."*

*[...] And again with your partner, it shouldn't be a thing of - they don't ask, so why should you ask to go for a walk "Can I please be excused?" We're all parents, and I think perhaps the way society is that if someone's a stay at home mum at the time, or working part time, they're still doing their full load of a lot of the housework and taking care of the children, and perhaps we still have that 50s mentality where the husband comes home from work and thinks "I've worked all day." [...]*  
*And I don't know what will change that attitude (Sophie).*

Sophie described what had worked in the past; putting a weekly calendar on the fridge to remind her partner when to be home so she could participate in the Hampstead Centre program.

*When I was starting at the Hampstead Centre, we had a thing on the fridge - he thought it was hilarious, but I just thought if you don't see it then I know you won't come home on time, and I only had a one hour window there, so I had it on the fridge Monday through to Sunday, and his running days, and then mine, and that worked really well at the time (Sophie).*

Sophie's account of her partner finding it hilarious that she would put a schedule on the fridge, together with finding it difficult to put herself first, provides a clear description of how inequitable gender relations operate at the family level, whereby men are dominant and women subordinate, thus being a strong factor affecting the women's participation in physical activity. Sophie's account shows clearly the complex interactions between social and individual factors influencing the women's participation in physical activity, highlighting the importance of partner support for those women in relationships.

*Anna*

Anna had always participated in some type of physical activity in her life;

mainly competitive netball. In Chapter Four I included Anna's account of how her reconstructive surgery had affected her arms and shoulders to the point of being unable to participate in netball and even struggling to coach her daughter's netball team. However, in addition to the effects of her surgery, at the time of her interview, Anna was unable to participate in any regular physical activity because of her lack of partner support for her busy life with three young children. Anna had completed year 12 and was starting a small business working from home at the time of her interview, while her partner who had also completed year 12, worked interstate as a high level executive.

Anna's family moved to Adelaide from interstate during her chemotherapy treatment to be closer to her parents and their support. Anna's partner continued to work interstate and would only be home for weekends, so she relied heavily on her parents' support. Her mother still worked fulltime and so it was her father who provided much of the day-to-day support. Above, I described how Anna's parents assisted with going to Qigong classes and she had also attended the YWCA Encore program. Though, it was difficult for Anna to maintain any regular physical activity. She expressed frustration that her partner's answer to being unable and unwilling to support her was to "hire a nanny" which was not what she wanted. Anna's account is illustrative of the ways in which the women who talked about feeling unable to put themselves first also spoke of putting oneself first as being a necessary element of participating in physical activity because it means having time away from their children. Typically, the women who felt that they did not receive the support they would have liked from their partners also talked in terms of women or mothers putting other people – especially their children and partners – before themselves.

*...my husband's answer is, "Get some help. Hire a nanny." It's a bit hard [...]*

*Well I find it really hard to put myself first. It's probably just me [...]. It's just being a mum. Like my family, my kids are really important to me and I run the household. I run the bills. I run everything. My husband [...] says, "Well if you want to exercise, just go and do it." And I find it really hard to just do that. For example when we got back from Queensland he spent*

*Saturday going for a half hour walk and then working out in the gym. I did all the unpacking and the washing and all of that. Like I find it really hard to just go, "oh well I'm not going to do everything" (Anna).*

Like Anna, and the other women's accounts above, the women typically talked about the importance to them of their children, creating a double-edged sword where on the one hand they expressed wishing to have time out, while on the other hand not wishing to put themselves first or missing out on time with their children. Anna's account, like Sophie's above, illustrates a dilemma of wanting to do some exercise, but finding it difficult to put herself first while noting that her partner simply leaves the house to participate in his own physical activity. She spoke of her partner going and doing his exercise, leaving her to unpack and clean up after a holiday away. While Anna acknowledged that her partner worked interstate, what disappointed her is that in the time that he was home, when he had the capacity to be supportive, he was unsupportive. Anna's account demonstrates a mix of individual enabling factors (enjoyment of team sports) and constraining factors (effects of reconstructive surgery), plus structural constraining factors (unsupportive partner and partner working interstate).

The women spoke of being most disappointed by their partners in the times when they felt their partners had the capacity to be supportive, but were either unwilling to, or did not think of offering support. In addition, the *less active* women who wanted to be more active often did not speak about attempting to negotiate support from their partners, but they did speak a great deal about the importance of putting their children first. I expand on these points in the discussion chapter, to look at ways in which unequal power relations between women and men affect physical activity participation for this sample of women.

## **Conclusion**

To summarise, this chapter has described the importance of social/structural and individual factors such as the effects of paid work, gendered



expectations regarding child care and housework on time, levels of fatigue or pain and levels of enjoyment in participation. While for a few of the women, information about health benefits of physical activity added some further imperative to participate, information was certainly neither key to the women's participation, nor enough to enable their participation. I have shown that even where the women did have in depth knowledge about benefits of physical activity for women who have had a breast cancer diagnosis, structural and individual features of their everyday/everynight lives, in particular partner support, strongly affected whether or not the women were able to participate regularly. The women's accounts show clearly that, for those women who had partners, the level of partner support they were able to obtain, especially through their treatment phase, affected their whole breast cancer journey and crucially to this thesis, the extent to which they participated in physical activity. Although not all of the women with supportive partners were *more active*, partner support was the most important enabling factor.

The women's accounts show the ways in which being diagnosed with breast cancer changed their everyday/everynight lives, and the ways in which their everyday/everynight lives in turn shaped their treatment decisions, treatment experiences and ultimately their health promotion actions.

In the analysis chapters I first of all described the ways in which some of the women formed their knowledge about physical activity and health specific to breast cancer over the course of their breast cancer journeys. I have described how the women typically did not separate sources of information; that is they talked about mainstream and complementary and/or alternative information sources interchangeably. I then described how many of the women responded to health promotion messages by linking information about supporting health to their ideas about causation and risk. My analysis shows that the women's theories of causation, framed in terms of their own experience, influenced the ways in which they viewed health promotion messages. My analysis of their responses goes part way to explaining why

physical activity may not have figured as highly as other health promoting activities such as juicing or going organic, particularly at the beginning of the women's breast cancer journeys.

Where the women's theories of causation were very different from their perspectives on health promotion messages, or where they had personal experience that in their view disproved the messages, they responded by taking health promotion messages with a grain of salt. In my analysis of the key cancer-related organisations' websites I drew some conclusions as to why the women may have responded to health promotion in the ways that they did.

Most of the women who described their own theories of individually modifiable risks or causes, described their theories with certainty. For the women who felt their breast cancer was caused by something they could control in their daily practices, their theory of causation offered some degree of hope that they could prevent recurrence. On the other hand, women who believed their breast cancer was caused by something they did, but remained uncertain about what it was, the unknown cause remained a source of anxiety. Therefore, I suggest that having certainty about cause helps regain a sense of control over one's life and future. Moreover, where cause is associated with gendered identities that constrain women from "putting themselves first" there is some potential for transforming or re-negotiating their gendered constraints and participating in health promoting practices. Nevertheless, there is the ever-present danger of falling into victim-blaming where re-negotiating gendered roles does not occur, or where recurrence suggests failure.

In the following chapter, I engage with literature from the social sciences, feminism and public health to theorise the main findings raised in my analysis chapters to answer the research question. I critique public health practice that promotes of population risk/protective factors (causation) to individuals, examine the effects of gender-power relations and gendered identity on the

women's participation in physical activity and the effects of socioeconomic factors (including the gendered division of labour) on the women's physical activity participation and explore individual factors affecting participation in physical activity, such as pain, fatigue, pleasure.



## **Chapter 7: Discussion**

### ***Introduction***

This chapter addresses the research questions by engaging with the literature to elaborate on the theoretical implications of the key themes relating to breast cancer, motherhood, physical activity and health promotion that I identified in the analysis chapters. The chapter is in three sections, each linking themes arising from different components of the research question to the literature. First of all, this chapter elaborates on the women's responses to health promotion messages, their sources of information and their decision-making about health. I consider the ways in which translating population-based risk/protective factors into promoting individual behaviour change (Baum, 2008; Rose, 1985, 1993) produced unintended consequences in this study sample, along a continuum from self-blame to rejection of the messages. I conclude that, as part of a critique of approaches to health promotion that focus on risk and that are based on an individualist social and political orientation (Baum, 2008; Tesh, 1988), the extent to which concepts such as the teachable moment are useful for promoting physical activity to this group of women requires further review.

In the second section of this chapter, I answer the research questions regarding the key factors that influenced the women's participation. Engaging with the qualitative public health and feminist literature, I consider the ways in which the women spoke about tensions between feeling they ought to, or want to, participate in regular physical activity, and the extent to which they reported actual participation. I examine the key structural factors that provided opportunities for, or constraints to, the women's participation. I return to the critical feminist leisure theories as they relate to motherhood (Bialeschki & Michener, 1994; Wearing, 1990) to consider, based on my findings, how normative expectations of gender identity and motherhood affect women's capacity to act on their knowledge about health benefits of participating in regular physical activity. The argument draws on feminist and Bourdieusian theories of embodiment to contribute to understanding how

women durably (although not immutably) embody (or internalise) classed and gendered social constructs (McNay, 2003).

Thirdly, I argue that the women's breast cancer journeys contributed to their development of embodied expertise in breast cancer. Synthesising feminist, Bourdieusian and lay theoretical approaches, I argue that the concepts of the journey and embodied expertise in breast cancer would be useful tools for building the capacity of those working in health promotion so they may be better equipped to enable women who have/ had breast cancer to participate in regular physical activity. I suggest that enabling women who have/ had breast cancer to undertake physical activity at a level that is likely to produce health benefit requires health promotion strategies that go beyond individualist behavioural approaches to include feminist influenced socio-environmental models. Finally, I conclude that the constraints and enablers to physical activity participation that this group of women experienced are similar to those found in national and state population-based survey data (Armstrong, Bauman & Davies, 2000; Bauman *et al.*, 2002; Brown *et al.*, 2001b; Gill & Taylor, 2004) and that my findings are therefore useful for those promoting physical activity participation to women at a general population level.

### ***Interpreting risk as cause***

In the analysis chapters I concluded that the ways in which the major health promotion organisations that the women referred to in their interviews promote population risk factors to individuals goes some way to explaining the women's responses to health promotion messages. One example was the Cancer Council SA's key health promotion message of their LiveSmart campaign: "How do I reduce my risk of cancer? By deciding to. If you want to reduce your risk of cancer, you can". Despite the "prevention paradox" (Rose, 1985), which highlights the distinction between causes of incidence in populations and causes of individual cases, the material presented earlier suggests some mainstream health promoting organisations continue to promote population risk factors as if they were able to be directly translated

into the risks of a particular individual developing the disease.

Similarly, I described how the National Breast and Ovarian Cancer Centre's online "risk calculator" takes individual women through a range of risk factors, finally coming up with a particular women's individual risk estimation. The problem with this type of calculation is that, "a risk factor is a probabilistic concept that applies to an aggregate of individuals, not to a specific individual" (Rockhill, 2001 p365). This pattern continues notwithstanding evidence about the "ecological fallacy" of attributing an individual's disease causation based on population aggregates (Baum, 2008; Krieger, 1994; Schwartz 1994).

Rockhill's (2001) criticism of the use of risk factors as individual screening tools for breast cancer risk draws on Rose's argument to show how, despite an enormous amount of epidemiological evidence about population risk factors, risk factors remain an unreliable method of assessing individual risk of disease. She terms the use of risk factors as screening tools the "privatization of risk", and criticises such public health approaches that, in the process, blame the victim for their individual disease.

Below, I argue that the women's responses to risk/protective factor-based health promotion messages ranged along a continuum, from acceptance (including self-blame), through to resistance, and most often degrees of, or a tension between, both. I conclude that the women's responses to health promotion messages were both reasonable and understandable when their own experience and the epidemiological evidence combined, suggests that direct translation of population research into individual risk factor promotion is unhelpful.

### **Individualising risk**

Three quarters of the women spoke about breast cancer causation as key to their response to health promotion messages. There is a great deal of literature drawn from research into how people think about causes of illness generally. The growing number of papers about how women with breast

cancer think about causes is suggesting that lay theories can assist health promoters to communicate health promotion messages more contextually (Blaxter, 1983; Hughner & Kleine, 2004; Pill & Stott, 1982; Potts, 2000; Wilkinson, 2000). My analysis suggests that the women spoke about causation in terms of the prospect of being able to control their everyday/everynight activities, and therefore their potential risk, and to varying degrees expected that it was possible to avoid breast cancer recurrence. The women's preoccupation with causation is particularly interesting because it shows how they interpreted health promotion within the context of their own experience. These women made a direct link between health promotion messages and advice about supporting their health and what may have caused their breast cancer.

When talking about their ideas on breast cancer causation, the women drew on information from mainstream, complementary and/or alternative medicine. Previous research has found that people speak about their ideas on causation and the importance of health promotion practices in terms of a synthesis of dominant ideals about health and their embodied experience of health and illness in their everyday/everynight lives, through the social filters of culture, class and gender (Backett-Milburn *et al.*, 2006; Lawton *et al.*, 2006; Lawton *et al.*, 2007; Lupton, 2005; Popay & MacDougall, 2007; Potts, Dixey & Nettleton, 2007). Moreover, some of the women used terms derived from mainstream, complementary/alternative medicine to describe their embodied experiences, for example by describing how they felt and legitimising their feelings using biomedical evidence, such as feeling good because of physical activity causing their bodies to release endorphins.

In contrast to the women's responses to health promotion that relies on population health risk/protective factor information to explain individual risk/benefits of everyday/everynight practices, the women spoke about making their individual treatment decisions based on population-based evidence on their effectiveness. While they made these decisions based on population-based statistics, they typically responded to this information very



differently from the ways that they responded to population risk/protective behavioural factors. The women who spoke about potential additional benefits of chemotherapy, for example, expressed understanding that the statistics were population-based and may not mean they, individually, would fall into one or the other portion of the percentage. The women therefore did not speak in the same way about behavioural health promotion risk/protective factors as they did about acute care treatments.

Women with the same prognosis and information nevertheless came to different treatment decisions in their weighing up of the harms and benefits of chemotherapy in the context of their everyday/everynight lives. Joanna, for example, decided against chemotherapy: “90 or 91% of women would be okay without any further treatment. Then add 1.5% if you have chemotherapy, so I kind of figured that I would run the risk of that”. Therese, by comparison, decided to have chemotherapy: “[my doctor] said, ‘There’s probably no need for chemo’ and I said, ‘But it’s that word “probably”” (Therese). Yet, once her acute treatment was complete, Therese decided against undergoing adjuvant therapy (tamoxifen) in spite of her doctors’ advice to take it. The women’s acceptance of, and/or resistance to, risk/protective factor health promotion, therefore can be understood as part of an ongoing process of filtering or testing information.

My findings suggest some new insights into ways in which lay theorising about causation and health promotion messages produce complex responses. The women knew about health promoting lifestyle practices and had taken a further step by applying their knowledge to theorising at a personal level what may (or may not) have caused their breast cancer, and/or other people’s cancer. These findings are similar to MacDougall’s (2003) findings, insofar as study participants tested theories on themselves. The women in my study tested the types of activities that were considered to be health promoting (that is, cancer preventive) against their own and other women’s embodied experiences, in the context of their everyday/everynight lives. As a result of this personal testing, the women developed a continuum

of responses to health promotion messages, ranging from blaming themselves through to resisting or being cynical about health promotion claims. In this way, the women responded to health promotion by interpreting the messages to fit their personal beliefs about causation and their everyday/everynight life experiences.

### **Self-blame**

Beginning at the self-blame end of the continuum, several of the women had clearly taken on the notion of individual risk, and therefore believed in the possibility that they somehow caused their own breast cancer. These women looked to mainstream, complementary and/or alternative medicine's ideas about breast cancer causation, including types and make-up of food, ways in which they dealt with stress, and/or their internal thought processes - having "a cancer personality" (Lauren). The ways in which the women thought about causation in terms of individual behaviour or environmental exposure corresponds with some previous research findings (Brown *et al.*, 2006; Lawton *et al.*, 2007; Pill & Stott, 1982; Potts, Dixey & Nettleton, 2007; Räisänen *et al.*, 2006). My findings resonated most closely, however, with a Swedish study with women who had been diagnosed with breast cancer. The majority of women in that study (half of whom sought anthroposophical<sup>24</sup> medicine and half mainstream medicine) believed that their breast cancer was caused by "a life lived", for example their diet, mental health or stress (Arman *et al.*, 2006). This Swedish study findings are relevant because the women's responses were similar to women in my study who felt that they had done something in their lives to cause their cancer.

Self-blame is not necessarily limited to a one-dimensional acceptance of blame. The conclusions from other studies on lay theorising about cause, particularly those that have primarily used qualitative methods, are that while

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<sup>24</sup> Anthroposophical medicine is a holistic (mind, body, spirit) style of medicine, based on principles developed by Rudolph Steiner. For more information see <http://www.paam.net/>

people often start out by using dominant individualistic discourses on causation which blame the victim (Lupton,1993; Tesh,1988), the conversation tends to turn toward alternative explanations that include collective causes, such as the environment or social inequalities (Popay and MacDougall, 2007; Popay *et al.*, 2003; Potts, 2004; Wilkinson, 2000). For some of the women in my study, self-blame appeared to be one part of their process of re-examining their lives thus far, and considering what steps to take to change their everyday/everynight life circumstances for the remainder of their lives. In this view, self-blame for some of the women was part of an overall change in life perspective that most of the women said they experienced after their diagnosis. This response has strong parallels with Giddens's notion of the fateful moment (Giddens, 1991) discussed in Chapter Two and to which I return below.

The women who changed their pre-cancer life perspective following their breast cancer diagnosis, and drew on elements of self-blame took action to make sense of breast cancer and regain a sense of control, or a belief or hope in the potential for control. Self-blame, for some of the women, initially presented a way to cope with breast cancer because it offered an understanding of cause/s that is/are (potentially) within their power to control, and therefore offered tangible steps that could be taken to prevent recurrence.

Moreover, for a few of the women, part of re-examining one's life included reassessing, questioning or resisting their gendered identities. These women said they believed they caused, or at least contributed to, their breast cancer, for example by not putting themselves first, by not living the way they wanted to, or by trying to be someone else. They typically described how they were trying to put themselves first more often, talking of a future that would be better for their health and describing the actions that they believed would achieve their goals. However, while a diagnosis of breast cancer was a life-changing moment for all of the women in this study, the changes, if any, that the women made as part of blaming themselves did not include the uptake of

regular physical activity. This calls into question the usefulness of concepts such as the teachable moment, especially if used in isolation, for physical activity promotion.

The women who spoke in ways that suggested self-blame seemed more likely to take on changes advocated by complementary and/or alternative health to promote health such as changing the way they thought about themselves or taking up juicing or going organic. Such changes were restricted to those which did not require others to change, for example they did not require their partners taking on more responsibility for child care arrangements. Those women who believed they were unable to reduce paid work hours were unlikely to make this particular change. Some of the women who spoke in terms of self-blame described daily practices they felt they could control and talked less about what they felt they could not control; taking up juicing but not taking up participation in physical activity being a typical example. Doing what is possible is another theme found in research on lay perspectives, where “trade-offs” are made between what needs to be achieved and what can be achieved (Backett, Davison & Mullen, 1994).

For some of the women, the practicalities of organising to actually do some physical activity were viewed as being a source of stress which was counterproductive for their health. This aspect of the women’s responses is consistent with research findings that lay theorising reveals complexity and ambiguity regarding actual health benefits of everyday practices purported by health promoters to be healthy (Backett-Milburn, Parry & Mauthner, 2000; Backett-Milburn *et al.*, 2006; Lawton, 2003; Lupton, 2005; MacDougall, 2007; Milburn, 1996; Popay & MacDougall, 2007; Popay & Williams, 1996).

The extent to which the women were able to change, therefore, was bounded by their classed and gendered everyday/everynight lives. A few of the women talked about what they thought caused their breast cancer, then went on to describe how their daily lives meant they were unable to act on their beliefs. For these women, the intersections of socioeconomic imperatives

and classed and gendered identities, as well as individual factors such as pain or fatigue, meant that at the time of their interviews, making changes to their everyday/everynight practices were nigh impossible.

Some of these women spoke of causation in victim-blaming terms; that is, if you know what caused breast cancer, then you can *and should* control those aspects of your life, thus drawing on a moral imperative to reduce risk of disease (Lupton, 1993). I described Elena's typical account in Chapter Five where she spoke of stress being "*a major cause of a lot of illnesses*" and that "*cancer was part of it*". She said she felt better believing that stress caused her breast cancer because: "*it's something that I think 'yeah that's good because it's something I can control'*". Elena then used victim-blaming (Lupton, 1993) terms to describe those who flout evidence about cause:

*So I think it's pretty silly if you know, if you have that kind of information and you just ignore it, it's like smoking causes lung cancer so if you smoke, well what do you expect (Elena).*

The dilemma for Elena and some of the other women in this study was that identifying a particular cause of breast cancer as, "*something I can control*", did not mean they were actually managing to control the cause in their personal lives. Elena had been diagnosed with breast cancer twice and at the time of her interview had still not managed to reduce her everyday/everynight life stress, nor participate in regular physical activity.

Elena also described weight bearing exercises as being extremely important for preventing osteoporosis after menopause, and saw this as an additional reason for her to participate in regular physical activity. Elena therefore viewed participation in physical activity as personally salient for at least two reasons; preventing osteoporosis and preventing breast cancer recurrence. Backett-Milburn, Parry and Mauthner (2000) found in their study of mid-life women's accounts of health knowledge that the extent to which the women considered osteoporosis a health issue depended on whether they had "experiential knowledge", including women who had had chemotherapy treatments. Even then, the authors found that the women largely dismissed osteoporosis as a health priority in the context of their everyday/everynight

lives (Backett-Milburn, Parry & Mauthner, 2000).

The notion of personal salience, which had meant that physical activity was important to Elena, still did not mean that Elena was *more active*. She described working (very long hours) full time, ferrying her children and doing all of the household shopping and cooking, as well as experiencing a prickly heat type of skin reaction when she did do some exercise, resulting from her chemotherapy treatment. In spite of Elena's main constraints to participation being a combination of an imperative to work to support her family and her unpaid domestic and child care responsibilities, she felt she should make changes at an individual level, even though it seemed thus far such changes had not happened. Elena's account illustrates an adherence to dominant individualist discourses whereby there is an expectation that individual control over disease is possible in spite of everyday/everynight life classed and gendered structural constraints. In other words, such narratives typically maintained an expectation that individual solutions were available while revealing details of structural constraints.

### **Resisting self-blame**

In contrast to the women who focused on self-blame, my analysis showed that several of the women questioned the veracity of information about individual protective/risk factors in light of their own diagnoses. While all of the women accepted that physical activity was beneficial to their health, many of these women at the same time resisted breast cancer specific risk/protective factor claims (such as breast feeding their babies and avoiding alcohol). A few of the women angrily stated they had avoided/done these things and were nonetheless diagnosed with breast cancer. These women therefore resisted the individualisation of breast cancer risk they identified in health promotion messages, and in so doing, extended their scepticism to information about health benefits of physical activity. Such responses are similar to those found in previous research, whereby people have felt angry about their cancer diagnoses because they have led healthy lives and developed disease anyway - particularly where the disease is cancer (for example, see Lupton, 2005). Indeed, a few of the women spoke angrily about

the concepts “think positive” and “survivor”, for example: *I’m alive and she isn’t, and there is nothing to do with being positive (Justine); ...it just shits me because you can’t tell me that you can stay positive every moment of every day for months going through this (Sarah); I did not like, and I still don’t like the survivor part of it. It is just a word I didn’t like (Jen).*

These women’s accounts can be seen as a reaction to a form of “moral oppression” (de Raeve, 1997). Feminist health researchers and social health theorists have been critical of health research and disease prevention policy and practice which places strong emphasis on individual lifestyles to prevent breast cancer (Broom, 2001b; Wilkinson, 2001) and have been working to counteract victim blaming approaches to breast cancer prevention (Baum, 2008; Broom, 2008b; Broom, 2001b; Brown *et al.*, 2006; Brown *et al.*, 2004; Brown *et al.*, 2001a; de Raeve, 1997; Potts, 2001; Potts, Dixey & Nettleton, 2007; Potts *et al.*, 2008; Wilkinson, 2001, 2000; Wilkinson & Kitzinger, 2000).

### **Cause as a social and political construct**

Apart from the few women who completely rejected individual protective/risk factor health promotion messages, almost all of the women in my study explored the idea of individual responsibility for reducing breast cancer risk at some point. This was the case even when they believed their breast cancer may have been caused by environmental carcinogens. In the United Kingdom and the United States of America, breast cancer movements have mobilised to lobby for research into environmental causes of breast cancer and collective approaches to cancer prevention (Brown *et al.*, 2006; Brown *et al.*, 2004; Brown *et al.*, 2001a; Potts, 2004a; Potts, 2004b; Potts *et al.*, 2007). The women in my study did not report knowing about or being involved in such large scale mobilisation in Australia.

While some of the women in my study identified the same risks that the women in the UK and USA breast cancer movements are concerned about, only two women said they thought the government should play a role in researching, preventing or reducing environmental causes of breast cancer. The remainder typically described individualistic strategies for avoiding

environmental risk, such as buying or growing organic food, and avoiding plastics for food storage or in microwave cooking. The women's responses to risk follow Tesh's (1988) argument that when an individualistic political paradigm prevails, individualist approaches to public health problems are favoured over collective approaches. Although the Australian breast cancer movement gained strength alongside the feminist health movement of the 1970s (Broom, 1991; Crompton, 2006), there was no reference to a collective environmental or feminist movement in these women's accounts.

Lay theorising reflects and uses socially, politically and geographically defined discourses on risk, control, choice and victim blaming, and also reveals the complexities of everyday life circumstances which are often spoken about as being outside individuals' control (Crabb, 2006; Popay and MacDougall, 2007; Popay *et al.*, 2003). When individual approaches to risk reduction are the political, social and cultural norm, it is not surprising that the women drew on individual explanations about how to reduce risk. Nor is it surprising that some of the women described the risk reduction steps that they took as individuals, such as growing or buying organic food.

My findings suggest that people who hold similar beliefs about causation can have multiple and/or discordant ideas about how to deal with risk. That is, beliefs about appropriate actions to avoid risk may vary between and within populations which have access to (often the same) global media (Lawton *et al.*, 2007; Lupton, 2005). My study findings also suggest the need for further comparative international research on lay theorising, social movements and health.

### **Reflections on the teachable moment**

In light of my theoretical analysis thus far, I now turn to examine the usefulness of the concept of the teachable moment to find out to what extent it could be drawn upon by health promoters to enable women who have/ had breast cancer to undertake physical activity at a level that is likely to produce health benefit. My analysis showed that a diagnosis of breast cancer was a time of crisis for the women in my study, which for most of the women led to



a change in perspective on life. Giddens' (1991) concept of the fateful moment does, therefore, contribute to understanding how the women reassessed their lives. So it would seem initially plausible that extending the fateful moment to using the concept of the teachable moment could help persuade women to participate in regular physical activity (Alfano *et al.*, 2009; Demark-Wahnefried *et al.*, 2005; Humpel, Magee & Jones, 2007; Lawson & Flocke, 2009; McBride *et al.*, 2008).

I argue however, based on the women's responses to risk factor promotion in this study, that the extent to which a diagnosis of (breast) cancer can be viewed as potentially a teachable moment is limited. Moreover, my analysis leads to the conclusion that the usefulness of the fateful moment of a breast cancer diagnosis being an opportunity for a teachable moment that could promote durable behaviour change is tenuous. Based on the women's responses to health promotion messages, the teachable moment would need to be used in the context of broader over-all health promotion strategies that work to avoid producing responses of self-blame or resistance, and structurally enable women to participate.

Individualist behavioural models of health promotion, based on my findings, are unlikely to be successful in promoting women's participation in physical activity after breast cancer without concurrently attending to gender and class contexts. If the teachable moment can be used in a way that incorporates lay theories and include attending to structural change and can draw on the notion of the journey, the concept may have some potential. Studies on lay theorising have suggested that public health policy and practice will be better placed to plan illness prevention/health promotion approaches if it can account for lay theories of the causes of disease (Hughner & Kleine, 2004; Macintyre, McKay & Ellaway, 2006).

Below, I examine the theoretical implications of the factors that contributed to or constrained the women from implementing health promoting activities generally and physical activity participation specifically.

## ***Social context and participation***

### **Gender, class and participation**

In this section, I look more closely at the question of what factors influenced the women's participation in physical activity. My analysis showed that all of the women in this study knew that physical activity produced health benefits, and almost two-thirds spoke about specific benefits for women who have/had breast cancer. This demonstrates the ubiquity of such health promotion messages (Lupton, 1995). The women demonstrated the pervasiveness of the message by often being unclear from which particular sources their knowledge came, for example Joanna's response to my question about how she knew: *I take it as general knowledge that everyone knows exercise is good for them. We all know we should be doing it more.*

For this group of women, participation in physical activity apparently had less to do with their knowledge about potential health benefits, and more to do with their daily lives. In line with the literature, (Brown *et al.*, 2001b; Dempsey, 1989; Henderson & Ainsworth, 2000; Henderson & Samdahl, 1995; Shaw, 1994), social and practical enablers and constraints including class (Dempsey, 1989; McKay, 1986), and embodied gendered identity (McNay, 2003) were powerful in framing what health promoting practices were possible for the women. Normative expectations of gendered roles, particularly motherhood, featured strongly. Returning to feminist theories of leisure and theories of embodiment I explore why the women's responses to information about health benefits of participation in regular physical activity often did not lead to changing their physical activity behaviour. Here, feminist applications of Bourdieu's Theory of Practice can assist in theorising how gender and class operate together to enable or constrain women's participation.

The women's accounts suggested those who experienced greater gender-equity in their relationships with their partners, and greater accessibility to social and material resources (capital), made up the majority of the *more active* women. It appears that for these women, class (for example, cultural

capital such as tertiary education, middle-class occupations, and material capital such as higher household incomes) and gender operated in their households to produce more equitable sharing of paid and unpaid roles and responsibilities, as exemplified by Grace's accounts throughout the analysis chapters. My study findings suggest that the women who were already in supportive relationships and regularly active prior to their diagnosis (Bernadette's account, as a typical example), continued to participate if they did not have other constraining factors (such as pain or fatigue, or didn't like exercise). The critical leisure literature has long argued that participation in leisure, and therefore in leisure-time physical activity, is class, gender and ethnicity based (Bauman *et al.*, 2002; Bialeschki & Michener, 1994; Brown *et al.*, 2001b; Dempsey, 1989; Gill & Taylor, 2004).

Some of the breast cancer research literature, however, suggests that women who have been diagnosed with breast cancer may make changes because of a reassessment of their everyday/everynight lives following their diagnosis, again like Giddens' "fateful moments" (Shannon & Shaw, 2005; Wilkinson, 2000a; Giddens, 1991). Moreover, the feminist leisure literature concluded that the experience of chronic disease potentially brings about a change in gendered expectations (Shannon & Shaw, 2005). In relation to breast cancer, Shannon and Shaw (2005) found that the women in their study moved outside their gendered roles following their diagnosis of breast cancer. The extent to which the women in my study implemented changes to their physical activity levels, however, were largely dependent on their everyday/everynight lives; their household socio-economic circumstances, the support they received from their partners and their physical bodies (pleasure/pain/fatigue).

My findings, therefore, differ somewhat from Shannon and Shaw's (2005) study. While some of the women spoke of reassessing their lives, and a few women talked about wanting to change particular dimensions of their lives by attempting to "put themselves first" more often, during interviews many of the women revealed little change in their unequal gender-power relations. For

some of the women, to varying degrees gender-power imbalances were implicitly or explicitly maintained by their partners and/or by themselves because of their gendered identities. Examples of women and/or their partners maintaining power imbalances include Anna's statement that it would be selfish of her to go out to do something for herself, such as exercise, in spite of her partner saying she should "just do it" (although not taking steps himself to enable her to "do it"). An example of implicit use of power by a partner was Sophie's account of her partner not taking her desire to participate in physical activity seriously by finding "hilarious" that she took steps to place a schedule on the fridge. As Martin points out, "there are a great many ways women express consciousness of their position and opposition to oppression" (Martin, 1987 p184). The women in my study who experienced the least equitable gender relations in their own relationships were entirely conscious of their status of being "bottom of the pile" (Joanna) *because* they were women, and especially because they were mothers (Martin, 1987). As Skeggs states, "women can often easily produce a perfect critique of masculine traits and dispositions, yet this does not lead to resistance or change as Bourdieu would predict" (Skeggs, 2004 p26).

Shannon and Shaw's (2005) study of women who have/ had breast cancer and Wearing's (1990) study of leisure time in new motherhood that argued leisure is a site for women to resist gendered roles. Very few women in my study who spoke of experiencing gendered constraints in their everyday/everynight lives, and were *less active*, re-negotiated their gendered social position despite being very much aware of it. For some of the women, especially those who acted to change the ways in which gender operated in their relationships (including three women who separated from their partners) breast cancer was a catalyst which, by my analysis, brought the gendered nature of their relationships to the fore. This is not to say that the women who spoke of this experience did not realise that their lives were gendered before their breast cancer diagnosis. Rather, their breast cancer journeys brought the effects of unequal gender-power relations into sharper relief and became unacceptable. The majority of the women, however, did not suggest they had

transformed their gendered roles, despite a change in perspective on life. While breast cancer was a catalyst for change in the lives of some of these women, in most cases the durability of their gendered identities appeared to be the stronger force.

Class (when assessed in terms of household income and particularly education) was an important factor on its own and operated alongside partner support and gendered identity. Only one of the 17 *more active* women who had partners reported having an unsupportive partner. Thus, the main reasons women gave for participating or not were similar to those found in the literature on physical activity participation of mothers of dependent child/ren (Bialeschki & Michener, 1994; Brown *et al.*, 2001b; Henderson, 1991; Henderson and Ainsworth, 2000; Lewis, 2001; Lewis and Ridge, 2005; Wearing, 1990).

### **Gendered identity, care work and participation**

Regardless of whether the women were more or less active and whatever level of support they felt they obtained from their partners, almost all of the women spoke of feeling a deep sense of responsibility to their child/ren which they typically spoke of as a normal and expected part of being a mother. For some of the women, trying to keep daily life as normal as possible for their children seemed important to maintaining their sense of self, which included their pre-breast cancer gendered identities as mothers. This is congruent with findings in the literature on recovery, where getting back to pre-illness “normality” is a sign of recovery (Thomas, 2004). Many of the women, however, found their recovery time lengthy and that maintaining normality, or the appearance of normality, required a great deal of effort. Moreover, few of the women seemed to feel that they would or could achieve pre-breast cancer normality.

Sulik (2007), in her study on women’s experiences after a breast cancer diagnosis in the United States, found that the women in her study struggled with dominant expectations of gendered “care work” for others (rather than the self). Sulik found that “care work for the self exposes the power of

internalized gender expectations that even breast cancer cannot easily transform” (Sulik, 2007 p875). The women in Sulik’s study attempted to negotiate a “balancing act” between the care work they did for others and the care work they needed to do for themselves (Sulik, 2007).

Breast cancer for many of the women in my study reinforced the women’s care orientation toward their children and did not automatically mean shifting more of their “care work” toward themselves. With few exceptions, in spite of a breast cancer diagnosis, the women continued to prioritise other family members’ needs (including physical and emotional needs) before their own health. While the women certainly spoke of resenting gendered caring obligations at times (but not their children themselves), several of the women also talked of feeling deeply that they wanted to maintain or reinforce their close connections to their families which meant foregoing time for themselves. In other words, these women appeared to resent the gendered stratification that existed in their families rather than their children, where their partners were unwilling to assist them in their care work.

Some of the women spoke of struggling emotionally with the thought of dying while they had young children. They spoke of the notion of *motherless* children being extremely distressing. The prospect of a shortened life span for these women reinforced the emotional imperative to spend precious time with their children. In this sense, my results were similar to Shannon and Shaw’s (2005), in that the women reassessed their use of time so that it would be spent on what they felt was important. Some of the women felt that they had already spent a great deal of time away from their children during their breast cancer treatments. Their own emotional connection to their children meant that it would be painful to arrange more time away from their child/ren to spend on their own participation in physical activity. In addition, some of the women said that it was their children (or their children’s need of them) who helped them get through their breast cancer and treatment experiences. Thus, the notion of motherhood as a constraint to physical activity, and therefore to women’s health, needs some contextualising

because for some of the women, the role of “mother” was potentially perceived as more beneficial to their wellbeing than being *less active* was detrimental.

In contrast, there were also some women who felt that time for themselves, away from their children, was important for their well being and contributed to “care work for the self”. Women’s participation in leisure can be viewed as political action, in the form of resistance to gendered roles, particularly for mothers of young children (Shaw, 2001; Wearing, 1990). A few of the *more active* women in this study spoke about their participation in physical activity in terms of time that they took for themselves, sometimes expressed as being “selfish”. The women used the term being “selfish” either in a negative sense, as a reason not to take time for themselves, or as a positive consequence of their reassessment of their lives following a breast cancer diagnosis, for which two women said they were unapologetic. Thus, while some of the women maintained gendered normative patterns of selflessness, a few resisted outright dominant social expectations that women, and mothers in particular, should not be selfish (Sulik, 2007; Thomsson, 1999).

Recent work on the role of children in families as active agents, rather than as passive recipients of care, suggests that children may be instrumental in recovery from breast cancer, for example by taking on more responsibilities to lighten the load for their parents. Children have been shown in other studies to be active agents in family boundary maintenance, for example maintaining the boundary between home and work by going to school when they are slightly unwell so that their parent/s (usually mother) can go to work (Cunningham-Burley, Backett-Milburn, & Kemmer, 2005, 2006). A few of the women in this study, particularly those with older more dependent children, described ways in which their children took on more household chores such as cooking and vacuuming, or avoided disturbing their mothers when they were feeling ill and sought their father’s or other adult’s help where required.

Notably, while above I have drawn out differences between women who

resisted normative patterns of gender and those who did not, most of the women demonstrated a tension between the two. These findings build on Sulik's notion of "finding balance", where (some of) the women were able to engage in "care for the self" without feeling that in so doing, they were being selfish, or if they believed they were, they were "unapologetic" about it. Similarly, a few of the women spoke about their decisions to participate in activities without their families as being something to which their families had become accustomed, or had accepted, illustrated by Isobel's account:

*I hadn't really struck out, for want of a better word. I suppose I'd always been there for them, I hadn't been involved in anything just for me. But I just decided that that needed to change. And I did and it worked (Isobel).*

These women thus made a break from traditional social expectations whereby mothers should always "be there" for their children (Reid Boyd, 2002). Theorising the ways in which women embody gendered practices enables a critical consideration of broader social structures, potentially revealing possibilities for women who continue to feel unable to participate if their constraints are socially-based.

Feminist leisure studies about women transforming gender-power relations have focussed on individual women's agency, examining in detail the (usually few) women in their studies who resisted dominant patriarchal and/or individualist paradigms (Shaw, 2001; Wearing, 1990). While some theorists have examined ways in which individual women resist, or reframe, dominant expectations of women (and mothers) in the context of participation in physical activity, their theorising has been largely limited to individualist notions of resistance (Lewis and Ridge, 2005; Shaw, 2001; Wearing, 1990). While women who resist show what types of strategies may be beneficial regarding how best to frame messages, in the end these strategies remain individual in their focus. As such, the strategies remain the women's individual responsibility to take action, rather than a collective responsibility to provide equitable opportunity for all to engage in health promoting practices.



Theorising the ways in which women embody classed and gendered practices could, on the other hand, enable a critical consideration of broader social structures, potentially revealing possibilities for women who continue to feel unable to participate if their constraints are socially-based. Thus, options would be available for women whose classed and/or gendered identities may not support individual resistance (Kitzinger & Wilkinson, 1997; Shaw, 2001; Lawler, 2004).

My study shows how the crisis of a breast cancer diagnosis draws together ideas about resistance and transformation regarding the women's gendered identities, which for some women led to transformation in their everyday/everynight lives. However, for women who did not have structural enablers in place, particularly partner support and socio-economic capacity, durable change was out of reach. The schism brought about by their experience of breast cancer is therefore not that the crisis of breast cancer necessarily revealed otherwise hidden oppression (gendered or classed *illusio*). Rather for some women, oppressive (or unsupportive) gender relations became unacceptable, even if seemingly unchangeable, particularly in light of a potentially shorter life.

Applying a feminist influenced Bourdieusian analysis, while some women demonstrated agency in their own, individual resistance and transformation (especially regarding gender-power relations), there needs to be structural change for any durable, more widespread effects. Following this analysis, health promotion organisations could benefit from an in-depth understanding of how gender and class operate to work out how to enable women to participate in regular physical activity after a breast cancer diagnosis. Below, I consider how embodiment is integral to the women's responses to physical activity promotion, and to the level at which they participated in physical activity. I argue that the use of embodied expertise of breast cancer would be an appropriate theoretical framework for health promotion aimed at enabling women who have/ had breast cancer to participate in regular physical

activity. I suggest a feminist Bourdieusian analysis may assist in exploring the potential for reframing health promotion in breast cancer supportive care.

### ***The journey, embodiment and health promotion***

In Chapter Two I suggested that lay theories, in conjunction with a feminist-influenced Bourdieusian theory or embodiment, could be useful for understanding how and why women respond to health promotion messages in the ways they do and therefore how to enable women to participate in regular physical activity. The breast cancer journey appears to be a useful conceptual framework for health promotion after breast cancer, because of its capacity to incorporate women's embodied expertise in breast cancer (Brown *et al.*, 2004; Potts, 2004b).

Crossley's (2003) use of Bourdieu's theorising of transformation potentially following a crisis shows how the women's world-views changed. For most of the women, while there was a (temporally defined) period of crisis, the subsequent journey when the immediate crisis was over (or substantially calmer) did not mean a simple return to normality, thus some aspects of their lives were durably changed (Crossley, 2003; McNay 1999). Giddens, by comparison, suggests that people "are often stimulated to devote the time and energy necessary to generate increased mastery of the circumstances they confront" (Giddens, 1991 p143). This view assumes that people have the power, as individual agents, to take on such an endeavour, thus minimising the effects of classed and gendered constraints. A diagnosis of breast cancer represented a crisis for all of the women in this study, which appeared to lead to a change in perspective, but did not necessarily lead to transformations in their everyday/everynight lives in terms of their gendered identities.

In the early part of their journey, the women made decisions based on their pre-breast cancer knowledge and beliefs in combination with the constraints and opportunities provided by their social and gendered positions. My findings resonate strongly with previous research that has investigated the

construction of women's knowledge from the moment of discovering a breast change and through the subsequent process of a breast cancer diagnosis, during which time women draw upon all of their pre-breast cancer knowledge to make sense of their own experience (Fosket, 2000). The women in my study, from the moment of discovering a breast change, built upon and reappraised their knowledge over the course of their journeys.

Some of the women spoke of knowing what felt right according to bodily experiences, for example Sophie said "*I kind of trust my gut*", and Zoe said she knows what makes her "*feel good*", based on her pre-breast cancer embodied knowledge. For many of the women, information was embodied to the extent that feelings in the body were drawn upon to assist in decision-making. Thus, the women reflexively filtered or tested new information. They commonly stated that the huge array of information was virtually impossible to negotiate, illustrated by Kate:

*You're getting advice from everywhere [...] it was overwhelming and I couldn't take it all in [...] part of what I'm learning now [is that] okay some of the stuff feels right then do it but if it doesn't, don't. Let it go.*

The women therefore filtered or tested information according to their pre-existing belief systems and their everyday/everynight lives and what felt right. I argue that the women's embodied knowledge comprised a complex mix of sources that they wove into something that became meaningful to them. As Hughner and Kleine (2004 p397) have stated:

Popular health worldviews are not watered-down versions of scientific understandings or simple dichotomies of health. They are complex interweavings of information drawn from different sources including lay knowledge, folk beliefs, experiences, religious and spiritual practices and philosophy.

Viewed in this way, I argue that the women actively generated knowledge about breast cancer and health, by internalising information from external sources and weaving it together with their own embodied experience of breast cancer and their everyday/everynight lives.

The women understood health promotion to include the promotion of

everyday practices from a wide range of sources, including mainstream medical, and complementary and alternative health, professionals and organisations. The women linked these practices together, rather than separating specific messages and practices one from the other, meaning that they spoke holistically about supporting their health (Arman *et al.*, 2006). This is in contrast to medical, epidemiological and biological evidence on health benefits of physical activity, which tends to separate specific benefits of participation in physical activity from other health promoting practices.

Thus, the women drew upon sometimes competing evidence from mainstream, complementary and/or alternative medicine to describe health benefits of everyday practices purported by those operating within the different paradigms to be beneficial, including participation in physical activity. These findings are not surprising as previous research has found that people speak about their ideas about causation and the importance of health promotion practices in terms of a synthesis of dominant ideals about health, their embodied experience of health and illness in their everyday/everynight lives, through the social filters of culture, class and gender (Backett-Milburn *et al.*, 2006; Lawton *et al.*, 2006; Lawton *et al.*, 2007; Lupton, 2005; Popay & MacDougall, 2007; Potts, Dixey & Nettleton, 2007). Applying the concept of the journey, the women moved toward embodied expertise through their lay theorising. Bourdieu offers some theoretical tools for understanding how the *habitus* internalises information and practices in terms of class, but the process calls for a more nuanced theoretical analysis that accounts, particularly for understanding gendered identities (Adkins, 2004; Skeggs, 2004).

### **The breast cancer journey and embodied expertise**

Bourdieu's theory of practice demonstrates how embodiment is not individualised. Rather, it is the process by which social *fields* and the *habitus* connect historically in the practice of everyday life. This fits with ways in which the women responded to representations of risk and how they simultaneously practiced their classed and gendered identities (particularly motherhood) (McNay, 1999). Further, synthesising this with a

phenomenological concept of embodiment, the women embodied information from internal emotional and somatic experiences (bodily feelings including pleasure and pain, happiness, anger), historical social practices (class, gender, social fields) and external sources (mainstream and complementary medicine, media, friends and family, other women's talk of their embodied expertise, reinforcement of gender role expectations). Thus, there is a flow between internal and external information, which at once affects the women's *habitus* and the social *fields* in which the women spend time. The women's decisions about their daily practices were made based on their knowledge from bodily experiences *and* their embodiment of external information and social structures, such as their theories of causation, their embodied histories and their gendered practices. A useful way to envisage this flow between embodiment and practice is Grosz's (1994) metaphor of the möbius strip. The möbius strip is a strip (for example, of paper) that is twisted and then connected at the ends to make a twisted circle and then twisted at the middle to make the shape of a figure eight. When tracing along the surface of the figure eight, the surface becomes external then internal in a continuous flow.

Embodied expertise in breast cancer, a concept derived from Potts' (2004b, 2008) citizen expertise and Brown *et al's* (2004) embodied health movements, can be seen as a dynamic accumulation of knowledge that continues beyond completion of their mainstream medical treatment. My analysis showed that the women spoke of breast cancer as an ongoing journey which has meant some temporary and some permanent changes to their physical, mental, emotional and spiritual bodies. Following a feminist informed, lay theory lens, the women articulated their embodied expertise in terms of their journey. They spoke about their sources of and responses to health-related information, their bodily experiences, their emotions, their everyday/everynight life interactions, practices and responsibilities, as well as differential experiences over their journeys simultaneously. The women's responses to information about health promoting practices seemed guided by, or filtered through or tested by, their own knowledge, and that of "other bodies" (returning to Marshall, 1996) particularly other women who have/ had

breast cancer.

The women's propensity to draw on the experiences of other women is similar to other research that has found women seek advice from other women who they believe have embodied knowledge as opposed to, or in addition to, medical scientific knowledge. One example is Lowe's (2005) study of women's contraception consultations, where in spite of the medicalisation of contraception, women were more inclined to trust advice from other women health professionals as perceived contraception users than they were written information, or information from male health professionals. Like the women in Fosket's (2000) study finding, these women appeared to develop an understanding of the ambiguity of medical evidence over the course of their own journeys.

The women's decision-making about breast reconstruction suggested differences between exploring other women's experiences and the views of their surgeons. Those who actively researched the experiences of other women prior to deciding to undergo reconstruction, including which type of reconstructive surgery would suit the ways in which they lived their bodies, appeared to be happier about their decision and the surgical outcomes than those who did not. Decisions about the type of reconstruction the women underwent appeared to be the most important regarding their long-term participation in their preferred type of physical activity. Decisions about reconstruction cannot be separated from the women's embodiment of sexist ideals that expect women to be evenly two-breasted (Cromptoets, 2006) nor the stigmatising effect of potentially revealing damaged breasts (Broom, 2001). These findings suggest that health promoters should include consideration of the ethics and effects of breast reconstruction in their development of physical activity promotion strategies.

### **Embodied decision-making**

As shown in Chapter Four, in the beginning of their journeys, during the initial period of crisis, very few of the women wished to make decisions on their own, outside their doctors' advice. Exceptions to this pattern were practices

the women viewed as outside the realm of mainstream medical treatment, for example to maintain or boost the immune system through chemotherapy treatment. Yet, later in their journeys, when making decisions about longer term treatment decisions or supporting health more generally, some of the women began to challenge their doctors' advice. Commonly, the women used the embodied expertise of other women who have/ had breast cancer to question their doctors' advice. By then, their resistance can be seen as having been "created by the dissonance between the felt experience of individuals and the 'official' version of those experiences" (Lupton, 1995 p134).

Longer-term decisions may not have felt like life-and-death decisions by comparison with acute treatment decisions. Rier (2000), in his autobiographical ethnography of his own critical illness found that his usual pro-active approach to mainstream medical care, and especially the "sick role", completely changed in the context of sudden severe illness. Similarly, Broom (2001b p250) described how she "numbly conceded responsibility to a local surgeon", in the context of on the one hand being a feminist advocate for women making informed decisions about health, but on the other, finding the lump whilst being in the somewhat vulnerable position of recovering from a total hip replacement. The experience of critical illness is therefore different from that of chronic disease, in that people may be more likely to want to distance themselves from having to make decisions, thus becoming a "passive patient" (Lawton, 2003; Rier, 2000).

The findings here suggest a distinction between decision-making processes about acute and chronic illness treatments or health promoting practices, and the importance of the passage of time (the journey) in the development of embodied expertise. In the initial period of crisis, where the women had to make decisions based on their immediately life-threatening cancer diagnosis, being able to rely on (or trust) medical advice was crucial. Such a distinction points to the importance of timing for information about future health, such as information about health benefits of physical activity.

I conclude that, over time, the women's decisions were increasingly based on their own and/or other women's embodied experience; their embodied expertise. Just as the women's individual experiences of breast cancer are more usefully viewed as a journey and not limited to *an* experience, embodied expertise can be seen as the action of the women reflecting on their breast cancer experience/s and their knowledge gained over time. Understanding embodiment as a socialising process that is intrinsically connected to individual bodily experiences and classes and gendered identities within broader socio-political structures helps understand the women's responses to information about health benefits of regular participation in physical activity. Exploring such ideas may be fruitful for those wishing to promote the uptake of health promoting behaviour/s to women who have/ had breast cancer.

### ***Conclusion***

In this chapter, I have answered my research questions that sought women's responses to information about health benefits of physical activity, the factors that influence their responses and their reported participation. While the research questions relate to physical activity promotion in particular, throughout my analysis I have used health promotion as a general umbrella for the promotion of practices purported to be healthy by mainstream, complementary and alternative medicine organisations and practitioners. This is because the women tended to talk about these practices together rather than separating physical activity from other practices.

I have shown how it is fundamental to the women's responses to health promotion messages that some of the major sources to which the women referred did not apply Rose's seminal distinction between population risk factors and individual disease. This fundamental misrepresentation is produced and reproduced through social and political bodies within the context of what Tesh (1988) describes as an overall dominant political paradigm in which the idea of individual responsibility for health and illness



prevails. Using the work of researchers such as Backett-Milburn, Popay and Lawton in the lay theory tradition, in addition to ideas about embodiment, I have shown how the women's responses to health promotion messages were connected to their own embodied experiences of breast cancer within the contexts of their classed and gendered everyday/everynight lives. It follows that where the women's experiences were discordant with the messages, it is understandable that they may respond to such messages with cynicism. Similarly, as Tesh (1988) and Lupton (1995, 2003) argue, individual responsibility for health is the dominant socially constructed ideal, it is equally reasonable that some women respond to health promotion messages by blaming themselves for their breast cancer diagnoses. My findings contribute to understanding ways in which lay theories and subsequent decisions about risk and health promotion are produced through bodily, social, political and geographical filters (Williams, 1995).

Proponents of participatory approaches to health promotion such as Baum (2008) and Popay and MacDougall (2007) argue that, for meaningful lay participation in the development of health services and health promotion to occur, power imbalances between "experts" and "lay" people must be redressed. My findings support the inclusion of lay theorising in health promotion strategies, in this case, by including women's embodied expertise in the development of health promotion for women who have/ had breast cancer. I argued that the women derived their embodied expertise from their everyday/everynight lives including their responsibilities as mothers, workers, partners and daughters; their theories of causation, their own and other women's experiences of breast cancer. Over time, the women became more likely to question the authority of their doctors' opinions and advice and to contextualise health promotion messages to account for their own bodies and everyday/everynight socio-economic and gendered contexts. Thus, the women became more activist (Zadoroznyj, 2001) in their negotiations between medicine and what they allowed to happen to their bodies. Supportive care and physical activity promotion should take account of the expertise women develop in breast cancer over the course of their breast

cancer journeys. Doing this would involve redressing power imbalances and ensuring women's embodied expertise in breast cancer be taken seriously as legitimate knowledge by those who work in breast cancer care and support services (Fosket, 2000).

I propose that the breast cancer journey is an important analytical tool for understanding women's responses to physical activity promotion and health promotion generally. Based on the theoretical discussion in this chapter, I conclude that the application of the teachable moment as a vehicle for promoting regular physical activity to this group of women should be approached with caution. There is a danger that the concept of the "teachable moment" perpetuates a power imbalance toward "experts" and that such an imbalance would not be helpful for those working toward enabling this group of women to participate in regular physical activity. I argue instead for a reframing of health promotion within the lay theory tradition (e.g. Backett-Milburn, Lawton, MacDougall, Popay) that would involve a shift in power whereby importance of the women's embodied expertise would be paramount, thus producing an integrated, whole-woman approach to promoting physical activity participation to this group of women. Returning to Tesh (1988), this would simultaneously require a collective approach to health and health promotion that moves away from the dominant individualist approach that separates individuals from their social contexts.

My analysis found that there is a strong breast cancer movement in Australia advocating for breast cancer awareness, medical research, and accessibility of expensive drug treatments. Activism directed at promoting collective approaches to women's health after breast cancer or dealing with issues of gender and power was not so evident. The women's health movement of the 1970s and 1980s, which supported a collective approach that uses principles of participation and empowerment (Broom, 1991; Shuttleworth & Auer, 1995), could be a useful model to revisit. Such an approach, drawing on the concepts of embodied expertise and the breast cancer journey, could then go some way to redressing the classed and gendered constraints to

participation in physical activity that these women encountered.

Many of the constraints that the women in my study sample experienced are, according to the literature I reviewed in Chapter Two, similar to those experienced by women at a population level, in Australia and internationally. Gender, class and social support are strongly indicated in the literature to be highly influential in women's regular participation in physical activity (Brown, Brown & Powers, 2001; Brown *et al.*, 2001b; Henderson & Ainsworth, 2000; Miller & Brown, 2005; Stahl *et al.*, 2001). These structural constraints result from inequitable gender and class relations, not from breast cancer. I therefore conclude that reframing health promotion activities toward including women's lay theorising may contribute to enabling women at a broader population level to participate in physical activity.

Eveline and Bacchi (2005) suggest we view gender (or any structural social determinant) as a process of embodiment that is very much influenced by political processes and thus public policy making. These ideas tie in with Bourdieu's concept of the *habitus*, which is the embodiment of social practices and explained by Krieger's (2008) ecosocial theory in which social determinants constitute people's embodiment of social and ecological contexts that are shaped by power and associated structures at a range of levels.

Socially inscribed expectations that women are predominately the unpaid carers of children, the sick and the aged do not allow space for many women to care for themselves when the need arises (Sulik, 2007). Bourdieu's Theory of Practice provides explanations as to how social structures are maintained, and also, with the help of those who have critiqued Bourdieu's theories, how those structures and thus people living within them, may change (Béhague *et al.*, 2008; Crossley, 2003; Lawler, 2004; McNay, 1999; Skeggs, 2004; Williams, 1995). Use of the language "social *determinants* of health" suggests that health *is* largely socially determined. This need not, however, mean "determinants" are unchangeable. Using a feminist

influenced Bourdieusian theoretical framework means that neither *habitus* nor structure (social *fields*) should be viewed as immutable.

In the concluding chapter of this thesis, I summarise my findings against the research questions, address the quality and limitations of this study, and make some suggestions for further research.

## **Chapter 8: Conclusion**

### ***Introduction***

In this chapter I summarise what I have found in terms of the research questions, under headings in the same order as the research questions. I consider the implications of my study for health promotion practice and make some suggestions. I then attend to the quality and significance of this study and make suggestions for further research based on questions raised by my findings.

### ***Summary of thesis aims, objectives and findings***

In this study, I set out to explore how Australian women respond to information about health benefits of participation in regular physical activity, in the context of having been diagnosed with breast cancer while mothers of dependent children. In Australia there are growing numbers of women who are surviving breast cancer longer and this study contributes to survivorship research by providing insights into women's responses to health promotion after a breast cancer diagnosis. Women who have/ had breast cancer treatment/s have specific impacts on their health, some of which are permanent. Physical activity participation provides a number of health benefits to women who have/ had breast cancer, as described in Chapter Two.

Prior to commencing this study, there had been no published research that had focussed on women's responses to the promotion of, or their participation in, physical activity in this context. The only studies that had explored women's experience of physical activity did so incidentally in the context of their general experience of breast cancer, their use of leisure time after breast cancer, or their body image. (for example, Cromptoets, 2006; Thomas-MacLean, 2005; Shannon and Shaw, 2005).

Over the course of my study, research interest in health promotion after a breast cancer diagnosis has increased (for example, see Emery *et al.*, 2009;

Girgis, 2009; Yang and Schuler, 2009). My study has shown that social expectations of motherhood and gendered practices more broadly, are for some women so durably inscribed that even a life threatening illness is unlikely to change health-related behaviour. Breast cancer research that investigates everyday/everynight health behaviour needs to give increased attention to overarching structures that influence social determinants of health. To this end, health promotion that engages with broader social movements could make better use of the concepts of embodied expertise and the breast cancer journey.

### ***Key findings against research questions***

#### **Responses to health promotion information**

The majority of the women responded to health promotion messages by linking health promotion messages to illness causation and theorising their own breast cancer causation specifically. The women expanded on this response along a continuum of self-blame through to cynicism and rejection of information that was translated from breast cancer population risk-factors. This response appears to have been related to the ways in which population risk factors are promoted to individuals as if they will make a difference to their individual health outcomes. This approach to health promotion seemed unhelpful for these women and did not appear to have the desired effect of changing their behaviour toward participating in health promoting practices. My study reinforces Rose's (1985) ground-breaking explanation of how it is that the promotion of population risk/protective to individuals is fraught with problems. Where the women took risk/protective messages seriously, they typically blamed themselves, and where they did not, they completely discounted the messages as, in their experience, simply wrong.

An example of ways in which risk/protective factors could be framed is in the ways that the Cancer Council Victoria accomplishes this, as I described in Chapter Four. The Cancer Council Victoria exemplifies how it is possible to describe population risk/protective factors as they are represented by the research evidence. That is, that causes of cancer are largely unknown and

that even if people live in the ways that health promoters suggest they may still develop cancer. Likewise, messages could emphasise that if people do not adopt practices purported to be healthy by mainstream, complementary and/or alternative medicine, it does not necessarily mean they will develop cancer. It is important that people are made aware that based on the available evidence, practices such as eating a balanced diet, participating in regular physical activity, practising meditation, and not smoking, most likely do support their health and wellbeing if they continue, or if they should start to participate in them. That is, to emphasise that while beneficial for general health, none of these practices guarantee people will not develop cancer. Based on my findings, how evidence is translated into health promotion messages is crucial to the ways in which people respond to them. If health promotion texts frame risk/protective factors as contributing or preventing individual disease, and use imperatives to tell people how they should or should not behave in order to reduce their personal risk, when people's experiences do not match the messages it follows as logical that they may then question the validity of the messages.

These findings have implications for the ways in which mainstream, complementary and/or alternative medicine communicate their ideas about practices purported to support or damage health; with each other and with women who have/ had breast cancer. Some of the women spoke about a schism existing between modalities, and how they found this unhelpful. The literature supports these findings, as there is some evidence that people avoid advising their mainstream health professionals about their complementary and/or alternative treatments (Bishop and Yardley, 2004; Boon et al., 1999; Salminen et al., 2004; Sered and Agigian, 2008). I suggest that it is crucial that the different paradigms strengthen their efforts toward more open dialogue between modalities, and that mainstream medicine practitioners in particular, consider ways in which they may provide information about everyday practices to support women's health, through the different stages of their breast cancer journeys.

### **Information sources**

The women spoke about their knowledge, their sources of, and their responses to, information together. They gathered information from a broad range of sources including their health care professionals, the media, other women who have/ had breast cancer, friends and family. They interpreted and integrated this information in terms of their everyday/everynight lives and their embodied experience of breast cancer.

My findings suggested mainstream medicine health professionals were typically not forthcoming in providing health promotion information beyond acute treatment. Very few women said they received any information about health benefits of physical activity participation from their primary breast cancer-related health professionals. Most of the women spoke about wanting information about how to support their health through everyday practices and for some of the women, this was an important reason for seeking such information from complementary and/or alternative medicine practitioners.

Nevertheless, the majority of the women spoke about benefits of physical activity that are promoted by mainstream medicine, and their sources were usually mainstream cancer organisations such as the Cancer Council (National and States) and the Breast Cancer Network Australia. Other important sources of physical activity information included physiotherapists, the women's involvement with dragon boat clubs and other women who have/ had breast cancer. The ways in which the key organisations that the women referred to framed their information appeared to influence how the women responded to health promotion messages.

### **Decision-making about health**

The women made decisions about their health, including participation in physical activity, in terms of their position in the breast cancer journey and their everyday/everynight life classed and gendered circumstances. The women's accounts revealed a distinction between the ways in which they



made decisions at the beginning of their breast cancer journeys, and the decisions they made once acute treatment was completed. In the early days of their breast cancer diagnoses, their decisions were limited to ensuring their best chance of survival. Therefore, at that time, physical activity did not feature highly. Most of the women said they felt a particularly strong imperative to do what they could to survive because of the responsibility they felt toward their child/ren and this influenced the types of acute treatment they decided to undergo. At the same time, their decisions about acute treatment were influenced by what they felt would be best for their children in terms of their children's life stage, such as starting school or being in year 12. Some of the women decided to delay treatment to avoid disrupting family or paid work commitments.

Over the course of their journeys, decisions about physical activity participation gained prominence in many of the women's accounts as a practice that provided specific benefits at particular stages. Their extensive knowledge, however, did not mean that they made the decision to participate.

The women's accounts of their decisions about their health included everyday/everynight lives, their bodily experiences over their breast cancer journeys, their paid work and family financial status, their relationships with their families, particularly their children, intersected with their relationships with and information from their health professionals, and information from other sources such as other women who have had a breast cancer diagnosis. It is these intersections which shaped the women's decisions about when and which treatment/s they would undergo and their decisions about their longer-term health.

### **Key influences on participation in physical activity**

The women spoke about everyday/everynight life structural and individual enablers and constraints to their participation in physical activity. In addition to journey-related constraints such as pain and fatigue, prominent constraints and enablers included the level of partner support they were able to obtain,

their access to financial and social resources, their own and/or their partners' paid work and the degree to which physical activity participation featured as a priority in their lives before their breast cancer diagnoses. The women's metropolitan or rural locations did not appear to influence their participation. Moving, however, did make a difference and this appeared to be because of leaving existing social networks.

A feature of the women's accounts was that they typically described the mental, emotional and bodily effects produced by participation in physical activity whether or not they participated in physical activity themselves. Here, my findings were similar to qualitative public health research which has explored ways in which people use dominant discourses, such as medical discourse, in their lay theorising about health, yet at the same time explain in terms of their everyday/everynight lives why their knowledge may not translate into behaviour (Crossley, 2002; de Raeve, 1997; Lawton *et al.*, 2007; Lupton, 2005). That is, while the women could describe health benefits of physical activity, those women who were less active would go on to describe how it was impossible for them to participate in the context of their everyday/everynight lives.

### **Enabling participation**

My study concludes that accounting for women's embodied expertise in the development of health promotion strategies to increase their participation would be useful. Part of this would be addressing the ways in which population risk factors are promoted to individuals. I have concluded that the teachable moment as a tool for changing people's health-related behaviour after being diagnosed with cancer (Alfano *et al.*, 2009; Demark-Wahnefried *et al.*, 2005; Humpel *et al.*, 2007; Lawson and Flocke, 2009; McBride *et al.*, 2008) would need to be used in conjunction with women's lay theorizing to have the desired outcome of changing health-related behaviour/s..

My findings suggest that health promotion practice in supportive care, guided by a synthesis of theories of embodiment, and feminist and critical leisure theories, would be useful. The women had embodied socially constructed

ideals about health and illness, which put together with social structures such as class and gender, appeared to frame their responses to physical activity information, and health promotion messages more broadly. Thus, an understanding of the ways in which people embody social structures is crucial to working out how to enable women to participate in regular physical activity after a breast cancer diagnosis.

My findings therefore suggest the need for structural change to bring about changes to the ways in which social expectations, including gendered ideals about motherhood, and dominant workforce expectations, operate to constrain women from participating in leisure time physical activity. My findings, however, are limited in the extent to which I can make concrete suggestions regarding structural change. To understand the changes that would need to occur at a structural level would require further research, with research questions framed specifically around gendered responsibilities, and workplace culture/s. For structural change to be implemented, a more disruptive approach, at the public policy level as well as the coalface of health services, would need to occur. Thus, in Tesh's terms, a combination of non-disruptive and disruptive approaches would ideally need to be taken to enable women who have/ had breast cancer, as well as women at a population level, to participate in regular physical activity (Tesh, 1988).

The peak women-centred breast cancer organisations described in Chapter Four have been lobbying for general practitioners to be responsible for ongoing holistic care throughout the women's breast cancer journey (National Breast and Ovarian Cancer Centre, 2009c). My study findings therefore support the need for a comprehensive, holistic approach to caring for women who have been diagnosed with breast cancer. An holistic approach would ideally involve caring for and supporting the whole woman, including taking into account her everyday/evernight life, throughout her treatment and beyond. Ideally, this would be an equitable, locally accessible, comprehensive state-funded system of care (Baum, 2008; Keleher, 2009b).

The majority of the women in my study were younger than 50 years old, and most of them spoke about feeling marginalised by the mainstream approach to breast cancer treatment and support services. Younger women had not, until recent years, been well represented by, or in, the peak breast cancer organisations, so in the last decade they have also mobilised to have their voices heard (National Breast Cancer Centre, 2004b; The Young Ones). Young women have since had their specific concerns taken up by the peak organisations such as fertility, sexuality, forming and maintaining intimate relationships, survival, workforce/career and child care (Fobair et al., 2006; Gould *et al.*, 2006; National Breast Cancer Centre, 2004b). However, most accounts of the women in my study suggest that their concerns are not yet being addressed in practice.

While concerns about child care and workforce/career are among younger women's concerns, the younger women's organisations appear to raise these issues in relation to breast cancer services rather than social structures. Breast cancer organisations have successfully ensured that women, as embodied experts, are involved in guiding breast cancer services and research. Yet, in Australia, perhaps because of the demographic nature of breast cancer being a major disease for women in higher socio-economic groups, women's lobbying has not been directed at changing gender or class based structures, thus it has been complicit in reproducing dominant social norms (Crompton, 2006). Similar criticisms have been made in relation to breast cancer organisations in the USA (for example, see Klawiter, 2000; Klawiter, 2004).

### **Physical activity promotion to women more broadly**

Lastly, in answer to my final question that asks how evidence from the women in my study may assist in promoting physical activity participation to women at a broader population level, I concluded that the women's responses were similar to studies found in the broader physical activity participation literature. While there is some evidence that a diagnosis of breast cancer, or other chronic illness, may work as a fateful moment which leads to the resistance to gendered, classed and cultural constraints to

physical activity participation (Shannon & Shaw, 2005), evidence of this occurring in my study was minimal. For the women who were less active, gendered identities, particularly relating to motherhood, were durably inscribed (McNay, 2003). While almost all of the women talked about their diagnosis of breast cancer as being a life-changing event, this fateful moment was not enough to bring about durable health behaviour change without associated social support.

Responses of women who have had a breast cancer diagnosis can, therefore, assist in promoting physical activity to women at a population level. Except for post-treatment pain and fatigue, which appeared to be resolved by five years (or less) from diagnosis, the constraints and enablers that the women talked about experiencing since their breast cancer diagnoses were similar to those discussed in Chapter Two (Bell and Lee, 2005; Brown et al., 2001b; Brown and Trost, 2003; Miller and Brown, 2005; Lewis, 2001; Lewis and Ridge, 2005).

Therefore, my findings do have implications for physical activity promotion for women more generally. On this basis, I suggest that it is crucial that those working in health promotion strengthen their efforts in advocating for structural change to improve gendered and classed determinants of health, including social determinants of physical activity participation. To this end, my findings support existing literature that indicates that broader social structures influence women's capacity for participation in physical activity, including workforce expectations, the gendered division of labour and the extent to which child care is publicly available and socially acceptable (Bialeschki and Michener, 1994; NSW Health, 2003; Reid Boyd, 2002).

I suggest that using a feminist Bourdieusian framework that makes sense of gendered and classed structural determinants of health, it is possible to imagine making changes at all levels. Reorienting the health system so that attention is given to overarching structures that influence social determinants of health is crucial to ensuring that women who have/ had breast cancer, as

well as women at a population level, have the best chance of being able to participate in health promoting practices.

### ***Study quality and limitations***

I described the study quality and limitations in Chapter Three, the thesis methodology chapter. One of the elements of rigour that I stated that I would follow up in this chapter is theoretical rigour, which requires that the analysis is supported by evidence from both this study and the literature. In Chapter Seven, I revisited the literature on health promotion and lay theories of causation in light of my study findings to theorise the women's responses to physical activity promotion and health promotion messages more generally. I demonstrated how my study is similar to other studies regarding women's, especially mothers', participation in physical activity. I also showed how my study provided new insights into the strength of gendered identity in the context of breast cancer, whereas other studies have found that women transform their gendered practices following a diagnosis of breast cancer.

In line with reflective research practice, my methodology included sending the analysis chapters to the women who participated in the study. Three of the women responded with comments about the ways in which I had presented my findings. While not in any way representative, their comments about my analysis included; it was respectful and sensitive; it demonstrated the women had different voices and that women who have/ had breast cancer are not an homogenous group; it showed some commonalities/themes to which the three women could relate. These women said they found reading the analysis rewarding in terms of reading about other women's stories and seeing what I made of their accounts. Any claims based on a small number of responses are speculative, nevertheless it is encouraging that a small number of women took the time to respond in detail and that there were no negative or critical responses.

My purposive sample included women from a broad range of demographic backgrounds, which ensured that I was able to gain insight from women in

rural and metropolitan locations, as well as women with lower and higher socio-economic status. While one quarter of the sample included women who had not completed year 12, almost one third did not have private health insurance, and some women were from low income households, the sample was weighted towards women who had achieved high levels of education and with relatively high household incomes. Therefore, while the study has highlighted the ways in which gender operates as a social determinant of physical activity participation for this group of women, the extent to which I have been able to thoroughly examine class effects has been limited.

### ***Further research***

This thesis has raised further questions about the ways in which women respond to health promotion messages. Firstly, it has called into question the ways in which evidence of population risk/protective factors are promoted to individuals. Further research is required to strengthen empirical evidence, both qualitative and quantitative, regarding the extent to which people respond to health promotion in terms of causation, self-blame or cynicism, to explore whether framing the evidence differently makes any difference to people's responses. Participatory research with health professionals working in health promotion and/or with women who have/had breast cancer would be useful to identify means of building the capacity of these professionals to understand structural determinants of health promoting practices better. In addition, research into health promotion in survivorship could benefit from tapping into health and social movements to explore concepts such as embodied expertise, by engaging breast cancer advocacy groups in participatory research. Such research, particularly international comparative studies, could gain insights into the extent to which lay theorising incorporates information from social movements and simultaneously deals with dominant social and political contexts.

Secondly, this thesis has highlighted the role of structural social determinants in women's capacity to participate in health promoting practices. Further research could explore the extent to which public policy may contribute to

structural constraints and enablers to physical activity participation of women who have/ had breast cancer, for example workforce policy, wealth distribution and child care policy. This would enable exploration of what policy steps could be taken to address gendered and classed enablers and constraints to participation in physical activity (and health promoting practices more broadly).

Finally, this thesis has demonstrated partner support as being a particularly strong determinant of physical activity participation for mothers of dependent children. Therefore, further exploring the nature of partner support would be useful for identifying how partners may be better equipped to provide support after their spouses are diagnosed with a life-threatening or chronic illness. This could include exploring how it is that partner support is experienced as being different from other forms of social support.

### ***Concluding reflections***

Krieger and Birn (1998 p1603) in their paper commemorating 150 years of public health suggested that “social justice is the foundation of public health” and that public health professionals should continue to strive for social justice as the key to making “the world a better place, free of misery, inequity, and preventable suffering, a world in which we all can live, love, work, play, ail, and die with our dignity intact and our humanity cherished”. For those of us who, like Krieger and Birn, believe ourselves to be striving for social justice, we need to reflect on how our research endeavour may affect people’s corporeal, social, emotional and spiritual lives.

My hope is that this thesis contributes to theoretical debates about the interplay between, and real effects of, gendered social structures and the people who live them. Ultimately, this study should stimulate those of us who are working in public health, health promotion, or breast cancer supportive care, to reflect on how we develop health promotion strategies, how we frame health promotion messages, and how we expect people to respond to them.



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## **Appendices**

Appendix 1: Letters of Introduction:

Focus group (small group interviews)

Interview

Reference group (advisory group)

Appendix 2: Information sheet

Focus group (small group interviews)

Interview

Reference group (advisory group)

Appendix 3: Consent forms

Focus group (small group interviews)

Interview

Reference group (advisory group)

Appendix 4: Invitation to participate flyer

Appendix 5: Demographic form

Appendix 6: Small group interview guide

Appendix 7: Final interview guide

Appendix 8: Examples of coding physical activity participation

**Appendix 1: Letters of Introduction:**

**Focus group (small group interviews)**

**Interview**

**Reference group (advisory group)**



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Department of Public Health  
School of Medicine

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Telephone: (+61 8) 8204 5983  
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### LETTER OF INTRODUCTION (focus group)

Dear Sir/Madam/Name

This letter is to introduce **Catherine Mackenzie** who is a PhD student in the Department of Public Health, School of Medicine at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a thesis and other publications on how South Australian women who have, or have had, breast cancer respond to information about health benefits of physical activity.

She would be most grateful if you would volunteer to spare the time to assist in this project, by participating in a focus group on this topic. The focus group would be no more than two hours duration.

The main purpose of the focus group is to refine an interview guide which will be used in interviews with women who have, or have had, breast cancer in the last ten years, and who were mothers of at least one child under the age of twelve years old at the time of diagnosis. Questions will focus on the women's views on their participation in physical activity and on their views on physical activity promotion and campaigns.

Please be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, summary reports or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since Catherine intends to make a tape recording of the focus group, she will seek your consent, on the attached form, to record the focus group, to use the transcript of the recording in preparing the thesis, summary reports or other publications, on condition that your name or identity is not revealed. The recording will be made available to professional transcribers, who will be advised of the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on (08 8204 5983), fax (08 8204 5693) or e-mail ([fran.baum@flinders.edu.au](mailto:fran.baum@flinders.edu.au)).

Thank you for your attention and assistance.

Yours sincerely,

**Professor Fran Baum**

Head of Department

Department of Public Health

School of Medicine

*This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee. The Secretary of the Committee can be contacted by telephone on 8201 5962, by fax on 8201 2035 or by email [sandy.huxtable@flinders.edu.au](mailto:sandy.huxtable@flinders.edu.au).*



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### LETTER OF INTRODUCTION (Interview)

Dear Sir/Madam/Name

This letter is to introduce **Catherine Mackenzie** who is a PhD student in the Department of Public Health, School of Medicine at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a thesis and other publications on how South Australian women who have, or have had, breast cancer respond to information about health benefits of physical activity.

She would be most grateful if you would volunteer to spare the time to assist in this project, by granting an interview on this topic. The interview would be no more than two hours in duration. At the time of the interview, Catherine will offer you the option of participating in one follow-up interview should you wish to participate further. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Please be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, summary reports or other publications.

Since Catherine intends to make a tape recording of the interview, she will seek your consent, on the attached form, to record the interview, to use the recording or a transcription in preparing the thesis, summary reports or other publications, on condition that your name or identity is not revealed. The recording(s) will be made available to professional transcribers, who will be advised of the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on (08 8204 5983), fax (08 8204 5693) or e-mail ([fran.baum@flinders.edu.au](mailto:fran.baum@flinders.edu.au)).

Thank you for your attention and assistance.

Yours sincerely,

*Professor Fran Baum  
Head of Department  
Department of Public Health  
School of Medicine*

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## LETTER OF INTRODUCTION (reference group)

Dear Sir/Madam/Name

This letter is to introduce **Catherine Mackenzie** who is a PhD student in the Department of Public Health, School of Medicine at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a thesis and other publications on how South Australian women who have, or have had, breast cancer respond to information about health benefits of physical activity.

Catherine would be most grateful if you would volunteer your time to assist in this project, by participating in a reference group on this topic. The purpose of the reference group is to guide the research component of her PhD and act as an advocacy group for women with breast cancer in relation to physical activity. The reference group would meet at intervals (no more often than every two months), times and location(s) to be negotiated by the participants.

Reference group participants will include women who have had a breast cancer diagnosis in the past ten years, professionals who care for or support women who have had a breast cancer diagnosis and professionals who promote physical activity or produce physical activity policy.

Any information provided in reference group meetings will be treated in confidence and none of the participants will be individually identifiable in the resulting thesis, summary reports or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to comment on particular discussions or questions.

Since Catherine intends to make a tape recording of the reference group meetings, she will seek your consent, on the attached form, to record the meetings, to use the transcripts of the meetings in preparing the thesis, summary reports or other publications, on condition that your name or identity is not revealed. The recording will be made available to professional transcribers, who will be advised of the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on (08 8204 5983), fax (08 8204 5693) or e-mail ([fran.baum@flinders.edu.au](mailto:fran.baum@flinders.edu.au)).

Thank you for your attention and assistance.

Yours sincerely,

*Professor Fran Baum  
Head of Department  
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## **Appendix 2: Information sheet**

**Focus group (small group interviews 1&2)**

**Interview**

**Reference group (advisory group)**



## **Information sheet for Participants in a focus group (Focus group 1 - women who have/have had breast cancer)**

My name is Catherine Mackenzie and I am a PhD student in the Department of Public Health, School of Medicine at Flinders University.

I am undertaking research leading to the production of a PhD thesis on how South Australian women who have, or have had, breast cancer respond to information about health benefits of physical activity.

I would be grateful if you could spare the time to participate in a focus group, to discuss your experiences of physical activity promotion, as a woman who has or has had breast cancer in the last ten years.

The main purpose of the focus group is to refine an interview guide which will be used in interviews with women who have, or have had, breast cancer in the last ten years, and who were mothers of at least one child under the age of twelve years old at the time of diagnosis. Questions will focus on the women's views on their participation in physical activity and on their views on physical activity promotion and campaigns.

At the focus group, I will invite participants to join an ongoing reference group that would meet for no more than two hours at approximately two month intervals. The purpose of the reference group is to guide the project and act as an advocacy group for women with breast cancer in relation to physical activity. Participation in the focus group does not require an obligation to join the reference group and you are free to decide whether or not you wish to continue participation in the project in this capacity.

I feel that your perspective would offer a valuable contribution to this research.

### **IMPORTANT INFORMATION**

- Any information that you provide will be strictly confidential
- You will not be identified in any summary reports of the research, my PhD thesis or other research outputs.
- The focus group will be tape recorded, when agreed. Your consent is sought for this on the consent form provided.
- The recording will be made available to professional transcribers, who will be advised of the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.
- You will not be identified in the written transcript of the recording.
- You will have the opportunity to review and edit your transcript. At any stage you can request that information be used in select ways. Similarly, you can ask for information to be omitted at any stage.
- The focus group will be no longer than two hours.
- All transcribed material will be retained and will be kept securely and not made available for viewing to any one but myself and my supervisors.
- If participation in this focus group should cause you any distress for which you would like counselling, please call The Cancer Council Helpline on 131120 during business hours, or Lifeline on 131114 anytime.
- I would like to offer you \$20 for reimbursement of any costs you may incur to participate in the focus group, and as a way of saying "Thank you!" for your contribution to this research.

## Any Questions?

If you have any questions about the project itself or your involvement in the research, please contact any of the people at the details below.

Ms Catherine Mackenzie  
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Head of Department  
Department of Public  
Health

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Co-supervisor

Senior Lecturer

Department of Public Health

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**Information sheet for Participants in a focus group  
(Focus group 2 - professionals involved in the care of women who have/have had breast cancer and/or physical activity promotion policy development)**

My name is Catherine Mackenzie and I am a PhD student in the Department of Public Health, School of Medicine at Flinders University.

I am undertaking research leading to the production of a PhD thesis on how South Australian women who have, or have had, breast cancer respond to information about health benefits of physical activity.

I would be grateful if you could spare the time to participate in a focus group, to discuss your experiences of caring for women who have, or have had, breast cancer and/or your experiences of physical activity promotion and policy development.

The main purpose of the focus group is to refine an interview guide which will be used in interviews with women who have, or have had, breast cancer in the last ten years, and who were mothers of at least one child under the age of twelve years old at the time of diagnosis. Questions will focus on the women's views on their participation in physical activity and on their views on physical activity promotion and campaigns.

At the focus group, I will invite participants to join an ongoing reference group that would meet for no more than two hours at approximately two month intervals. The purpose of the reference group is to guide the project and act as an advocacy group for women with breast cancer in relation to physical activity. Participation in the focus group does not require an obligation to join the reference group and you are free to decide whether or not you wish to continue participation in the project in this capacity.

I feel that your perspective would offer a valuable contribution to this research.

**IMPORTANT INFORMATION**

- Any information that you provide will be strictly confidential
- You will not be identified in any summary reports of the research, my PhD thesis or other research outputs.
- The focus group will be tape recorded, when agreed. Your consent is sought for this on the consent form provided.
- The recording will be made available to professional transcribers, who will be advised of the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.
- You will not be identified in the written transcript of the recording.
- You will have the opportunity to review and edit your transcript. At any stage you can request that information be used in select ways. Similarly, you can ask for information to be omitted at any stage.
- The focus group will be no longer than two hours.
- All transcribed material will be retained and will be kept securely and not made available for viewing to any one but myself and my supervisors.

## Any Questions?

If you have any questions about the project itself or your involvement in the research, please contact any of the people at the details below.

Ms Catherine Mackenzie  
PhD Student

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Dr Christine Putland

Co-supervisor

Senior Lecturer

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## **Information sheet for Participants for Interview**

My name is Catherine Mackenzie and I am a PhD student in the Department of Public Health, School of Medicine at Flinders University.

I am undertaking research leading to the production of a PhD thesis on how South Australian women who have, or have had, breast cancer respond to information about health benefits of physical activity.

I would be grateful if you could spare the time to participate in an interview to discuss your experiences of physical activity promotion, as a woman who has, or has had, breast cancer in the last ten years and was a mother of at least one child under the age of twelve at the time of your diagnosis. If you wish to participate in a follow up interview, please discuss this option with me at the time of interview.

The main purpose of the interview is to explore your views on your own participation in physical activity as well as your views on physical activity promotion and campaigns.

I feel that your perspective would offer a valuable contribution to this research.

### **IMPORTANT INFORMATION**

- Any information that you provide will be strictly confidential
- You will not be identified in any summary reports of the research, my PhD thesis or other research outputs.
- The interview may be tape recorded, when agreed. Your consent is sought for this on the consent form provided.
- The recording will be made available to professional transcribers, who will be advised of the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.
- You will not be identified in the written transcript of the recording.
- You will have the opportunity to review and edit your transcript. At any stage you can request that information be used in select ways. Similarly, you can ask for information to be omitted at any stage.
- The interview will be no longer than two hours (most likely one hour).
- All transcribed material will be retained and will be kept securely and not made available for viewing to any one but myself and my supervisors.
- If participation in this interview should cause you any distress for which you would like counselling, please call The Cancer Council Helpline on 131120 during business hours, or Lifeline on 131114 anytime.
- I would like to offer you \$20 for reimbursement of any costs you may incur to participate in the interview, and as a way of showing my appreciation for your contribution to this research.

## Any Questions?

If you have any questions about the project itself or your involvement in the research, please contact any of the people at the details below.

Ms Catherine Mackenzie  
PhD Student

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## **Information sheet for Participants in a reference group**

My name is Catherine Mackenzie and I am a PhD student in the Department of Public Health, School of Medicine at Flinders University.

I am undertaking research leading to the production of a PhD thesis on how South Australian women who have, or have had, breast cancer respond to information about health benefits of physical activity.

I would be grateful if you could spare the time to participate in an ongoing reference group that will at least initially be attached to my PhD research. The purpose of the reference group is to guide the research component of my PhD and act as an advocacy group for women with breast cancer in relation to physical activity. The reference group would meet at intervals (for example, 2 months), times and location(s) to be negotiated by the participants.

Reference group participants will include women who have had a breast cancer diagnosis in the past ten years, professionals who care for or support women who have had a breast cancer diagnosis and professionals who promote physical activity or produce physical activity policy.

I feel that your perspective would offer a valuable contribution to this group, and ultimately to this research.

### **IMPORTANT INFORMATION**

- Any information that you provide will be strictly confidential
- You will not be identified in any summary reports of the research, my PhD thesis or other research outputs.
- Reference group meetings will be tape recorded, when agreed. Your consent is sought for this on the Consent Form for Participation in Research provided.
- I will be making observations of the reference group processes as part of my research. Your consent is sought for this on the Consent Form for Observation of Professional Activity provided.
- The recording will be made available to professional transcribers, who will be advised of the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.
- You will not be identified in the written transcript of the recording.
- You will have the opportunity to review and edit your transcript. At any stage you can request that information be used in select ways. Similarly, you can ask for information to be omitted at any stage.
- All transcribed material will be retained and will be kept securely and not made available for viewing to any one but myself and my supervisors.
- You are free to withdraw from the reference group at any time.

## Any Questions?

If you have any questions about the project itself or your involvement in the research, please contact any of the people at the details below.

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PhD Student

Department of Public Health

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## **Appendix 3: Consent forms**

**Focus group (small group interviews)**

**Interview**

**Reference group (advisory group)**

**CONSENT FORM FOR PARTICIPATION IN RESEARCH  
(by focus group)**

I .....  
being over the age of 18 years hereby consent to participate as requested in the Letter of Introduction and Information Sheet for the research project on how South Australian women who have, or have had, breast cancer respond to information about health benefits of physical activity.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to my information and participation being recorded on tape.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
  - I may not directly benefit from taking part in this research.
  - Participation is voluntary and I am free to withdraw from the project at any time and am free to decline to answer particular questions.
  - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
  - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
  - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

**Participant's signature.....Date.....**

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

**Researcher's name.....**

**Researcher's signature.....Date.....**

*NB. Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Items 6 and 7, as appropriate.*



**CONSENT FORM FOR PARTICIPATION IN RESEARCH  
(by interview)**

I .....  
being over the age of 18 years hereby consent to participate as requested in the Letter of Introduction and Information Sheet for the research project on how South Australian women who have, or have had, breast cancer respond to information about health benefits of physical activity.

I have read the information provided.

1. Details of procedures and any risks have been explained to my satisfaction.
2. I agree to my information and participation being recorded on tape.
3. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
4. I understand that:
  - I may not directly benefit from taking part in this research.
  - Participation is voluntary and I am free to withdraw from the project at any time and am free to decline to answer particular questions.
  - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
  - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
  - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

**Participant's signature.....Date.....**

I certify that I have explained the study to the volunteer and consider that she understands what is involved and freely consents to participation.

**Researcher's name.....**

**Researcher's signature.....Date.....**

*NB. Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Items 6 and 7, as appropriate.*

**CONSENT FORM FOR PARTICIPATION IN RESEARCH  
(by reference group)**

I .....  
being over the age of 18 years hereby consent to participate as requested in the Letter of Introduction and Information Sheet for the research project on how South Australian women who have, or have had, breast cancer respond to information about health benefits of physical activity.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to my information and participation being recorded on tape.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
  - I may not directly benefit from taking part in this research.
  - Participation is voluntary and I am free to withdraw from the project at any time and am free to decline to answer particular questions.
  - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
  - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
  - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

**Participant's signature**.....**Date**.....

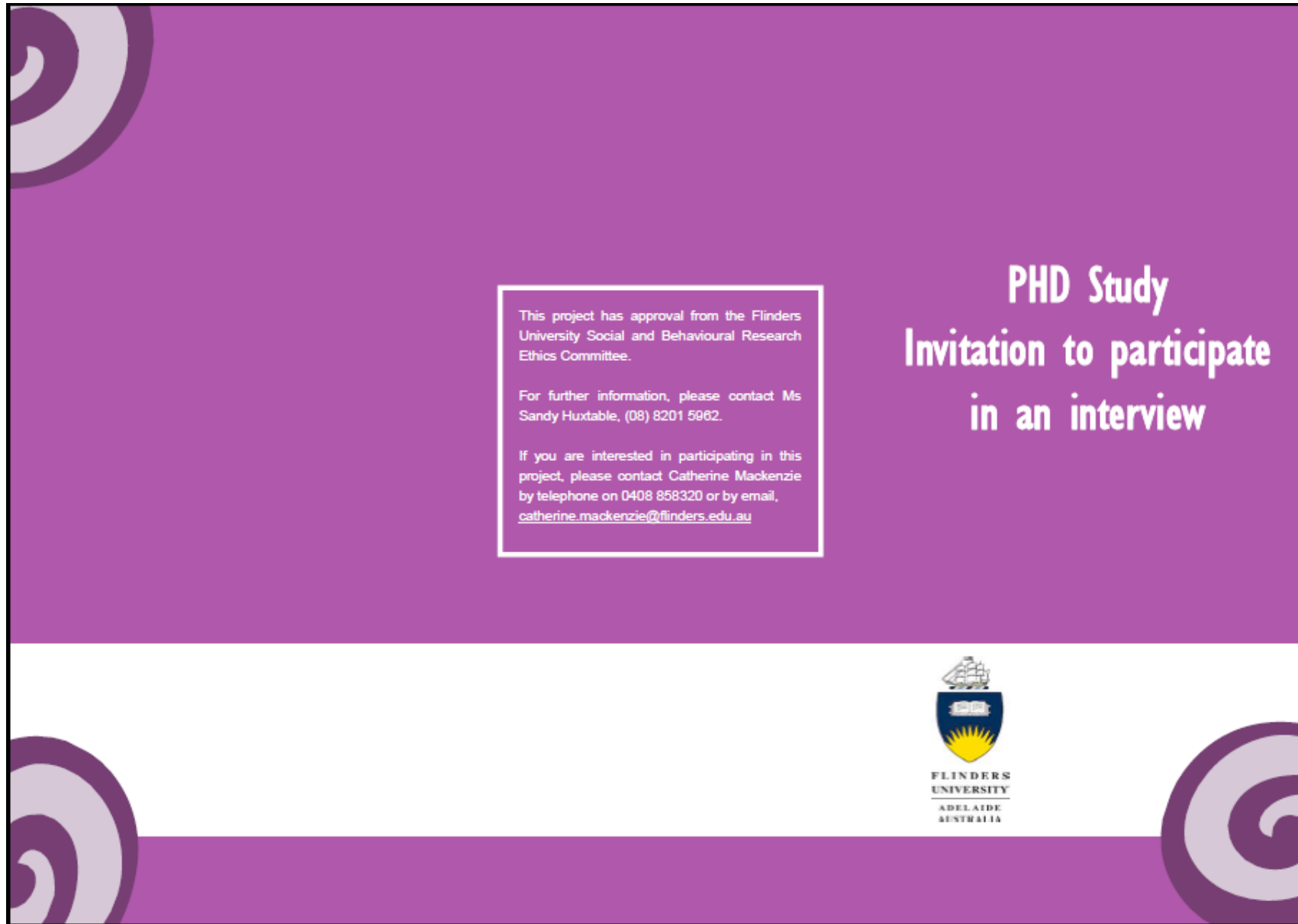
I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

**Researcher's name**.....

**Researcher's signature**.....**Date**.....

*NB. Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Items 6 and 7, as appropriate.*

## Appendix 4: Invitation to participate flyer




This project has approval from the Flinders University Social and Behavioural Research Ethics Committee.

For further information, please contact Ms Sandy Huxtable, (08) 8201 5962.

If you are interested in participating in this project, please contact Catherine Mackenzie by telephone on 0408 858320 or by email, [catherine\\_mackenzie@flinders.edu.au](mailto:catherine_mackenzie@flinders.edu.au)

# PHD Study Invitation to participate in an interview



FLINDERS  
UNIVERSITY  
ADELAIDE  
AUSTRALIA

## Invitation to participate in an interview...

### What?

This study is interested in how Australian women, who had young children at the time of their breast cancer diagnosis, respond to information about health benefits of physical activity.

The study focus is to listen to women's own accounts of their breast cancer experiences in relation to participating in physical activity, and what they have to say about ways that physical activity is promoted.

### Why?

Medical evidence suggests that exercise provides many benefits for women who have or have had breast cancer. Yet, there is not any evidence on how women with a past or recent breast cancer diagnosis feel about or respond to messages promoting physical activity.

### How?

The project research methods include:

- Focus groups
- Interviews with women who had dependent children when they were diagnosed with breast cancer
- Ongoing reference group
- Workshop/s

### What is asked from you?

- To participate in an interview In 2007 or early 2008 at a location that is convenient for you. The interview will be conducted by Catherine Mackenzie who is a PhD student
- The main purpose of the interview is to explore your own experience of participation in physical activity as well as your views on physical activity promotion and campaigns.

If you wish to participate further, you may volunteer to be involved in the ongoing reference group from time to time - there will be no pressure to do this.

### What are the benefits?

Your perspective would offer a valuable contribution to:

- Knowledge about women's experience of breast cancer and breast cancer survival in relation to their everyday lives as mothers of young children and participation in physical activity.
- Future development of appropriate approaches to physical activity promotion and policy development.
- Increasing the knowledge of those involved in the care and support of women who have or have had breast cancer.
- Supporting women who have breast cancer in the future.

If you are interested in participating in this project, please contact Catherine Mackenzie by telephone on 0408 858 320 or by email, [catherine.mackenzie@finders.edu.au](mailto:catherine.mackenzie@finders.edu.au), or by posting the tear-off slip below.

### Postal response

#### Your details

Name \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Phone \_\_\_\_\_

Mobile \_\_\_\_\_

Email \_\_\_\_\_

(please circle how you would prefer to be contacted)

Best time to contact you \_\_\_\_\_

#### Please return to:

Catherine Mackenzie  
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## Appendix 5: Demographic form

### About you

Please complete and return to Catherine Mackenzie at the time of your interview. If you do not wish to complete any part of this form, please leave blank.

Name			
Date of birth			
Address			
<b>1</b>	Highest education attainment:		
<b>2</b>	Occupation:		
<b>3</b>	Family structure (please tick): <input type="checkbox"/> married/ living with partner <input type="checkbox"/> single  <input type="checkbox"/> other		
<i>If you are married / partnered, please complete 4 and 5. If not, please go to 6.</i>			
<b>4</b>	Partner's highest education attainment:		
<b>5</b>	Partner's occupation:		
<b>6</b>	Household income (please tick): <input type="checkbox"/> Up to \$20,000 <input type="checkbox"/> \$20,001-\$40,000 <input type="checkbox"/> \$40,001-\$60,000 <input type="checkbox"/> \$60,001-\$80,000 <input type="checkbox"/> More than \$80,000		
<b>7</b>	Private health insurance (please tick): <input type="checkbox"/> yes <input type="checkbox"/> no		
<b>8</b>	Date of your breast cancer diagnosis:		
<b>9</b>	Medical treatment/s related to your breast cancer (past or current):    		
<b>10</b>	<b>Child/ren</b>		
	Child's age at time of your breast cancer diagnosis	Child's sex (M/F)	Relationship to you (eg biological, step-child, adopted)
<p>Would you be willing to participate in a follow-up interview? (please tick)</p> <p><input type="checkbox"/> yes _____ <i>(signature)</i></p> <p><input type="checkbox"/> no</p>			

**Thank you very much for your time!**

## Appendix 6: Small group interview guide

### Small group interview guide – women who have/ had breast cancer

Thank you, welcome & introductions.

Background - my research question.

My main question is - how do South Australian women, who had young children at the time of their breast cancer diagnosis, receive and act on information about health benefits of participation in regular physical activity?

Today's discussion:

#### 1. Interview guide

- Introduction: The main part of this research will be interviews with women who have or have had breast cancer, and who had young children at the time of their diagnosis. As I have not had breast cancer, I would like to explore with you the best ways to ask women the questions I have, to ensure that my questions are appropriate. (Hand out interview guide)
- Could you please tell me how you feel about this set of questions in terms of whether you think I could ask them in different ways, whether I have left anything out that, or whether you think I ought to leave something out.
- I'd also like your views on something that other researchers have found. In the reading that I have done, researchers have stated that it is best to ask about the time of women's diagnosis of breast cancer, no matter what the topic is about, at the very beginning of an interview - what are your thoughts on this?

#### 2. Your experiences

- I'd then like to explore with you your own experiences and feelings about physical activity campaigns and health messages - in the media, friends and family, from your doctors or other health professionals. We could refer to the interview guide to help this process.

#### 3. Next steps

- I would like to explore with you whether you'd like to continue your involvement with this research project by joining a reference group and/or participating in an interview.
- The reference group will include women who have or have had breast cancer, as well as health professionals who care for women who have breast cancer. The aim is to influence the ways in which health professionals discuss topics like exercise/physical activity with women who have or have had breast cancer.
- I will be conducting interviews until around August. Interviews will be conducted at locations and times most convenient for the women, and would be no more than two hours long - most likely around one hour.
- The next step for this research is to hold a similar focus group to today's with health professionals. I'll feed back the outcomes from today, and ask them to look at the interview guide to see if they think there is anything else they would like to add/change. I will also be inviting them to join the reference group.

### **In-depth interview guide:**

What sorts of things have you seen or heard about that are said to be good for our health? (*prompt* - for example on TV, in the paper or magazines or brochures)

What do you think about these/them/this?

Where do you get most of your health information from?

Do you talk about things that might be good for your health with friends or family? (*prompt* - what do they say? What do you think/feel about this?)

What about your doctors? What do they say? (*prompt* - how do you feel about this/ this advice?)

How do you feel about these (various/different) health messages, especially about physical activity/exercise, that you have seen or heard?

(*If not mentioned*) Do these messages influence what you do in any way?

(*If not mentioned*) Do *you* think being physically active, that is, doing some sort of exercise, is good for your health?

What about you personally - what sorts of things do you think keep *yourself* healthy or feeling good?

Are you able to get to do these things (*relate question to answer above*)? (*if yes, how/ what contributes to you being able to? If no, what changes in:*

- your life
  - in the environment around you
  - your neighbourhood
- would help you to do these things?

What about before/since having child/ren - do you think having young child/ren makes a difference to whether or not you do things that make you feel healthy/good? In what ways?

Thinking back to before you had breast cancer, was it any different for you to do things to keep yourself feeling healthy/good? (*prompt* - was it easier before, or has the experience given you more impetus to do those things?)

When you think about doing some exercise, how do you feel? (*prompts* - What sorts of things do you think about?/ What thoughts and feelings do you have?)

How do you feel, in your body, when you do some exercise (*prompt* - for example, going for a walk)?

(*If not mentioned above*) Since having breast cancer, do you feel differently about doing exercise? (*prompts* - effects of treatment/surgery/body image).

## Appendix 7: Final interview guide

### 1. The experience of having breast cancer.

1a	Could you tell me about your experience of breast cancer?	<ul style="list-style-type: none"> <li>• When first diagnosed?</li> <li>• Treatments that you had/ are having?</li> <li>• What it's like for you now?</li> </ul>
1b	Since your diagnosis, what sorts of things have your health professionals suggested would be helpful for your health and wellbeing?	<ul style="list-style-type: none"> <li>• While going through treatment</li> <li>• After treatment</li> <li>• Always/ongoing</li> </ul>
1c	Whose advice, and at what stages, have you found most useful?	
1d	Has anyone discussed with you whether or not, or how much exercise would be appropriate for you?	<ul style="list-style-type: none"> <li>• Who has?</li> <li>• At what stage/s?</li> <li>• Can you tell me what they said?</li> <li>• Consideration of family commitments/ whether its possible?</li> </ul>
1e	What do the terms 'physical activity' or 'exercise' mean to you?	

### 2. 'Health promoting lifestyles' as they are discussed in the public domain.

2a	Could you tell me what sorts of things you have read about, heard about or watched on TV that are supposed to be good for our health?	<ul style="list-style-type: none"> <li>• Women's health?</li> <li>• Women who have or have had breast cancer?</li> <li>• Specifically about physical activity/exercise for women who have/ have had breast cancer?</li> </ul>
2b	Where have you seen or heard this information?	<ul style="list-style-type: none"> <li>• TV/radio commercials?</li> <li>• Health promotion literature - eg brochures doctors surgeries?</li> <li>• TV series or documentaries or films?</li> <li>• Books?</li> <li>• Radio - interview segments?</li> <li>• Magazine articles - women's/ health &amp; lifestyle magazines?</li> <li>• Newspapers?</li> <li>• Computer/internet?</li> <li>• Other sources?</li> </ul>
2c	Which of these sources of information would you be most likely to believe?	
2d	How do you feel about the various health messages relating to physical activity/exercise?	
2e	Where would you go if you wanted more information?	



## Appendix 7: Final interview guide

### 3. Conversations about 'health promoting lifestyles' with friends, family and health professionals.

3a	<p>Do you talk about things that might be good for you with people you know:</p> <p style="margin-left: 20px;">I. Generally - not necessarily related to breast cancer</p> <p style="margin-left: 20px;">II. In relation to having breast cancer?</p>	<ul style="list-style-type: none"> <li>• Family?</li> <li>• Partner?</li> <li>• Children?</li> <li>• Friends? Do you find them willing to talk about it?</li> </ul> <p>Who initiates discussions?</p>
3b	<p>What about your health care professionals?</p> <p>What do they say, in relation to what you can do (or should avoid doing), that would be helpful for you, because of having/ having had breast cancer?</p>	<ul style="list-style-type: none"> <li>• Your GP?</li> <li>• Your surgeon?</li> <li>• Your breast care nurse?</li> <li>• Your oncologist/s?</li> <li>• Complementary medicine professionals?</li> <li>• Other health professionals, eg physiotherapists/occupational therapists?</li> </ul>

### 4. Responses to health promotion messages and discussions.

4a	<p>Do any of these messages influence what you do in any way?</p>	<ul style="list-style-type: none"> <li>• Positively?</li> <li>• Negatively?</li> </ul>
4b	<p>Do you feel that being physically active, that is, doing some sort of exercise, is actually good for your own health?</p>	<ul style="list-style-type: none"> <li>• <i>Prompt</i> (eg going for a walk or a swim, or more structured activities such as playing sport or doing an exercise program)</li> <li>• In what ways?</li> <li>• What type/s of exercise/activities?</li> </ul>

### 5. Effects of life events on physical activity/exercise.

5a	<p>Can you tell me about ways that your participation in exercise/PA has changed over your life? <i>E.g. What kinds of PA/ exercise did you do, and how often:</i></p>	<ul style="list-style-type: none"> <li>• <i>If in a relationship</i> - before you were in the relationship?</li> <li>• Did the type and regularity of your participation in exercise/PA change?</li> <li>• Did your partner's?</li> <li>• Since being in/ when you were in - a relationship with .... but before having child/ren:</li> <li>• After having your child/ren</li> <li>• when you were first diagnosed with breast cancer</li> <li>• <i>If more than a year post-diagnosis:</i> What about a year later?</li> <li>• What about more recently?</li> </ul>
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## 6. Constraints and enablers to being active in everyday life

6a	If you are able to get to do any form of exercise that you think helps you to keep healthy or to feel good, what contributes to you being able to?	
6b	If you are not able to, what changes in:	<ul style="list-style-type: none"> <li>• your life - support systems/child care possibilities</li> <li>• your relationship (if in one)</li> <li>• the environment around you</li> <li>• your neighbourhood</li> <li>• other</li> </ul> <p>would help you to do these things?</p>

## 7. Feelings about actually doing some physical activity/exercise

7a	When you think about doing some exercise, how do you feel?	<ul style="list-style-type: none"> <li>• <i>prompts</i> - What sorts of things do you think about?/ What thoughts and feelings do you have? Does it cause you any stress to think about it?</li> </ul>
7b	When you do some physical activity, do you prefer to do it with others or by yourself?	<ul style="list-style-type: none"> <li>• In a group - a peer group/family/partner/friends/other groups?</li> <li>• As a social outing</li> <li>• On your own</li> </ul>
7c	How do you feel, in your body, when you actually do some exercise?	<ul style="list-style-type: none"> <li>• <i>prompt</i> - for example, going for a walk/swim</li> </ul>
7d	Since having breast cancer, do you feel differently about doing exercise?	<ul style="list-style-type: none"> <li>• <i>prompts</i> - effects of treatment/surgery/body image/who you exercise with</li> </ul>

## Appendix 8: Examples of coding physical activity participation

Below are some of the women's accounts of the range of activities in which they described participating, to a total of at least three times per week (thus being coded as *more active*).

*I started last year when day light saving started. I decided I would go for a walk three nights a week for an hour which I've been doing (Janine).*

\*\*\*

*I am trying to do a fitness program just at home to try and increase my fitness, which I am starting to win. I have had a lot of trouble getting back into it, just from a stamina point of view as well [...] and it's taken me a while to get back into things, and I just started in the last two months. I have just joined Dragon's Abreast, which I really enjoy. [...] I quite enjoy it so that's twice a week so I have just started doing that [too] (Danielle).*

\*\*\*

*Because when I first joined the gym I was going to go to gym, say, Monday, Wednesday, Friday and then walk on Tuesday and Thursday so I'm still doing something most days. That was how it started, to change [from] walking every day. And plus I'm involved in Dragons Abreast (Isobel).*

\*\*\*

*I started probably in the 5th week [post breast surgery], I started doing classes because I am a fitness instructor. I was doing Body Pump and I started back doing that, but only I was just using the bar, just no weights initially to start with, and then just slowly increased my weights with that. Bike riding, I cycle with squad [laughs]. Had a couple of falls [laughs].*

CM Yes. That one on your knee looks a bit sore.

*Yes it's healing. It looks worse than what it is [...] I went and saw the surgeon, I said, "look I have got a bike ride in November that I want to do", and even if I was going through radiotherapy, you know, I am thinking, "oh yes, that should finish a week before the bike ride", and yes hopefully I will be right for it. So ...*

CM How long was the bike ride?

*Four hundred k's.*

*[...] I have two classes at the moment. I teach one tonight at 6 o'clock. It's what we call the Three Ss, it's just a bit of step, sweat*

*and sculpt. So you mix it up a bit, a bit of boxing and cardio work and step, and then I do the Body Pump (Melissa).*

\*\*\*

*I do exercise like nearly every day of the week. I do some [days] two or three lots of exercise. [...] I do strength training three times a week, and I do aerobics on Tuesday mornings. And I do half an hour exercise with the TV, five days a week. Oh, four days a week. [...] And I walk the dog with my husband in the evening (Monique).*

\*\*\*

*On my I-pod I've got my gym play list and it might sound really boring but it is the same jobs every time. But I know where I should be in my program. They are the songs that I like to, you know, when I'm on the treadmill I know what songs I'm going to be listening to or on the cross trainer. When I get to doing my stretches I've got different songs and it is just my routine and I am very selfish about it and I'm not going to be apologetic about it.*

*CM So when do you go to the gym?*

*It is open until 9:30 so I usually go after eight because it is much quieter [...] and I always go on the weekends. Yeah. And now, with daylight savings sometimes I just prefer to go for a walk because we're not far from Princes Park. So it is about a 2k walk across to Princes Park, three and a bit around and then another two ks home and that is a nice walk (Rebecca).*

Illustrations of coding women's accounts as *less active*, where their descriptions of activities were fewer than three times per week are below. Included in the *less active* group are descriptions of activities that they participated in occasionally (or were no longer doing) in the two weeks preceding the interview.

*CM So what other stuff do you do, like when you say sailing, do you do regular stuff, like walking or anything?*

*I do nothing regularly – no. If I feel like going for a bike ride, I'll go for a bike ride. If I want to go on the bike outside or just peddle away on an exercise bike I do, but I don't do a lot (Jen).*

\*\*\*

*I walk down to the school sometimes. The walk to the school is easy. It is walking like from the school to the post office or to the hotel or something, because you've got a very steep hill from the Princes Highway up the school (Nora).*

\*\*\*

*When I was first diagnosed [my partner] and I would go every night for a walk and we were doing it every night, you know, just get out of the house and get a bit of exercise.*

*[...] and we did that up until I had chemo and then I tried to but it just wasn't happening and then I got sore and I just didn't ... and we keep meaning ... we've done a few walks as I've started to get better in the last month, but we're not doing it every night. But now that daylight savings<sup>25</sup> is here we'll probably get back into it, but we're all tired after tea and it takes a real effort to get out the door, but I need to because I've put on that much weight, like I need to do something and I keep saying I'll go join a gym and I'll do this and I'll do that and I haven't done any of it (Sarah).*

\*\*\*

*And I was doing lots of exercising. I was involved in lots of different classes and in different levels of activities as well. Just become slack in the last six months (Vanessa).*

\*\*\*

*A friend of mine, we were walking every day. We'd get up at 6 o'clock and we'd walk an hour. And we were also going to the gym so every alternate day we'd go to gym and – we were doing it to lose weight and after 18 months we found it wasn't doing anything. So we actually stopped going and then ended up stopping walking because she had family issues. So, yeah, I haven't even been doing anything in the last 12 months, at all, sport-wise (Annette).*

\*\*\*

*CM So do you still walk quite a bit?*

No. it's intermittent. I find that I do try and put a little bit of extra walking in, because I know if I was to say: "I'll walk down to the shops at North Park" I'd get down there and then I wouldn't get back so I've tried to build up a bit but I can't be bothered (Tanya).

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<sup>25</sup> Daylight saving refers to the period of time over warmer months in Australian states where clocks are turned back one hour to enable longer daylight time at the end of the day, usually commencing mid-late October and ending late March.