

**Rare and tragic:  
Young women diagnosed with advanced breast cancer;  
a discourse analysis**

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for the degree of Doctor of Philosophy

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## DECLARATION

I certify that this thesis does not incorporate without acknowledgement 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.

A handwritten signature in black ink, appearing to read 'K. Breaden', with a stylized flourish at the end.

Katrina Breaden

Date: 19<sup>th</sup> October 2009



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## TABLE OF CONTENTS

DECLARATION.....	III
ACKNOWLEDGEMENTS.....	V
TABLE OF CONTENTS.....	VII
SUMMARY .....	XI
PROLOGUE.....	XIII
DEFINITION OF TERMS.....	XV
<b>CHAPTER ONE: AN INTRODUCTION.....</b>	<b>1</b>
1. INTRODUCTION .....	1
2. AIMS OF THE THESIS .....	4
3. OUTLINE OF THE CHAPTERS THAT FOLLOW: .....	6
<b>CHAPTER 2: YOUNG WOMEN AND (ADVANCED) BREAST CANCER: A REVIEW OF THE LITERATURE .....</b>	<b>8</b>
1. THE SCOPE OF THE LITERATURE REVIEW .....	9
2. THE PHYSICAL NATURE OF ADVANCED BREAST CANCER IN YOUNG WOMEN.....	9
<i>a. Prognostic indicators for a highly lethal disease .....</i>	<i>9</i>
<i>b. Prognosis.....</i>	<i>12</i>
<i>c. Accuracy of staging breast cancer: a determinant of survival .....</i>	<i>13</i>
<i>d. Survival.....</i>	<i>14</i>
<i>e. Treatments .....</i>	<i>15</i>
<i>d. What predicts long-term survival? .....</i>	<i>20</i>
<i>e. Fertility, Pregnancy and Sexuality.....</i>	<i>22</i>
<i>f. The problem lies in the genes .....</i>	<i>25</i>
<i>g. Palliative care's involvement in the care of young women diagnosed with (advanced) breast cancer. ....</i>	<i>26</i>
3. SUMMARY OF THE PHYSICAL NATURE OF ADVANCED BREAST CANCER IN YOUNG WOMEN .....	27
<i>a. Limitations.....</i>	<i>28</i>
<i>b. Expert knowledge .....</i>	<i>29</i>
4. PSYCHOLOGICAL AND INDIVIDUAL ASPECTS OF ADVANCED BREAST CANCER IN YOUNG WOMEN. ....	30
<i>a. Depression.....</i>	<i>30</i>
<i>b. Psychological morbidity .....</i>	<i>32</i>
<i>c. Body image .....</i>	<i>33</i>
<i>d. The experience of young women living with advanced breast cancer .....</i>	<i>34</i>
5. SUMMARY AND LIMITATIONS OF PSYCHOLOGICAL AND INDIVIDUAL ASPECTS .....	39
<i>a. Body and mind.....</i>	<i>40</i>
<i>b. Scales and surveys.....</i>	<i>40</i>
<i>c. Interpretation.....</i>	<i>41</i>
6. RESEARCH STUDIES CONDUCTED ON THE MEDIA .....	42
<i>a. Three broad areas of research.....</i>	<i>43</i>
<i>b. Breast cancer and the media .....</i>	<i>44</i>
7. SUMMARY AND LIMITATIONS OF BREAST CANCER IN THE MEDIA .....	52
8. A DISCOURSE ANALYTIC PERSPECTIVE .....	53
9. IMPLICATIONS OF THIS CHAPTER .....	55
<b>CHAPTER 3: THEORETICAL PERSPECTIVES .....</b>	<b>56</b>
INTRODUCTION.....	56
1. STRUCTURALISM .....	56
2. POSTMODERNISM OR POSTSTRUCTURALISM? .....	57
3. POSTSTRUCTURALISM .....	58
<i>a. Language .....</i>	<i>58</i>
<i>b. Language and meaning.....</i>	<i>60</i>
<i>c. Language and subjectivity .....</i>	<i>60</i>
<i>d. Subjectivity and positioning.....</i>	<i>62</i>
4. LANGUAGE AND DISCOURSE.....	62
5. FEATURES OF FOUCAULT'S CONCEPT OF POWER .....	66

6. THE SHAPING OF HUMAN BEINGS .....	69
7. BIOPOWER AND GOVERNMENTALITY .....	71
8. THE INSCRIBED BODY: THE TARGET, OBJECT AND INSTRUMENT OF POWER .....	73
9. THE UNCONSCIOUS AND EMOTIONS.....	75
10. IMPLICATIONS OF A THEORETICAL POSITION .....	78
<i>a. Humanism: a critique</i> .....	78
<i>b. Foucault: a critique</i> .....	79
<i>c. A feminist contribution</i> .....	82
11. IMPLICATIONS OF THIS CHAPTER AND CONCLUSION .....	82
<b>CHAPTER 4: METHODOLOGY AND RESEARCH CONTEXT .....</b>	<b>84</b>
INTRODUCTION .....	84
1. APPROACHES TO DISCOURSE ANALYSIS .....	85
2. INSIGHTS ON DISCOURSE ANALYSIS .....	87
3. STEPS FOR IDENTIFYING DISCOURSES.....	91
<i>a. Look for discourses in the text</i> .....	91
<i>b. Next step: sorting and coding</i> .....	96
<i>c. Final step: analyse the material discursively</i> .....	101
4. THE ISSUE OF RIGOUR .....	107
<i>a. Reflexivity</i> .....	107
<i>b. Credibility</i> .....	109
<i>c. Generalisability and representativeness</i> .....	109
5. AN ETHICAL COMPORIMENT.....	110
6. DESCRIPTION OF THE PARTICIPANTS .....	112
7. SUMMARY AND CONCLUSION .....	121
<b>RESULTS AND DISCUSSION .....</b>	<b>123</b>
<b>CHAPTER 5: THE DISCOURSE OF NUMERACY.....</b>	<b>125</b>
INTRODUCTION.....	125
<i>A brief history of numbers – from the outside looking in</i> .....	126
1. IN THE PROFESSIONAL LITERATURE .....	128
<i>a. Medical texts (n=5)</i> .....	128
<i>b. Professional medical journals (n=251)</i> .....	131
<i>c. Clinical practice guidelines (n=2)</i> .....	136
2. THE NEWSPAPERS .....	138
<i>a. Staging and prognosis</i> .....	138
<i>b. A game of chance</i> .....	139
3. IN THE YOUNG WOMEN’S STORIES.....	142
<i>a. Treatment factors</i> .....	142
<i>b. Staging and prognosis</i> .....	143
<i>c. The search for survival: non-conventional therapies</i> .....	146
4. DISCUSSION: THE PROBLEM WITH NUMBERS.....	149
<i>a. Probabilities refer to groups of people, not individuals</i> .....	150
<i>b. The discourse of numeracy can be used to manipulate people</i> .....	152
<i>c. The discourse of numeracy fuels the responsibility to survive</i> .....	154
<i>d. The discourse of numeracy forms its object: non-survivor</i> .....	156
<i>e. The discourse of numeracy and the calculated management of life and death</i> .....	158
5. CONCLUSION .....	159
<b>CHAPTER 6: THE DISCOURSE OF TRAGEDY .....</b>	<b>160</b>
INTRODUCTION .....	160
<i>Tragedy – a play in four acts</i> .....	161
TRACING THE DISCOURSE .....	162
1. TRAGEDY IN THE NEWSPAPERS .....	162
2. TRAGEDY IN THE PROFESSIONAL MEDICAL LITERATURE .....	172
3. TRAGEDY IN THE WOMEN’S STORIES .....	178
4. DISCUSSION .....	186
<i>a. The use of the tragic genre</i> .....	186
<i>b. Effects of the tragic genre</i> .....	188
5. CONCLUSION .....	196

<b>CHAPTER 7: DISCOURSES OF THE BODY .....</b>	<b>197</b>
INTRODUCTION.....	197
<i>The body in medicine</i> .....	198
TRACING THE DISCOURSES .....	199
1. IN THE STORIES TOLD BY THE YOUNG WOMEN .....	199
a. <i>The ‘volume in perpetual disintegration’: the discourse of a body in decline</i> .....	200
b. <i>The thin body discourse</i> .....	208
c. <i>In summary</i> .....	211
2. IN THE PROFESSIONAL MEDICAL LITERATURE (JOURNALS AND TEXTBOOKS).....	212
3. IN THE MEDIA .....	221
4. DISCUSSION.....	230
<i>Effect 1: The urge to be thin</i> .....	231
<i>Effect 2: Looking (ab)normal– a disturbance of body image</i> .....	236
<i>Effect 3: The gendered body</i> .....	237
<i>Effect 4: The body as a site of abjection</i> .....	240
5. CONCLUSION .....	241
<b>CHAPTER 8: CONCLUSION.....</b>	<b>242</b>
1. SUMMARY OF RESULTS .....	242
2. DISCUSSION OF THE THEORETICAL SIGNIFICANCE OF THE STUDY .....	245
3. LIMITATIONS OF THE STUDY .....	247
4. AREAS FOR FURTHER RESEARCH .....	248
5. IMPLICATIONS FOR PRACTICE .....	249
6. REFLECTIONS ON THE RESEARCH PROCESS .....	251
7. FINAL THOUGHTS .....	252
<b>EPILOGUE.....</b>	<b>253</b>
<b>APPENDICES .....</b>	<b>255</b>
APPENDIX 1: CHRONOLOGICAL LIST OF MEDICAL JOURNALS, CONTENT AREAS AND TITLES .....	255
APPENDIX 2: LIST OF NEWSPAPERS AND CODING SCHEMA .....	266
APPENDIX 3: CHRONOLOGICAL HEADINGS OF NEWSPAPER ARTICLES .....	271
APPENDIX 4: INTERVIEW GUIDE .....	279
APPENDIX 5: PARTICIPANT INFORMATION.....	280
APPENDIX 6: PROCESS OF SORTING AND CODING .....	282
APPENDIX 7: INFORMATION SHEET .....	284
APPENDIX 8: CONSENT FORM .....	286
<b>REFERENCES.....</b>	<b>287</b>



## **SUMMARY**

Recent research into advanced breast cancer has suggested that young women in general tend to have more aggressive disease, present at a later stage of disease progression and suffer many more issues and concerns than their older counterparts. Whilst breast cancer in women in general has been the target of a vast amount of research and public attention, values and beliefs surrounding advanced breast cancer have not been a focus of concern.

The aim of this thesis is to explore scientific journals, the media and to listen to the young women themselves in order to identify the understandings of advanced breast cancer in young women and the ways in which these understandings are perpetuated and sustained over time. The goal is to illuminate the various discourses that are currently being drawn upon to understand this life-limiting illness and the impact these discourses have on the lives of young women concerned.

Poststructuralism is the theoretical perspective within which this thesis is located. This approach allowed for a focus on language, power and text. Discourse analysis of three data sets was used. These data sets were drawn from scientific and medical journals (251), medical texts (5), clinical practice guidelines (2), newspaper articles (230) and transcribed conversations with 12 young women diagnosed with advanced breast cancer.

The main discourses identified within and across the various data sets were; the discourse of numeracy, the discourse of tragedy and several discourses of the body; the thin body, the declining body, the object body and the gendered body. While the emphasis of each of these discourses varied across the three data sets, they were all present in each to some degree, reflecting broader cultural stories within which the individual stories are located.

Young women diagnosed and living with advanced breast cancer are currently being portrayed as living with a tragic disease, controlled and constrained by the statistics and probabilities and played out within and on a body in 'perpetual disintegration'. The discourses of tragedy, numeracy and the thin, object, gendered and declining body all relate to larger stories of what it is to be dying before one's time in Western society today.

## PROLOGUE

For many years now, I have worked as a nurse in the field of palliative care. To some, this may seem like a difficult and morbid path to follow, yet I do not find it so. There are other nursing contexts that I consider to be beyond my level of expertise and comfort. I admire those nurses who work in rural and remote areas, nurses who work in prisons and those who work with the mentally ill. These are indeed challenging areas.

I am not saying that caring for people for whom cure is no longer a possibility does not contain its own challenges and complexities; it does. However, the challenges and complexities are ones that I am mostly familiar and comfortable with. Except for one area that is, caring for young women, with young children, who are facing the end of their lives. The extract from my professional journal highlights this personal and professional difficulty.

*The room is overflowing with flowers - flowers on the overhead table, on the windowsill, and on the side near the washbasin. On the wall opposite the bed, proudly displayed at eye level are pictures hand drawn by a young child of maybe eight or nine years old. The captions underneath the various colourful outdoor scenes say 'Get well soon Mummy'. The poignancy of these hand-written messages hits home as I stand in the room. The woman in the bed before me is in her late thirties. She seems tired, with dark circles under her eyes. She is not sleeping well according to the progress notes and the pain is escalating, making it difficult for her to find a comfortable position in bed. She has advanced breast cancer. The disease has spread to her bones and is now in some of her organs as well. The statistics on advanced breast cancer in younger women suggest that advanced breast cancer is incurable and, while each woman is unique in her cancer journey, I suspect that this woman in particular has only months rather than years to live. And it was only a few months ago, before the diagnosis of the cancers spread that she no doubt considered herself to be a survivor. Now her prognosis is very poor indeed. Overnight she has moved from being a cancer survivor to a victim of cancer's unfortunate progression.*

*I enter the room to answer the call bell. We end up talking about the things we have in common, children, our age and the passion for good wine. We laugh at our similarities, and yet we are so different. She is facing a life-threatening crisis and I am not. Tomorrow she leaves the hospice for another round of chemotherapy. I wonder why she is going down that pathway again, that is until I look at the pictures on the wall, 'Get well soon Mummy'. She is facing more time in hospital, more time apart from her family, more time feeling unwell. She is aiming for survival and while she may not be considered by many to be a survivor in the accepted sense, she is surviving nonetheless.*

I have thought long and hard as to why I am uncomfortable with caring for women of a young age and it does not take much to see that I identify with these women on a very personal level. Like the woman in the story above, I too am a wife and mother and dread the thought that, if I were to be diagnosed with a life-limiting illness, I may have to face the awful prospect of leaving children behind to be brought up by someone else. I would agonise over the missed birthdays and milestones that I would not be there for and would probably go for every cure known to humankind to ensure that I would be able to experience as much of my children's lives as possible.

I did not shirk caring for these women, yet my professional relationship with them was tempered by thoughts of tragedy, pity and my own sense of mortality. The experience of caring for these younger women left me raw and vulnerable and I found it an emotionally taxing experience. I am sure I was not alone in feeling as I did yet I, like others, hid these feelings well so that I could function from day to day.

I tell this story, not to romanticise or trivialise the events surrounding one woman's search for survival, but to provide the genesis for the research that follows.

## **DEFINITION OF TERMS**

Before introducing the thesis, I will clarify a few terms that have an important bearing on the study.

### **Advanced breast cancer**

The definition of advanced breast cancer has been taken directly from the National Health and Medical Research Council (NH&MRC) and the National Breast Cancer Centre's (NBCC) publication *Clinical Guidelines for the Management of Advanced Breast Cancer* (National Health and Medical Research Council 2001a). The definition that follows appears to be widely accepted within the national and international medical community.

1. Locally advanced tumors (tumors greater than 5mm diameter that have skin involvement or ulceration and are fixed to the underlying tissues or inflammation). Any one of these characteristics corresponds to the International Union Against Cancer (UICC) classification of stage III, or
2. Recurrent breast cancer, or
3. Metastatic breast cancer, which is a cancer that has spread beyond the breast to distant sites and corresponds to stage IV in the UICC's classification system.

### **A young woman**

The age that is considered *young* is more difficult to clarify. One of the difficulties lies in the fact that there appears to be no consistent definition of *young* within the clinical research literature. Some research identifies women 35 years and less as *young* (Anderson, B et al. 1995) while for others a young woman is one who is premenopausal at the time of diagnosis (Bines, Oleske & Cobleigh 1996). We all have a different idea of what we consider *young* depending on our vantage point. In the world of breast cancer, women who are premenopausal at diagnosis are considered *young*; the age at which this occurs varies. In this thesis, I have defined *young* to mean a woman who is under the age of 45 when she receives a diagnosis of advanced breast cancer. However, I acknowledge that this is an arbitrary definition.

## **Discourse**

The term 'discourse' is central to this thesis and attracts several definitions. My use of the term 'discourse' follows Foucault who defined discourses as 'practices that systematically form the objects of which they speak' (Foucault 1972, p. 49). These practices involve networks of meaning that are found in various sites such as texts, the spoken word, visual media and institutions (Parker 1999a). The objects that are formed by such practices comprise 'all the things that we see, refer to and take for granted as actually existing "out there"' (Parker 1999a, p. 3). As Cheek (2004) succinctly states, 'a discourse consists of a set of common assumptions that sometimes, indeed often, may be so taken for granted as to be invisible or assumed' (p. 1142). Within this thesis I am therefore using a poststructural understanding of discourse to mean the ways in which understandings and ideas filter through a multitude of texts, variously defining who we are and how we live (Ward 1997, p. 212).

## CHAPTER ONE: AN INTRODUCTION

### 1. Introduction

Breast cancer is an increasingly common condition in the Western world and, despite its familiarity within everyday conversations, the word *breast cancer* still instils fear into the lives of many individuals. In Australia, breast cancer is the leading cause of cancer deaths in women. In 2005 alone, 2719 women died of this disease, accounting for 21% of all female cancer deaths (Australian Institute of Health and Welfare 2008). While breast cancer is usually associated with women over 50 years of age and resources such as mammography and screening programs are targeted towards this age group, there are significant numbers of younger women who die of breast cancer each year. In Australia in 2004, 188 women under the age of 45 died from this disease (Australian Institute of Health and Welfare and National Breast Cancer Centre 2006)<sup>1</sup>. This figure represents nearly 7% of the total Australian female breast cancer population who die of the disease, and a significant loss of life.

There appears to be some controversy in the literature as to whether or not breast cancers in young women actually have a poor prognosis. Many health care professionals suspect this is so and several studies appear to support this suspicion (Chung et al. 1996; Miller, W, Ellis & Sainsbury 2000; Walker et al. 1996). There are also some studies that refute this assertion (Anderson, B<sup>2</sup> et al. 1995; Backhouse et al. 1987; Ezzat et al. 1998). The latest statistical account of breast cancer survival and prevalence in Australia states that young women (< 40 years of age) have a five-year relative survival of 83.6 percent, compared with 90.4 percent for women over the age of 50. The very young women (under the age of 30) have a very poor prognosis (82.4%) (Australian Institute of Health and Welfare Cancer Australia & Australasian Association of Cancer 2008). Furthermore, beyond the five-year mark, relative survival is lowest for women less than 40 years of age, irrespective of tumour size at diagnosis (Australian Institute of Health and Welfare & National Breast Cancer Centre 2007).

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<sup>1</sup> Breast cancer does and can occur in men of all ages. In Australia in 2002, 84 men were diagnosed with breast cancer and in 2004, 20 men died from the disease (Australian Institute of Health and Welfare and National Breast Cancer Centre 2006).

<sup>2</sup> Throughout the thesis, occasionally an author's initial will appear in the textual reference. The use of this initial is to differentiate one author from another who also happens to have the same surname..

In spite of the afore-mentioned controversy, the available evidence does suggest that breast cancer before the age of 45 is associated with poorer survival than that of older women with breast cancer (Albain, Allred & Clark 1994; Australian Institute of Health and Welfare and National Breast Cancer Centre 2006; Bonnier et al. 1995). The evidence is not limited to developed nations. One recent research project in Indonesia has supported the view that a young age at diagnosis is associated with poor prognosis (Aryandono, Harijadi & Soeripto 2006). In addition, young black women appear to have cancers that are more aggressive and have a poorer prognosis than those of young white women (Porter, P et al. 2004). There are many possible explanations for the poorer survival. Breast cancer in younger women is difficult to detect by mammography due to the density of breast tissue, and has been shown to be of little diagnostic value in this age group (Bennett, Freitas & Fentiman 1991). Therefore, breast cancer is less likely to be diagnosed in its initial stages through a mass screening process. In addition, lumps found in the breast tend not to be considered suspicious in the younger age group. This lack of suspicion may lead to a delay in diagnosis. A delay in diagnosis means that there is a shorter interval between diagnosis and death. Genetics also has a part to play. The strongest risk factor for breast cancer at an early age is a history of the disease in a first-degree relative (mother or sister) (McCredie et al. 1998). In addition, younger women tend to have adverse prognostic indicators when presenting with breast cancer, such as axillary node involvement, oestrogen negative tumours, poorly differentiated tumours and larger tumours at presentation, all factors that have been shown to correlate with more aggressive disease and associated poorer survival (Crowe et al. 1994). It may be that a different tumour biology is at work in the younger age group (Albain, Allred & Clark 1994).

Breast cancer in young women does seem to be associated with particular problems for the individual concerned. Concerns regarding fertility, raising children, sexuality, body image, early menopause, poorer mental health, changing finances and roles, and complex relationship issues affect younger women more (Albain, Allred & Clark 1994; National Breast Cancer Network 1998; Vinokur et al. 1990). Young women warrant further research as a distinct group irrespective of whether or not they present with advanced disease. Many studies exclude women with metastatic or advanced disease from their sample. For a young person to be told that she has a diagnosis of cancer is profound enough without also having to contend with the further threat of a disease that

cannot be cured. Indeed, Turner and her colleagues who conducted a review of the literature on the psychological impact of cancer concluded that advanced disease at diagnosis was a forerunner of profound psychosocial morbidity (Turner, J, Wooding & Cameron 1998).

A clear separation of the terms ‘advanced breast cancer’ from ‘early breast cancer’ did not appear in the medical literature until the introduction of the clinical practice guidelines by the National Breast Cancer Centre (NBCC) in 2001. In this year, the NBCC published two separate guidelines to direct clinicians in their management of breast cancer; the *Clinical practice guidelines on the management of early breast cancer* and the *Clinical practice guidelines for the management of advanced breast cancer* (National Health and Medical Research Council 2001a, 2001b). The reason for this separation relates to treatment protocols. Early breast cancer necessitates a different treatment regime from that of advanced breast cancer. The separation also relates to prognosis; early breast cancer has a far better prognosis than that of advanced disease. Yet, for younger women, the separation is an artificial one as they already have limited prognosis at diagnosis irrespective of their stage of disease.

The term ‘advanced’ in this context means ‘far along’ or ‘progressive’ (Macquarie Encyclopedic Dictionary 1990). It is a classification that attracts more fear than the general term of ‘breast cancer’, for ‘advanced’ breast cancer not only indicates the spread of cancer cells into bodily spaces where they were never meant to be; it refers to an illness inscribed with meanings and understandings derived from our current social and political context. A young woman living with advanced breast cancer lives with these inscribed meanings as she struggles to come to terms with the nature of a life-limiting illness. In order to try to understand and explain this illness to herself and others, she draws upon the available cultural material or discourses that are percolating throughout society at one point in time (Seale 1998b).

Consequently, advanced breast cancer can mean different things to different people depending on the discourses that are available and from which they can draw. For example, when I hear the term ‘breast cancer’ and ‘young woman’ used together, I draw upon the discourse of science and equate these words with numbers, i.e. she has a 20% chance of being alive in five years time. Similarly, if the young woman diagnosed with

advanced disease views her cancer as punishment for past sins, she will be drawing on a discourse of retribution and she might see her deteriorating condition as inevitable. Therefore, understandings will vary depending on the discourses one draws upon or is drawn to.

Mass media is an influential medium in the promulgation and perpetuation of discourses especially when it refers to younger women with breast cancer (early or advanced). Both the professional and popular press, as they write about this topic, affect the perceptions of breast cancer in the wider community. The information from these print sources represents the reality of advanced breast cancer in a particular way and this reality is taken up by the population at large. For example, large population surveys overseas have shown that the popular press is the leading source of information about many health issues including mammography (Lupton & Chapman 1995). An investigation by Wilkes and others found that the information in the lay press was often inaccurate (Wilkes et al. 1998). An accurate picture of young women living with advanced breast cancer, which includes her personal context, is missing from both the lay press and the professional literature. When identifying its research priorities for the future, the Australian National Breast Cancer Foundation (2003) highlighted two areas that were to be the focus of their concern.

1. Research into special populations. Young women are considered a special population
  2. Research into the needs of women in the terminal stages of breast cancer
- (2003, p. 15)

This research falls within these.

## **2. Aims of the thesis**

This thesis aims to provide an understanding of the processes by which the beliefs about and attitudes towards advanced breast cancer in young women that are commonly portrayed in the professional and popular press shape the experiences, motivations, preferences and subjectivities of individual women who are living with the disease. Specifically, it examines and critiques the public discourses of advanced breast cancer in younger women as reflected in the 'expert' literature and the popular press, and

compares and contrasts these with the views of young women living with advanced disease. Guiding this study are two questions:

1. What discourses in the professional and popular literature are currently being produced and drawn upon to represent advanced breast cancer in younger women? and,
2. How do these discourses shape and regulate the experiences and understandings of young women diagnosed with advanced breast cancer?

These are important questions. While breast cancer in women in general has been the target of a vast amount of research, the terms ‘advanced breast cancer’ and ‘young women’ do not appear together in many research projects. The research provides a timely analysis into the way discourse, meaning and reality are constructed in this patient population.

I am not aiming to test a particular hypothesis in this study for there is no theory about advanced breast cancer that I am trying to support. However, the framework of poststructuralism drives this research, especially the concepts of language and discourse. As the following chapters indicate, there is no single truth concerning advanced breast cancer in younger women. The young woman herself has multiple truths from which to draw as she attempts to come to terms with and to find meaning in the relentless progression of her illness. The central finding in this study is that in order to understand the values, attitudes and beliefs surrounding the nature of advanced breast cancer in young women, one has to examine also the socio-political, cultural and historical context in which they occur.

### **3. Outline of the chapters that follow:**

#### **Chapter 2**

Chapter 2 contains a critical review of the extensive research literature pertaining to young women diagnosed and living with advanced breast cancer. The scope of the review covers the physical, psychological, social and individual aspects and effects of advanced breast cancer in young women. The review also includes studies conducted on the media in the general area of breast cancer.

#### **Chapter 3**

Chapter 3 contains a description of the theoretical framework of poststructuralism within which this thesis is located. Foucault's ideas on discourse, knowledge and power are outlined, together with the work of several other theorists such as Julia Kristeva and Ian Parker.

#### **Chapter 4**

In this chapter, I discuss the interdisciplinary approach of poststructural discourse analysis and outline the criteria used to analyse the data. I describe the data collection process and the steps taken to ensure the authenticity and integrity of the research findings. I also discuss the ethical requirements and the challenges that arose during the course of the study before concluding with a description of the study participants.

#### **Chapter 5**

Chapter 5 focuses on the discourse of numeracy. I trace the discourse through the public media (professional medical literature and newspaper articles), and compare and contrast these representations with the young women's narratives. I argue that this discourse shapes a young woman's experience in such a way as to leave her feeling confused and isolated.

## **Chapter 6**

Chapter 6 explores the discourse of tragedy. I again trace this discourse through the public and professional media, and compare and contrast the findings with the young women's narratives. In this chapter I argue that the discourse of tragedy results in a dissonance between the public perception and the actual experience of those young women living with advanced breast cancer. The struggle with this dissonance leaves them feeling alienated from the world in which they live.

## **Chapter 7**

Chapter 7 traces several discourses of the body. In this chapter, I show how these particular discourses have shaped the young woman's experience of herself and her body in advanced disease.

## **Chapter 8**

In this chapter, I answer the two questions posed in this research, thereby providing a summary of the results. The chapter also contains a discussion of the theoretical significance of the study together with its limitations, suggestions for areas of further research and several practical implications of the study. Finally, I reflect upon the research process before offering some concluding remarks.

## **CHAPTER 2: YOUNG WOMEN AND (ADVANCED) BREAST CANCER: A REVIEW OF THE LITERATURE**

Research into breast cancer abounds. Indeed, it is hard to pick up any oncology journal, either medical or nursing, without noticing many references to breast cancer. In spite of this abundance, when conducting this review it became clear that few research articles focused specifically on young women diagnosed with advanced disease. This lack has also been noted by Turner and McGrath (1997). Therefore, the search was expanded to include references specifically to young women with breast cancer at either an early or an advanced stage.

The aim of this chapter is to review critically the extensive research literature pertaining to young women diagnosed and living with advanced breast cancer. The literature reviewed fell into three distinct categories; those studies concerned with the physical nature of advanced breast cancer in young women and the effects of a disease upon bodies and cells, those studies that explored psychological and individual aspects of living with the disease, and finally those studies which examined the writing and representation of breast cancer within the popular press. After each of these three sections, I have included a summary and a discussion of the limitations of this particular 'reading' of breast cancer in young women. Finally, I outline research from a discourse analytic perspective, the orientation within which this thesis is located.

The studies that focused upon the physical manifestations of breast cancer in young women lay within the positivist tradition. These are by far the majority of the studies reviewed. The studies that focused on the psychological realm were also largely derived from positivism. The media studies were conducted mainly from within a constructivist framework. Studies from within constructivism tap into the experiences of disease and the forces that have shaped those experiences. The gaps in this knowledge base are outlined. I then re-examine all approaches explored and make explicit the link between this literature review and the methodology chosen for this research.

### **1. *The scope of the literature review***

This review covers the last 10 years of research (1997 – 2008) specifically on breast cancer in young women. The age of the young women within the research conducted was not uniform, but generally it included women under the age of 45. The review was limited to those reports written in English. The search terms used were: breast neoplasia – subset, secondary neoplasia, breast cancer, advanced breast cancer, metastatic breast cancer. These terms were then limited to the age range 19-44 years. Additional search terms used were ‘young women’ and ‘premenopausal women’. Young women in high-risk categories of developing breast cancer (DDT exposure, induced or spontaneous abortions, certain genetic factors, a high body mass index, early age at menarche, etc) were beyond the scope of the review and therefore excluded. Breast cancer also occurs in men; however, men are not the focus of either my research or this review. The articles reviewed were drawn from several common databases including Medline, Embase, Psychlit, CINAHL, as well as the ‘grey literature’ such as conference proceedings and dissertations. (Refer to pages 93-94)

### **2. *The physical nature of advanced breast cancer in young women***

#### **a. *Prognostic indicators for a highly lethal disease***

The treatment of advanced breast cancer in young women is rigorous and aggressive, not unlike the tumour itself. There is a commonly held view within the oncology community that an attempt at cure is the very least that should be aimed for, even though the advancing cancer is, by its very definition, non-curable (National Health and Medical Research Council 2001a). The young women themselves understandably support this view. However, the treatment regime needs to be tailored to the individual otherwise some women will undergo significant treatment-induced morbidity and reduced quality of life for very little gain in terms of quantifiable time (Thewes 2005).

Not all advanced breast cancers are the same. They differ according to a number of factors that have been the subject of intense research over the years. These factors include over-expression of HERs - a human epithelial growth factor, the presence of oestrogen negative receptors, obstructed lymph drainage, the number of lymph nodes containing cancer at diagnosis and genetic alterations or mutations. The presence of any one of these factors has been associated with limited survival (Zhou, Gautam & Recht

2007). The literature calls these factors 'prognostic indicators'. Young women have a greater proportion of these ominous markers than do older women. There have been several studies that have looked at the associations of these prognostic markers, resulting in attempts at predicting which group of young women will live the longest and hence benefit from specialised treatment (Aryandono, Harijadi & Soeripto 2006; Hartley et al. 2006). In a study conducted by Hartley and others, women diagnosed with breast cancer were divided into two groups: women under the age of 40 were matched with women over the age of 40. The latter group provided the control arm of the study. Notably, women with metastatic disease were excluded. Seventy-eight women under the age of 40 were matched with 228 controls. The researchers concluded that the women over the age of 40 had a lower rate of the cancer's recurrence. They also found that the younger women had a lower overall five-year survival rate when compared to that of the older women (Hartley et al. 2006).

Similarly Chan, Pintilie, Vallis, Girourd and Goss (2000) reviewed the case notes of 1002 women. These women were 35 years and younger and were followed for 30 years. As these authors rightly mention, a difficulty exists when analysing data from such an extensive period due to the changing treatment protocols for the management of breast cancer. However, their findings do support the hypothesis mentioned above, that breast cancer in younger women is a more aggressive disease. This study reflects the majority of studies into breast cancer in younger women that have been conducted during the review period (Albain, Allred & Clark 1994; Australian Institute of Health and Welfare and National Breast Cancer Centre 2006; Bonnier et al. 1995; Fernandopulle, Ang & Tan 2006; Holli & Isola 1997; Jayasinghe, Taylor & Boyages 2005; McCredie et al. 1998; Yankaskas 2005). These studies overall are large audits of disease characteristics in certain patient populations. The large numbers involved in the studies make the results more credible within the eyes of the scientific community.

Breast cancer has been shown to spread to the lymph nodes and the lymphatics that drain the breast quadrant (Bundred, Morgan & Dixon 2000). Originally, the presence of three or more lymph nodes containing cancer cells predicted limited survival (Jayasinghe, Taylor & Boyages 2005). In addition to the number of affected lymph nodes, the obstruction or impairment of lymph drainage also plays a part in the survival

jigsaw. For example, the study conducted by Kett, Szilagyi, Anga, Kett and Kiralyfalvi (2002) looked at the association between lymph node drainage and long term survival and not merely the number of lymph nodes involved. They followed 25 women of varying ages who had, at diagnosis, metastatic spread and obstructed lymph drainage. They found that 18 (72%) of these women died within the 10 year follow up period. They concluded that if axillary drainage was obstructed, then the chance of long term survival was poor (Kett et al. 2002).

In some advanced cancers, a protein called ‘osteopontin’ circulates in the blood and within the fabric of the cancer itself. Its levels can be measured at the diagnosis of metastatic disease. High levels of this protein have been associated with a shorter survival period in young women with advanced breast cancer. Knowing which of the women have this poor prognostic indicator at diagnosis helps to tailor ongoing treatment (Bramwell et al. 2006). And knowing that she has an even shorter lifespan (a median of nine months), a young woman may choose to forgo aggressive treatments in order to enhance the quality of her remaining life.

The size of the breast lump is also considered a prognostic factor. Many young women present late with large cancers (2-5cms), because there is a low index of suspicion that the lump will turn out to be cancer (amongst the medical profession and in the women themselves) (Miller, W, Ellis & Sainsbury 2000). Larger cancers at diagnosis are associated with a greater risk of recurrence (Gilewski & Norton 2000). However, young women with small cancers (10mm and smaller) are not safe either. Some small cancers in the breast can turn out to be even more deadly than larger ones (Tabar et al. 2000).

More recently, the recognition of a certain gene expression has shown promise in determining a young woman’s prognosis (Hayes 2005). The presence of this gene ‘signature’ can single out with a fair degree of accuracy those young women with a favourable prognosis from those without (Van de Vijver et al. 2002).

## **b. Prognosis**

Young women living with advanced breast cancer usually seek information on prognosis; indeed, they often want all the information that they can get (Cassileth et al. 1980). They need this information in order to make significant decisions about treatment, to plan or prevent a pregnancy or to plan for future life events around important milestones. The ability to predict accurately how long a person might live is difficult, even with the assistance of prognostic scales and indices. In several studies, predictions have been found to be notoriously wrong (Christakis 1999; Higginson & Costantini 2002; Lamont & Christakis 2001). Many oncologists and palliative care physicians are reluctant to provide prognoses at all because they know that the estimates are unreliable (Higginson & Costantini 2002). However, in order to make prognoses more accurate, the scientific and medical community has invented prognostic indices. The most common of these indices is the Nottingham Prognosis Index (NPI) (Guerra et al. 2003). The NPI is calculated using an equation involving tumour size, histological grade, and lymph node involvement (Miller, W, Ellis & Sainsbury 2000). A high score indicates a poor prognosis. However, these indices reflect the survival potential of groups and not of individuals.

Nikolas Christakis is a physician who studied the relationship between prognostication and death. According to Christakis, in the past there was a relationship between prognosis and available treatment (1999). When there was curative treatment available, doctors focused on this and seldom discussed prognosis with patients. However, in the case of incurable diseases, prognosis became the focal point of clinical conversations (Christakis 1999, p. xx). In the case of advanced breast cancer, prognosis becomes important for all the reasons mentioned above. Advanced breast cancer is an incurable and chronic illness and yet many of the articles reviewed focused on clinical trials evaluating the effectiveness of various treatment regimes (Jonat et al. 2002; Klijn et al. 2001; Pritchard et al. 2006; Veronesi et al. 2006) and did not address prognosis. Christakis suggests that prognostication tends to be neglected for three reasons. Firstly, doctors are often inaccurate in their predictions. Secondly, doctors often err on the side of optimistic predictions, especially if the woman is young and well known to them. Calculating prognoses using indices is one thing, but sitting in front of a young woman and saying that she has a poor prognosis is another. Thirdly, doctors are often not trained for conversations involving the communication of bad news and find the

discussion of percentages and probabilities difficult because of the fear that the stark numbers may harm a woman and her family and they may even become a self-fulfilling prophecy (Christakis 1999). Prognostic indices are one way of coping with the uncertainty in the future course of events. The use of prognostic indices is also a way of controlling death - by managing and predicting it.

It is therefore not surprising that the technological forces arrayed to treat serious illness, in an effort to control death by postponing it, have in recent years come to be focused on controlling death by managing and predicting it. The development finds expression in ... recent efforts to develop prognostic models of considerable sophistication, models themselves requiring technologies such as computers, statistical algorithms ... (Christakis 1999, p. 27)

Therefore, it appears that prognostic indices may be social constructions that assist in the management of uncertainty.

### **c. Accuracy of staging breast cancer: a determinant of survival**

Another way of predicting long-term survival has been the development of more sophisticated diagnostic and imaging techniques. For example, sentinel node biopsies are now much more common than they were in the past (Samphao et al. 2008). Prior to the development of this technique, axillary dissection was the gold standard for assessing lymph node status; however this procedure was and is associated with significant morbidity such as arm pain and lymphoedema (Samphao et al. 2008). A sentinel node is a lymph node that lies closest to the area in the breast that contains the cancer. In this technique, only the lymph node that drains the cancer-involved area is investigated for metastatic cells. The sentinel node is isolated by injecting dye into the lymph system. If this node is clear, further axillary node removal is avoided, thus significantly decreasing lymphoedema-associated morbidity (Golshan, Martin & Dowlatshahi 2003). Research into the accuracy and efficiency of differing histology techniques has been undertaken in order to contribute to an individual's prognostic picture (Johnston et al. 2006; Kollias et al. 1997). However, the assumption that if the sentinel node is clear of cancer cells then it has not spread beyond the breast has come into question in recent years (Di Nubila et al. 2006). There is no single lymph node from which all other channels branch, but rather a group of nodes (Rovere & Benson 2006). Therefore, sampling only a single node is bound to give rise to false negative

results from time to time. In addition, sentinel node biopsies are only suitable for women with early and operable breast cancer (National Breast and Ovarian Cancer Centre 2008c)<sup>3</sup>. The recommendations also exclude pregnant or breast-feeding women (p.3).

#### **d. Survival**

At diagnosis, it is the pathologist's job to stage breast cancer and, with this information, the treating doctor predicts survival in terms of probabilities. Therefore, the visible signs of breast cancer at its cellular level assign the 'truth' of the disease, (Stacey 1997, p. 55). However, survival in breast cancer is not a simple matter. Terms such as overall survival, disease-free survival, relapse-free survival and distant-disease-free survival are all common within research reports and they complicate the picture as they all mean slightly different things. For example, overall survival is calculated from the date of initial treatment until death occurs. This death can be from any cause, not necessarily breast cancer. Disease-free survival is the time that has elapsed from the initial treatment to disease recurrence or death (Heinman & Hellman 2000). Consequently, care needs to be taken when translating results from research reports into lay language.

The biomedical definition of breast cancer survival is generally couched in terms of the number of women who are still alive at the five-year mark, though not necessarily disease free (Hudis et al. 2007). Statistics and probabilities represent a medical view of survival in which cure is equated with length of survival. Survival and non-cure are treated as mutually exclusive terms and separate those women for whom cure is possible from those who will never hear the term 'you're cured'. Therefore, the five-year mark is significant. However, this period is arbitrary as cancer can and does return 20 or even 30 years later.

The dominant metaphor of survival within the reviewed studies has been 'survival as time' (Breaden 1997). This view has its origins in Western thought that considers time as being linear, travelling in one direction only, from point A in the past to point B in the future. Watching the months and years pass by is one of the objective parameters

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<sup>3</sup> In February 2008, the National Breast Cancer Centre was renamed as the National Breast and Ovarian Cancer Centre.

used by the medical community and the women themselves to indicate the risk and rate of cancer's spread. Nevertheless, as Hassey Dow states, 'within the context of surviving illness, where understanding is the priority, disease survival is just one indicator' (1990, p. 511). Understanding advanced breast cancer in young women in terms of statistics and probabilities is one aspect of survival, but understanding the illness experience from the young women's perspective offers another. This understanding of the illness experience is seen in some qualitative studies, (refer to Pelusi 1997), some of which will be discussed later. On a final note, like Klawiter, I do not believe that there is a universal category of a *breast cancer survivor* (2000, p. 75).

### **e. Treatments**

Breast cancer treatment can be traced back through four separate historical periods (Bowcock 1999, pp. v-vi). First, there was the incurable phase that lasted up until the end of the 19<sup>th</sup> century. Women who had breast cancer during this time died with untreated disease, often hiding its presence from all around them. Large fungating cancers were common. The second treatment period occurred half way through the 20<sup>th</sup> century and was influenced by a new surgical procedure invented by a surgeon William Halstead. The radical mastectomy did save some lives, but left women with terrible disfigurements and ongoing shame. The third period began in the early 1970's and was heralded by the addition of chemotherapy and radiotherapy to surgery. This combination of treatment modalities certainly improved the rates of both morbidity and mortality in women with this disease. According to Anne Bowcock, we are now in the fourth phase of breast cancer treatment with the introduction of more targeted therapies and improvement in our knowledge of the genetic basis of breast cancer (1999, p. v). Today, preventive medical options are also available for those deemed at high risk of developing breast cancer, including prophylactic mastectomy and tamoxifen-like drugs (Petersen, J 2004).

#### **1. Surgery**

Surgery has come a long way since the early days of the disfiguring radical Halstead mastectomy. Breast conserving surgery and breast reconstruction following a modified mastectomy are now much more common, especially in younger women. In spite of this surgical evolution, young women continue to have a three times higher local

recurrence rate than do older women with breast cancer (van Nes & van de Velde 2006). There is some evidence to suggest that breast conserving surgery, offered to many young women, is not the best treatment option, as the cancer tends to reoccur in the remodelled breast tissue (Zhou, Gautam & Recht 2007). However, this finding has not been supported by other research studies. For example, Coulombe, Speers, Paltiel and colleagues (2007) compared a mastectomy to breast conserving surgery in women under the age of 49. The follow up period spanned nine years and all the women recruited had early stage breast cancer; 1597 young women received breast-conserving surgery while a further 801 had a modified mastectomy. The younger women (20-39 years) who were treated by breast conserving surgery did nearly as well as those who had had a mastectomy. The researchers concluded that being young was not in itself a contraindication to having breast-conserving surgery.

While surgery is the mainstay of breast cancer treatment, it is not without its concerns. There is a suspicion amongst some that the actual act of cutting breast tissue during surgery in younger women may induce angiogenesis (Retsky, Demicheli & Hrushesky 2005). Angiogenesis is the formation of new blood vessels and is a prerequisite for breast cancer to spread and accelerate. This finding is yet another concern for a young woman undergoing surgery. However, for women whose cancer has already spread beyond the breast, surgery is not usually recommended, for the cancer is considered incurable and therefore surgery unnecessary. Many young women who have had surgery for breast cancer often find the experience traumatic and tend to resist talking about the absent breast (Manderson & Stirling 2007). Yet, this aspect (the devastation and the trauma) is missing from the above studies.

## **2. Adjuvant treatments**

For many years, the mainstay of treatment for breast cancer, apart from surgery, has been chemotherapy and hormone therapy. Lately however, antibody therapy, specifically the drug 'trastuzumab' (Herceptin), has been added to the treatment armamentarium (Gilewski & Norton 2000). This drug is a monoclonal antibody and assists in controlling advanced breast cancer in those women whose cancer cells over-express a human epidermal growth factor receptor 2 (HER2). About 25% of women with breast cancer have this growth factor over-expression and these women are at

greater risk of recurrence and metastasis, and have a reduced overall survival (Kondro 2005). A recent trial of women receiving both chemotherapy and trastuzumab found a significant improvement in overall survival amongst these women when compared with those receiving chemotherapy alone (Slamon et al. 2001).

Adjuvant chemotherapy is chemotherapy that is commonly given some time after breast cancer surgery. The rationale for its use is that even though a young woman may not have evidence of spread at diagnosis, she may have undetected micro metastases already present in her body (Gilewski & Norton 2000). Adjuvant chemotherapy is aimed at these hidden cells. Kroman, Jensen, Wohlfahrt and Mouridsen (2000) conducted a large population based study using retrospective data of ten thousand women less than 50 years of age with breast cancer. They found that there was a survival benefit in the young women who received adjuvant chemotherapy during the ten-year follow up period. In this study, it also appeared as though the risk of dying increased with decreasing age. Adjuvant chemotherapy is therefore recommended to all young women diagnosed with breast cancer (Aebi et al. 2000). The addition of tamoxifen after adjuvant chemotherapy has also been shown to increase survival in younger women, but only if their cancers were oestrogen positive (Aebi 2005; International Breast Cancer Study Group 2006). Furthermore, a survival advantage has also been observed in young women with early breast cancer who have an oophorectomy and are given tamoxifen (Love et al. 2008). Removing the oestrogen-promoting factors from the body appears beneficial.

New developments such as the synthetic retinoid fenretinide have been shown to reduce the risk of breast cancer spreading to other areas of the body by 50% in young women, especially those women under the age of 40 (Veronesi et al. 2006). This observed effect lasted for several years after stopping the drug. A new chemotherapy agent – epothilones – is currently being trialled in women with advanced breast cancer who have become resistant to other chemotherapies (Pronzato 2008). Ongoing trials are continuing in this area. In addition, newer regimes of endocrine therapy have been trialled in the setting of advanced breast cancer in premenopausal women. Endocrine therapies (including tamoxifen and goserelin) aim to suppress ovarian function, thereby limiting the role of oestrogen in the promotion of cancer (Pritchard 2005). The current recommendations, based on a meta-analysis of four randomised trials, are that young

women with oestrogen and progesterone positive advanced breast cancers receive a luteinising hormone-releasing hormone agonist as well as tamoxifen. Taking such a combination of drugs appears to improve their overall survival, progression-free survival and reduces the incidence of hot flushes (Klijn et al. 2001). There is however conflicting evidence concerning a young woman's quality of life during such treatments (National Breast and Ovarian Cancer Centre 2008b, p. 7).

All the various treatments mentioned above (surgery, adjuvant therapies and newer treatments) assume that once she has completed her therapy, the young woman will immerse herself in life again, picking up the pieces and moving on. Yet as Lethborg and Kissane (2003) suggest, the lived experience of breast cancer does not end with the last day of a treatment protocol or blood test; the legacy lives on, disrupting a woman's life in ways that are often unforeseeable.

### **3. Complementary and alternative therapies**

The term *complementary therapies* refer to those therapies that are used to support conventional treatments. These therapies, such as meditation and massage, are not aimed at cure but may help to lessen the symptom burden or improve a person's sense of well being. *Alternative therapies* generally refer to those therapies that are used with the hope of cure and are sometimes used in place of conventional treatments (Ernst, Schmidt & Baum 2006). In this review, I am using the term *complementary and alternative treatments* (CATs) to refer to those therapies that lie outside conventional treatment pathways (Jacobson, Workman & Kronenberg 2000). The therapies include acupuncture, herbal and dietary supplements, psychological therapies and spiritual practices. Whilst some of the treatments mentioned here could be considered experimental, they are all classified as either 'conventional' or 'proven' remedies within the field of breast cancer care.

Not all women who undergo conventional breast cancer treatment eschew other ways of healing. Indeed, the use of complementary or unproven treatments is considerable, especially amongst younger women living with advancing disease - 84% within a few months of diagnosis (Adler & Fosket 1999; Sollner et al. 2000). Their use often parallels conventional treatments or are brought into play once conventional treatments

have failed. The treating doctor often has no idea that these other therapies have been used. In one Australian survey, 57% of CAT users admitted to withholding this fact from their treating doctor (MacLennan, Wilson & Taylor 2002). This omission can mean that significant drug reactions can occur between the alternative therapy and chemotherapy (Adler & Fosket 1999). A large survey of alternative therapy use amongst USA women with early breast cancer revealed that dietary therapies, spiritual healing and herbal remedies were the most commonly reported alternative therapies used (Lee, M et al. 2000). In contrast, an earlier Australian survey amongst cancer patients in general found relaxation/meditation, diet therapy and megavitamins were the most common CATs used (Begbie, Kerestes & Bell 1996).

Young age is only one factor that influences the use of CATs, especially in the setting of advanced breast cancer (Gross, Liu & Bauer-Wu 2007). Other factors include a higher socioeconomic status and the desire for control (Verhoef et al. 2005; Verhoef & White 2002). In addition, a further factor identified in the literature as influencing the use of CATs is having a close relative or friend who has undergone conventional treatment die of cancer (Verhoef & White 2002). Witnessing another's decline and death may influence a person's decision to opt for non-conventional treatments. Furthermore, debilitating side effects can also steer people towards alternative approaches, as does poor communication between the woman and her treating physician (Verhoef & White 2002). Another factor that influences choice is ethnicity. For example, black women in the USA have been found to use spiritual healing more often than do white women (Lee, M et al. 2000).

While some studies have suggested that the use of alternative approaches is a signal of distress (Burstein et al. 1999; DiGianni, Garber & Winer 2002), others have shown that their use is an active coping strategy on the part of the person with cancer (Bishop, Yardley & Lewith 2007; Sollner et al. 2000). While the study by Sollner et al. (2000) was conducted on cancer patients in general, and not young women in particular, the findings do suggest that the use of other approaches to healing can be one way of counteracting passiveness in the face of conventional treatments and can assist the individual to cope with feelings of hopelessness.

While evidence from available research suggests that the use of CATs does assist in reducing the significant side effects that many women experience during chemotherapy (Mok et al. 2007), the benefits of CATs in the management of breast cancer remains controversial. While treatments such as melatonin have been shown to be helpful in the treatment of advanced cancer (Lissoni & Lissoni 2002), many studies reviewed lacked adequate sample sizes (Jacobson, Workman & Kronenberg 2000) or did not focus directly on young women with breast cancer. Furthermore, studies in this area lack randomised controlled trials and what counts as a complementary or alternative therapy in one culture may be different in another; ‘the boundaries between conventional medicine and [CATs] vary across time and space’ (Elliot, Kealey & Olver 2008, p. 59).

From a sociological point of view, the increasing popularity of CAT’s may be explained by the increasing authority of CAT therapists within the health care sector and a decline in medical dominance (Coulter & Willis 2004). Consumers, in an attempt to gain control over health and illness, are embracing other ways of healing. In an attempt to stem the popularity of CAT’s, medical disapproval of their use has been replaced with concerns about the safety of these products and their potential harmful effect on consumers (Myers & Cheras 2004).

#### **d. What predicts long-term survival?**

Thus far, I have explored a number of prognostic indicators in the cancers of young women. These factors, such as tumour size or the presence of lymph nodes, relate to the cancer itself and are established at diagnosis. However, certain behaviours that a young woman adopts may also prolong survival. For example, Abrahamson, Gammon, Lund, Britton et al. (2006) found that in young women there was an association between the level of activity prior to diagnosis and the length of survival. They concluded that participation in physical activity may confer a protective factor against a cancer’s recurrence, particularly if the young woman was overweight or obese to start with (Abrahamson et al. 2006).

Obesity has long been associated with the development of several cancers such as breast, colon, endometrium, oesophagus, prostate and kidney cancers (Bianchini, Kaaks

& Vainio 2002). The mechanism for this association remains unclear, but it may be because many obese people have other comorbid conditions such as high blood pressure and/or cholesterol (Dignam & Mamounas 2004). It is these 'other' conditions that lead to an earlier death, not the cancer itself. Greater increases in weight after breast cancer treatment have been noted in younger women (Duffy, Allen & Clark 2005). The study by Berclaz, Li, Price et al. (2004) explored the relationship between body mass index (BMI) and survival in women with breast cancer. A large cohort (n=6792) of women diagnosed with breast cancer were divided into three categories based on their BMI. A woman was considered as being of normal weight if she had a BMI between 18.5 and 24.9; she was overweight if her BMI was between 25 and 29.9 and obese if the BMI was over 30. These researchers found that women with a normal BMI had significantly longer overall survival than women who were overweight or obese. They concluded that BMI was an independent prognostic factor for overall survival in women with breast cancer, *especially* amongst younger women (Berclaz et al. 2004). These findings are supported by other studies conducted on body weight and survival in women less than 45 years of age (Chlebowski, Aiello & McTernan 2002; Daling et al. 2001; Holmberg et al. 1994). Obesity is a modifiable risk factor and ostensibly within the woman's control; so too is physical activity. However, this view makes it easy for society to blame the woman herself when she fails to live beyond the five year mark and ignores the wider social factors that may be contributing to weight gain and poorer survival.

However, not all predictors of overall survival are within a young woman's control. There are other factors taking place at a cellular level that impact on how long a young woman might live. For example, the response to treatment can also predict survival. In the context of advanced breast cancer, women who have a complete response to an anthracycline type of chemotherapy live for longer than those women who show little or no response to the treatment. The length of survival is still short however. One study that explored this response to treatment found that in the case of those women who had a complete response to treatment, the median survival time was 43 months. For those women who did not respond, their median survival time was only five months (Pierga et al. 2001). Another predictor of survival, again not under a woman's control, is the number of circulating cancer cells in her blood stream. One study found that the overall

survival in women with breast cancer depends a great deal of the number of circulating cancer cells within the blood. Women with more than five cancer cells in their blood stream survived just over 8 months, compared with 18 months in the women with fewer than five circulating cells (Cristofanilli et al. 2004).

In the setting of advanced breast cancer, an additional predictor of survival is the presence of oestrogen and progesterone receptors within the cancer cells. Oestrogen and progesterone are steroid hormones that have been shown to alter the pathology of breast tissue (Dickson, Pestell & Lippman 2005). Women who have oestrogen negative receptors do not live as long as those women with these receptors (Lower et al. 2005). Young women are more likely to have oestrogen negative cancers at diagnosis (Aebi et al. 2000).

#### **e. Fertility, Pregnancy and Sexuality**

The experience of being diagnosed and living with breast cancer and its treatments is similar for both older and younger women. However, concerns relating to infertility, pregnancy and sexuality appear to be specific to the younger age group (Connell, S., Patterson & Newman 2006). Many young women, because of the aggressive treatment of their breast cancers, are prematurely placed in menopause and this is sometimes an irreversible state. These women suffer from distressing symptoms such as mood swings, hot flushes and painful intercourse. One internet-based survey involving women less than 40 years of age found that the presence of these symptoms interfered significantly with the women's quality of life (Leining et al. 2006). Another survey of 204 women under the age of 50 considered premature menopause and issues around pregnancy to be the areas of greatest concern (Avis, Crawford & Manuel 2004). In the general population of women, menopausal symptoms – signs of ovarian function failing - are often countered with hormone replacement therapy (HRT). However, HRT is contraindicated in breast cancer survivors as it may actually promote the growth and recurrence in oestrogen positive breast cancers (Collaborative Group on Hormonal Factors in Breast Cancer 1997).

Currently in Australia, most young women diagnosed with breast cancer will receive adjuvant chemotherapy (National Breast Cancer Centre 2004). This treatment has both long term and short-term effects. In the short term, ovarian suppression occurs, and half

of the women under the age of 40 will experience the cessation of menstruation and therefore become infertile (Leining et al. 2006; Walshe, Denduluri & Swain 2006). Indeed, it may be prognostically better for some women with axillary node involvement if menstruation does cease (Leining et al. 2006; Pagani et al. 1998; Walshe, Denduluri & Swain 2006). However in the long term, with the loss of oestrogen, osteoporosis and cardiovascular disease are likely consequences (Shapiro, Manola & Leboff 2001). Both the short and the long term consequences have a significant impact on the lives of younger women (Gantz et al. 2003). Many young women diagnosed with breast cancer may not receive counselling from the oncology team concerning the impact that chemotherapy will have on their ability to reproduce. A study conducted by Duffy, Allen and Clark (2005) showed that this aspect was missing from the majority of discussions concerning treatment options for younger women. These researchers found that only 34% of the 657 women they interviewed had discussions with their doctors regarding fertility (Duffy, Allen & Clark 2005). Young women want this information and often rate it as being more significant than information on premature menopause (Thewes 2005).

As mentioned previously, infertility is a likely consequence of breast cancer treatment and appears to be a major issue for some young women (Dunn & Steginga 2000; Siegel, Gluhoski & Gorey 1999). However, egg retrieval and cryopreservation prior to treatment are possibilities for only selected women (Madrigano, Westphal & Wapnir 2007). This is expensive technology and not available to all young women at the commencement of treatment. While the harvesting of eggs remains a possibility, concerns about the loss of fertility is present for most young women at the commencement of their breast cancer journey (Partridge et al. 2004).

Some breast cancers (3% of all breast cancers) in young women are discovered during pregnancy (Gemignani, Petrek & Borgen 1999). These women often present with poor prognostic indicators and have a poor prognosis (Ring 2007). Pregnancy-related breast cancer places the women concerned in a position where difficult decisions must be made and emotional distress is common (Dow 2000). When breast cancer is diagnosed in the last three months of pregnancy, it is thought safe by some treating oncologists to wait until the baby is born before starting treatment; the delay is not thought to be detrimental to the mother's long term survival (Naughton & Ellis 2007). However, if a

woman is diagnosed within the first 3 months of her pregnancy, a delay in treatment may shorten her survival as the cancer is often aggressive and fast growing (Middleton et al. 2003). She then faces a difficult decision involving her baby's life. Surgery and chemotherapy may be an option once she has moved beyond this vulnerable 3-month period (Naughton & Ellis 2007). More recently, Herceptin has been given to pregnant women with no apparent adverse effects (Waterston & Graham 2006).

One Australian based study interviewed women between the ages of 29-40 years about their concerns regarding fertility, pregnancy and breast-feeding. For the 13 women interviewed, Connell, Patterson and Newman (2006) found that perspectives on fertility changed over time. Initially, a number of the participants considered themselves to be infertile, only to have their periods return after the cessation of treatment. Some women wished that they had had their eggs preserved because even though survival was the focus initially, as life returned to normal concerns about fertility came to the forefront again. These researchers also found that the decision to use a contraceptive pill was one that was fraught. Hormone based contraceptives were often viewed with great suspicion by young women, even though many experts have attested to their safety. An unwanted pregnancy is not just about bringing a child into the world, but the very real possibility that the woman might die and therefore leave this child without a mother. Fears of cancer's recurrence being activated by breast-feeding were also a significant concern for these women.

In spite of the possibility of infertility, for approximately 50% of young women treated for breast cancer, pregnancy is still an option (Mastro, Catzeddu & Venturini 2006). However, retaining ovarian function could have a detrimental effect on survival if their cancer is hormone dependent, i.e. oestrogen positive (Lower et al. 2005). Therefore, during the months and often years of treatment, a pregnancy is deemed inadvisable because of this potential effect. Even after the cessation of treatment, many doctors advise against pregnancy because of the unknown affect of hormonal surges on the possible progression and recurrence of breast cancer (Partridge et al. 2004). However, other researchers have found that pregnancy in women treated for early stage breast cancer does not affect their subsequent survival and is therefore not contraindicated (Dow 2000; Velentgas et al. 1999). These women are usually counselled against becoming pregnant for two years following a diagnosis of breast cancer because, if the

cancer is going to recur, it will be most likely during this time frame (Isaacs 1995). Young women who are diagnosed with metastatic disease are advised not to fall pregnant at all. If they do, the chance of these women living beyond 5 years is between 0-15 percent (Averette, Mirhashemi & Moffat 1999). This is not a chance that many women are prepared to take.

After breast cancer treatment, many women face issues regarding sexuality and body image. Surgery leaves disfiguring scars and chemotherapy often results in hair loss and early menopause, vaginal dryness and mood swings. Younger women especially find these changes disturbing as they are often accompanied by a loss in bodily confidence, dissatisfaction with their appearance and the ability to feel sexually attractive. These difficulties have been noted to be more common in young women than older women (Fobair et al. 2006). In addition, Pikler and Winterowd (2003) found that the women who had a robust image of themselves and their bodies tended to be more confident in dealing with breast cancer. Consequently, how a woman feels about herself can make a difference in how she experiences survival.

However, many of the studies in the area of sexuality and fertility narrowly assume that sexual satisfaction and reproductive capacity can be measured by asking about frequency of sexual intercourse or about concerns regarding pregnancy. Such studies, like that of Fobair and her colleagues (Fobair et al. 2006), are quantitative in nature and focus on a women's ability to have sexual intercourse, equalling this with sexuality. Research from within the qualitative domain proposes that while the ability to have sexual intercourse is important to young women, it is not the most important thing on her horizon (Wilmoth & Ross 1997). Losses such as the loss of womanhood, self-esteem and body image appear to be of greater concern (Burnard 1995).

#### **f. The problem lies in the genes**

A genetic predisposition to cancers such as breast and ovarian cancer has been noted in younger women (McPherson, Steel & Dixon 2000). Young women diagnosed with breast cancer are more likely to have this predisposition than are other women with breast cancer (Eccles et al. 2007). Several studies have examined the link between genetic damage and the risk of breast cancer. It has long been hypothesised that young

women have a greater propensity for DNA mutations such as BRCA1 and BRCA2 and hence first degree relatives of these women are also at a greater risk of developing breast cancer (Cefle et al. 2006). There is also some evidence to suggest that it is an abnormality within chromosome 8 that is associated with the development of advanced breast cancer in young women (Weber-Mangal et al. 2003). Therefore, the presence of certain genetic alterations may predict decreased survival for young women (Weber-Mangal et al. 2003). As mentioned earlier, this prediction can assist in tailoring treatment options. However, in spite of narrowing down the specific part of chromosome 8 that may be implicated in the development of advanced breast cancer, scientists have isolated at least 70 other genes that have been associated with the risk of early cancer spread in young women with node-negative disease. A profile of these genes can predict which women will develop metastases in the five years after diagnosis (Van de Vijver et al. 2002) and may assist in decision-making around treatment options in the future.

**g. Palliative care's involvement in the care of young women diagnosed with (advanced) breast cancer.**

Due to the limited survival of many young women diagnosed with breast cancer, one would assume that the young women would feature in the research around symptom management at the end of life: but this appears not to be the case. The surveyed research articles that focused on young women diagnosed with advanced breast cancer rarely mentioned palliative care. It appears as though few young women have access to this specialised service as death approaches. This last statement is supported by a Canadian study conducted by Gagnon, Mayo, Hanley and MacDonald (2004). These researchers used a large database to create a score profile that related to care provision during the last 6 months of life for 2291 women dying of breast cancer. They found that younger women (<50 years) were less likely to receive palliative care than older women during this phase in their disease trajectory (Gagnon et al. 2004). This finding contradicts that of a systematic review conducted in the UK in which older people were the group found to be less likely to receive specialist palliative services (Burt & Raine 2006). This finding was also supported by a recent study conducted in Western Australia between 2000 and 2002. The researchers found that in relation to age, it was the people with cancer who were over the age of 80 who were less likely to access specialised palliative care services (Rosenwax & McNamara 2006). It was the younger

people with cancer (between 25 and 44 years of age) who were more likely to access specialised palliative care than this older age group (73% compared to 51%) (Rosenwax & McNamara 2006, p. 443). This study did not contain information on individual cancer diagnoses and therefore inferences cannot be made about young women's access to palliative care (Rosenwax & McNamara 2006). However, a population-based study conducted in South Australia in 1999 found that women who were diagnosed with breast cancer were among those who were less likely to receive palliative care (Hunt et al. 2002). Therefore, from an examination of the studies on service provision, there does appear to be some variation concerning who accesses palliative care and who does not, depending on the region in which one lives.

This lack of reference within the research literature to palliative care is not always the fault of the health care sector. Sometimes the women themselves refuse access to this service as it can be seen as 'giving up'. However, from the available evidence, women with metastatic disease do become severely distressed as death approaches (Fulton 1997; National Breast Cancer Centre 2004) and therefore would perhaps benefit from the support of a multidisciplinary palliative care team during this time. Consequently, the National Breast and Ovarian Cancer Centre (NBOCC)<sup>4</sup> has recently published some guidelines for multidisciplinary teams involved in caring for people with advanced disease (National Breast and Ovarian Cancer Centre 2008a).

### ***3. Summary of the physical nature of advanced breast cancer in young women***

To sum up thus far, the research on breast cancer in young women shows that it is a highly lethal disease, containing several adverse prognostic indicators. Prognosis is limited for these women and conveying such dire news is frequently difficult for doctors. The calculation of prognoses has become quite sophisticated and can be seen as an attempt by medicine to tame or control the uncertainty of future events - death especially. The staging of breast cancer has also become quite sophisticated. Sentinel node biopsies are now common. Pathologists have become pivotal in this staging process for the microscopic appearance of breast cancer is of vital importance in the recommendation of certain treatment regimes. The calculation of survival is also quite complex and like prognosis, involves statistics and probabilities. These calculations

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<sup>4</sup> In February 2008, the National Breast Cancer Centre changed its name to National Breast and Ovarian Cancer Centre.

equate survival with a length of time and ignore the possibility that cancer can and does recur many years later. In relation to treatments, the research literature is extensive. Surgery and chemotherapy remain the focus of treatment; however, newer endocrine therapies have begun to make a difference to the longevity and quality of life for younger women. Treatments however are not without their side effects and infertility is common sequelae after some therapies. Issues of pregnancy and sexuality are also of great concern to younger women. Complementary and alternative therapies have become more popular in the healthcare arena, especially amongst younger women. Some additional factors within a woman's control such as body weight and exercise have the potential to make a difference to her overall survival. There have also been great advances in the area of genetic research with the discovery of abnormalities within individual chromosomes that are common within the population of young women with advanced breast cancer. Finally, even though breast cancer is often a highly lethal disease in younger women, palliative care's involvement in their lives is by no means universal.

### **a. Limitations**

The scientific and medical community have largely controlled and directed the majority of research and writing in the area of advanced breast cancer in young women. This research is based upon rationality, prediction and control - central tenets of logical positivism<sup>5</sup>. Research anchored in this tradition relies on facts and hypotheses, the outcome of which is objectively verifiable knowledge. Speculations, assumptions or other subjective sources of knowledge have no place in this model (Crotty 1998). In addition, within this tradition, a human being is seen as being in charge of his or her own destiny (Audi 1999). This type of research has been extremely valuable in exploring more effective and efficient treatment protocols and delving into the biological and genetic bases of the disease. However, it also has its less positive side. It is afforded a great deal of status in the area of cancer care, and is used by powerful groups and institutions within the community such as medicine and the media to dictate what can be said and by whom about the nature of advanced breast cancer in young women. In addition, this type of research does not reflect the individual experiences of

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<sup>5</sup> Logical positivism is the belief that the only things that exist and are real, are those things that can be verified by our senses (Crotty 1998).

the young women, nor does it tap into social, cultural and psychological aspects of living with advanced disease at the beginning of the 21<sup>st</sup> century. I will return to this point shortly.

### **b. Expert knowledge**

Medicine relies on its expert knowledge, conveyed through its professional research journals, to keep its authority in the domain of cancer care and the material contained within these journals enjoys a particular status. These journals, like the ones reviewed, use particular styles and conventions of language that distinguishes them from other publications such as magazines and newspapers. According to Tonkiss (2004, p. 375), expert knowledge does three things. Firstly, it outlines what counts as knowledge within the field and in this case, the field is cancer care. *Advanced breast cancer* is clearly a medical term. Experts use scientific language to describe this disease such as, *highly undifferentiated cells, poor prognostic indices, and extensive lymphatic invasion*. These same experts exclude knowledge proposed by alternative practitioners who also treat this disease. Therefore, expert knowledge excludes other ways of knowing. Secondly, expert knowledge dictates who can belong to a particular group. Group members tend to use the same language to communicate with each other and this language use is often unconscious and automatic. Thus, the rules and conventions concerning language use that are adopted by the medical community are both internalised and externalised, thereby allowing its members to operate competently within their professional field. Hence, doctors are socialised into the medical profession and are regulated by practices such as peer reviews and publication protocols. Thirdly, expert knowledge authorises who can speak on a given subject and who cannot; it therefore exerts disciplinary power (Foucault 1995). Consequently, the medical profession can easily dismiss competing views, like those held by complementary and alternative practitioners.

The philosophy of objectivism underpins quantitative research. Objectivism is the belief that objects which we see and touch have meanings that are independent of our thinking about them or of our experience of them (Crotty 1998). Meaning lives inside these objects and in order to access this meaning, careful scientific studies are required. For example, breast cancer is presented as an object for study. From an objectivist's point of view, its meaning already existed before scientists discovered it. When they

did discover it, they were only discovering ‘a meaning that has been lying there in wait for them all along’ (Crotty 1998, p. 8).

There are several assumptions underpinning the philosophy of objectivism and objectivist research. One assumption is that in research, a causal link exists between independent and dependant variables (Grbich 1999). For example, advanced breast cancer in young women is an independent variable and pessimism or faulty genetic materials are dependent variables. In research, a causal link has been found between these two variables and in some cases, a calculated average of the sample has been taken to represent the population at large.

#### ***4. Psychological and individual aspects of advanced breast cancer in young women.***

Due to its increasing incidence, researchers have extensively studied breast cancer and its psychological impact (Payne, Sullivan & Massie 1996). Yet, rarely has the research focused on the psychological sequelae of advanced breast cancer in younger women. The psychosocial impact of breast cancer sees the young woman constantly juggling competing demands on her time and her life; her future career choices are severely affected. In addition, she often faces decisions concerning having children, or not having children. Understandably, she may become depressed. Several studies outlined below show that younger women have a higher level of emotional distress and have more difficulty in adjusting to the diagnosis of breast cancer than do older women (Dunn & Steginga 2000; Kroenke et al. 2004).

##### **a. Depression**

Depression is not uncommon in women diagnosed with breast cancer, irrespective of age. Logically, because of the life limiting nature of advanced cancer, one would suppose that a young woman would be more depressed knowing she has advanced breast cancer than a woman diagnosed with early breast cancer. However, research such as that conducted by Aragona, Muscatello and Mesiti (1997) and Wong-Kim and Bloom (2005) does not support this assertion. Depression is a multi-faceted phenomenon and is affected by many more things than just disease severity. Wong-Kim and Bloom tested the hypothesis that young women with advanced breast cancer,

with severe treatment related symptoms, with little support from those around them, with low self-esteem, who work outside the home, who have dependent children, and who are either single or divorced/separated, will be more likely to experience depression than women without these numerous factors. They interviewed 331 young women in various stages of breast cancer and used several scales to tap into the physical, psychological and social domains of the experience. Wong-Kim and Bloom (2005) found that the variables that were significantly associated with depression were high pain levels, low self-esteem and low levels of emotional support, not simply the advanced nature of the disease itself.

There have been a number of interventions trialled, which were aimed at assisting young women with breast cancer to reduce their levels of anxiety and to cope better with depression. For example, Rossman used guided imagery to help young women tap into their inner resources in order to cope better with cancer and its treatments (2002), and supportive group therapy has been used with some success in women with advanced breast cancer to express effectively negative emotions without becoming hostile (Giese-Davis et al. 2002). Giese-Davis, Koopman, Butler et al. (2002) discovered that this expression of negative emotion had a survival benefit. However, other studies that have examined the link between supportive-expressive group therapy and survival have found that while women allocated to the group experience reported less pain, their survival was not prolonged (Goodwin et al. 2001; Penson et al. 2004).

Another intervention that has been trialled, this time for women with advanced breast cancer, is that of cognitive therapy. Cognitive therapy is a form of psychotherapy, based on the work of Aaron Beck (Beck 1975). Levesque used cognitive therapy with a group of six women and found that there was a statistically significant improvement in depression at the end of study period (2004). Levesque's study contained a very small sample and therefore has limited usefulness when trying to generalise these findings to other women. While this next study also contains a small sample size, it describes an intervention aimed at younger women. Danahauer, Rutherford, Hurt, Gentry, Lovato and McQuellen (2007) offered a support group to 24 young women with breast cancer whose disease stage was unknown. The sessions covered education on symptom related issues, and gave an opportunity for discussion and relaxation exercises. These researchers concluded that there were no changes in the women's quality of life or

emotional distress by the end of the group sessions and these findings raise questions about the usefulness of such support groups in general. However, small numbers were used in both studies mentioned above and therefore have limited usefulness when arriving at recommendations for the value of support groups generally.

The place of psychological support (educational, cognitive [thinking positively], behavioural or group support) remains controversial. An earlier study by Spiegel, Bloom, Kraemer and Gottheil (Spiegel et al. 1989) found that participation in support groups did indeed increase survival. The research community has since disputed these findings, as the results have not been able to be replicated since (see (Goodwin et al. 2001). Furthermore, in Australia, a Cochrane review on the psychological interventions for women with advanced breast cancer found no strong evidence to support the notion that psychological interventions, such as support groups, increased survival (Edwards & Hubert-Williams 2008). However, the report did find that there were psychological benefits of such interventions, at least in the short term (p. 2). Therefore, while support groups might not increase the length of a young woman's survival, such participation seems to confer other benefits. Support groups might help a young woman cope with advancing disease by assisting her to think positively about her situation. Thinking positively and talking positively have been linked with emotional well being (Laccetti 2007). Wilkinson and Kitzinger (2000) found in their interviews with women with breast cancer that the command to think positively was common in the women's talk. However, there was a sense amongst these women that they should think positively, whether they liked to or not. The command or necessity to think positively can place an additional burden upon young women struggling with a life threatening illness.

### **b. Psychological morbidity**

The term *psychological morbidity* was first used in the psychotherapy literature in 1953 to refer to 'psychoneurotics' (Barron 1953). However, the term did not emerge in the breast cancer research literature until 1986<sup>6</sup> when it was used in a study to explore the psychosocial effects of mastectomy in a population of young women (Alagaratnam & Kung 1986). In the cancer literature, the term *psychological morbidity* refers to the development of anxiety and depression that some women experience in the aftermath of diagnosis and treatment for breast cancer (Bleiker et al. 2000). These symptoms affect a

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<sup>6</sup> In 1984, Greer commented on the considerable psychosocial morbidity after cancer treatments in general, but not specifically breast cancer treatments (Greer, S 1984).

woman's psychological well being. Several studies have found that up to 30% of women diagnosed with breast cancer will experience psychological morbidity during their first year (Bleiker et al. 2000; Maguire 2000). However, after the first year, the distress and fear of recurrence reduces significantly (Vickberg, Suzanne et al. 2000). In relation to advanced breast cancer, 40% of women have been found to experience psychological morbidity (Grabsch, Brenda et al. 2006). Importantly, it is the population of younger women diagnosed with breast cancer that show the greatest fears and emotional distress (Goodwin et al. 2001). Indeed, risk factors for psychological morbidity in breast cancer are; young age, treatment related side effects, and the use of complementary therapies (Bleiker et al. 2000). Therefore, it can perhaps be anticipated that the majority of younger women will experience ongoing fears about the cancer's recurrence and have some degree of psychological morbidity, rendering them vulnerable when faced with a diagnosis of advancing disease.

### **c. Body image**

It might be expected that young women living with a removed or altered breast and a forever-altered body would have disturbances in the way they view their bodies, the assumption being that the mind can perceive an objective body with some degree of precision (Blood 2005, p. 6). There have been studies conducted on the differences between various surgical approaches and their effect on body image (Lee, C & Foster 2005; Moyer 1997). Researchers have developed a scale specifically to measure body image in a population of breast cancer survivors (Hormes et al. 2008). It appears that women have different levels of investment in body image depending on their age (Grogan 2006) - the younger the woman, the greater the investment. In addition, women living with advanced breast cancer appear to be more dissatisfied with their body image compared to those diagnosed with early disease (Kissane et al. 2004).

The loss of hair is a considerable stress for many women, and for some it is the most feared aspect (Batchelor 2001; Frith, Harcourt & Fussell 2007). Losing hair means that many women feel the need to hide this aspect of their illness and treatment, not wanting to be classified as a 'cancer patient' (Harcourt & Frith 2008). Therefore, body image is tied up with self-identity and involves more than just a woman's physical appearance. A longitudinal study conducted by Carver et al. (1998) found that body image involved a feeling of integrity, a sense of wholeness and normal bodily functioning (p. 168).

These researchers concluded that women who were concerned about their body image were at risk of poorer mental health when dealing with breast cancer and its treatment.

While the majority of the studies cited here have been conducted on women with breast cancer in general, they do allude to the fact that the view that a young woman has of her body during the cancer experience makes her particularly vulnerable to psychosocial morbidity.

#### **d. The experience of young women living with advanced breast cancer**

The experience of living with advancing disease is not found in the statistics or percentages mentioned earlier in this chapter. The voices of the young women themselves are notably absent. In response to this omission within the biomedical and psychological realm, several qualitative studies have been conducted into the lived experience of breast cancer. For example, Arman and Rehnsfeldt looked at the phenomenon of suffering amongst women with breast cancer (2003). Thomas-Maclean explored a woman's experience of embodiment (Thomas-MacLean 2004a), and Langellier and Sullivan examined breast talk amongst women with breast cancer (1998). Such studies, though fewer than those conducted from within a quantitative framework, have an important part to play in contributing to breast cancer knowledge in all its complexity. However, these studies were conducted on women of all ages and stages of disease and not specifically on younger women. Therefore, the studies reviewed below are important because they specifically focus on younger women. I will now describe some of these in order to illustrate the breadth of the research in this area.

In the first study, Gould, Grassau, Manthorne, Gray and Fitch examined the information and support needs of young women with breast cancer in Canada (Gould et al. 2006). Using focus groups, they consulted 65 young women diagnosed with breast cancer before the age of 45. They found that the theme of 'nothing fit me' seemed to encompass the majority of the women's experience. For example, pamphlets given to the women explaining breast cancer and its treatments did not focus on the needs of these young women, nor their families. They rarely discussed sexual difficulties, common in younger women following breast cancer treatments. Next, the support groups they were directed to mostly consisted of older women. The young women found little in common with the experiences of these older women. Next, they found

that the provision of services ‘ill-fitting’. For example, childcare facilities or the realisation that young women might have to make arrangements concerning the care of children was lacking. Finally, when the young women presented with a lump to their local practitioners, they were rarely treated with the seriousness that a diagnosis of breast cancer in this age group should attract. Consequently, *nothing fit* the specific needs of young women with breast cancer. One aspect that this study highlighted which was different to other studies reviewed was the finding that there was a considerable financial burden for the young women diagnosed. These women often had to choose between carrying on working through the treatment or taking time off work (Gould et al. 2006, p. 166). Financial hardship was less a feature of the older women’s experience. An Australian study supported this finding. Gordon, Scuffham, Hayes and Newman (2007) attempted to quantify the financial burden on women with breast cancer. These researchers looked at the monetary costs by age and stage of disease and found that most women in their sample suffered some degree of economic loss by 18 months post breast cancer diagnosis. Yet, it was the young women in particular who suffered the greatest financial loss (Gordon, L et al. 2007). Fosket (2000) also found financial distress a common theme amongst the women she interviewed. Therefore, financial losses can be added to the long list of issues that young women with breast cancer often face.

Lymphoedema is a significant complication following breast cancer surgery, lymph node dissection and/or radiotherapy. A perpetually swollen arm can hinder everyday activities and has been shown to reduce a woman’s quality of life (Velanovich & Szymanski 1999; Williams, A, Moffat & Franks 2004; Woods, Tobin & Mortimer 1995). In the past, amputation was not uncommon. Advanced breast cancer at diagnosis is a major factor in the development of lymphoedema (Koczek & Overgaard 2000). A cross-sectional survey conducted in Australia examined the frequency of psychiatric morbidity in a population of women living with advanced cancer. Of the 227 women surveyed, the reported incidence of lymphoedema was 11.5% (Grabsch, B et al. 2006). Other studies have placed the incidence of lymphoedema between 10-35% (Golshan & Smith 2006). While the studies cited above add to our knowledge of breast cancer and the side effects of treatment, not one of them reveals what it is like to live with lymphoedema from the woman’s perspective. Two studies were reviewed that explored this very issue. The first was conducted in Sweden and it explored the

experience of lymphoedema in 12 employed women – their ages were not specified (Johansson et al. 2003). The second study was conducted in the UK and examined the impact of lymphoedema on the lives of 15 women. Again, the age range was not specified (Williams, A, Moffat & Franks 2004). Both studies highlighted the uncertainty that a diagnosis of breast cancer brings, the difficulty in accessing treatment and the reactions of others to their disability. Manual lymphatic drainage appears to help reduce the arm swelling (Harris & Piller 2003; Williams, A et al. 2002), as does the newer technology – low-level laser therapy (Carati et al. 2003).

Many young women diagnosed with early breast cancer go on to develop advanced disease. While the age of the women in this next study was unspecified, it is relevant to this review because it relates to the experience of living with advancing disease, a factor missing from many research reports. The study involved interviews with 10 women living with advanced breast cancer in a hospice in the UK. The researchers found that the women felt fearful as their disease progressed and felt isolated from others around them (Davies, M & Sque 2002). Davies and Sque termed the theory of living with advanced breast cancer as ‘living on the outside looking in’ to help explain the experience (2002). Fear appears to be common amongst young women living with a breast cancer diagnosis (Ohlen & Holm 2006; Siegel, Gluhoski & Gorey 1999; Vickberg, Suzanne 2003).

So far, the studies that I have described were conducted either in the UK or in Canada. Coyne and Borbasi (2006) explored the lived experience of six young women living with breast cancer in Australia. As other researchers have found, the experience of receiving a diagnosis was traumatic. Apart from the great distress of discovering that they had cancer, the young women tried to make sense of why cancer had occurred, especially why they had cancer at such a young age. They also had deep concerns around such issues as being mothers, their families and their ongoing fertility. The women in this study felt that they had to remain well for their family’s sake and this was a heavy burden to carry.

Australia was also the setting for the next study. Dunn and Steginga (2000) interviewed 23 young women with breast cancer. Their definition of *young* did not rely on a chronological distinction, as has been the case for all the studies reviewed thus far.

Rather, they defined a *young woman* as a woman who was of childbearing age, who had young children not yet in high school and who had not yet reached menopause. Dunn and Steginga found that the key concerns of young women were; worry about not seeing their children grow up, thinking that they were too young to get breast cancer, feeling different to other women their age, and the loss of choice concerning having further children. These key concerns complement the findings of similar studies conducted by Connell (2005) and Siegel, Gluhoski and Gory (1999). These latter researchers conducted a thematic analysis of the transcripts of 34 women, aged 36 years and less. The women all had a diagnosis of early breast cancer. The researchers described the dominant stressors in the lives of these young women as being unfairness of diagnosis in terms of missed opportunities, being betrayed by their bodies, guilt at the toll that the disease pulled from partners and families, lost opportunities in relation to childbearing, feeling different from others, and feeling isolated (Siegel, Gluhoski & Gorey 1999). This sense of isolation and being apart from others has also been found in other studies involving women with advanced breast cancer (Davies, M & Sque 2002). The slight differences in the findings between the two studies may be attributed to the different settings or times in which they were conducted. The combination of the findings adds to the picture of concerns and stressors that many young women face.

The studies mentioned above were all conducted in Western countries. However, Lam and Fielding (2003) conducted a phenomenological study and interviewed 17 Chinese women, eight of whom were under the age of 45; and amongst these six had advanced breast cancer. These researchers found that the concerns of Chinese women with breast cancer paralleled those from the West mentioned above (Lam & Fielding 2003).

A young woman diagnosed with cancer often has young children in her care and these children are a continual source of concern and stress. There is a very real possibility that her children will have to grow up without her, a distressing thought for any mother. The lived experience of mothers diagnosed with breast cancer was the focus in a study conducted in Sweden by Ohlen and Holm (2006). They interviewed nine women who were part of a support group programme and found that these women described their experience of having dependent children as a movement away from a state of desolation towards one of consolation. Yet before coming to the point of consolation, these

women struggled with desolating experiences and they interpreted this experience in the following way.

We interpret the desolating experiences as being in exile, which includes concerns and threats for themselves, their children and partners, and others. (Ohlen & Holm 2006, p. 25)

To be exiled was to feel completely alone; however, out of a desolating experience the women found a sense of consolation, which paradoxically became more meaningful in the light of the previous desolating experiences. It is not uncommon for people to say that life becomes more meaningful in the light of some traumatic event (Frank 1995). The women also described the experience of straddling two worlds, one world where they tried to keep everything the same, and the other where they were living with a serious illness necessitating numerous changes. Ohlen and Holm concluded that there was a value in offering support groups targeted at young women with children, a finding that others have also mentioned (Gould et al. 2006).

As already indicated, prognosis tends to be poor for young women diagnosed with breast cancer. Discussions about the chance of long term survival are fraught with misunderstandings and miscommunications (Christakis 1999). The researchers in the next qualitative study interviewed both women (n=17) with advanced breast cancer and their health care professionals (n=13), and asked them questions about the communication of prognosis (Butow et al. 2002). The aim of the study was to find the preferred way of communicating bad news. The identified themes included communicating within a trusting long term relationship, repeated negotiations about patient's preferences for information, and the encouragement of hope (Butow et al. 2002, p. 167). Butow, Dowsett, Hagerty and Tattersall concluded that talking about prognosis in a population of people for whom cure was no longer an option needed considerable sensitivity and resources. Interestingly, unlike the 1999 Christakis study mentioned earlier, they found that patients in this study rarely were asking about how long they might live, but were rather seeking reassurance and hope.

The latter group (patients) argued that when patients request prognostic information they are rarely seeking statistics on life expectancy, but rather reassurance and hope, forewarnings concerning the impact of side effects and symptoms on their lives, and/or guidance regarding practical decisions they may need to make. (Butow et al. 2002, p. 167)

Communicating prognosis is a difficult conversation to have and often not wanted by the young women themselves. These findings are similar to those of other studies conducted on decision making preferences and ways of communicating prognosis in the setting of advanced breast cancer (Grinfeld et al. 2006).

### ***5. Summary and limitations of psychological and individual aspects***

In summary, like the research into the physical aspects of breast cancer and young women, research into the psychological aspects is extensive. In contrast however, studies into the lived experience of the disease have been few. This review into the psychosocial aspects revealed that young women with breast cancer tend to have greater levels of depression, fear and emotional distress. Interventions aimed at assisting young women cope with breast cancer have been moderately successful; however, it is debatable whether participation in psychological support groups extends a women's survival. In addition, young women with breast cancer have been shown to be at great risk of developing psychological morbidity.

In the past, supportive care for young women has not been tailored to their specific needs and these specific needs often revolved around dependent children. In addition, many young women carried a financial burden during the course of their illness. The published research has also suggested that young women tend to suffer from distressing symptoms such as lymphoedema and often feel isolated from those around them. They also have many concerns and stresses relating to their disease. Fear was also a constant companion. Given that breast cancer has a poor prognosis in a population of young women, the preferred conversations around prognosis for these women was one of reassurance and hope.

### **a. Body and mind**

Historically, the body has been given primacy in the field of breast cancer research and research on the mind has been allocated second place. This focus can be seen by the amount of studies that exist into the physical nature of both early and advanced breast cancer in young women. In order to understand this disease, the biomedical model necessitates a mutually exclusive division between mind and body. The separation of mind from body has pervaded Western thought since Descartes in the 17<sup>th</sup> century put forth the notion that there was a separate mind and body and, furthermore, that the mind was not only separate from the body, but from nature as well (Grosz 1994). The body could be then seen as any other object in the natural world and therefore subject to the same physical laws. Because of this separation, the body as a machine metaphor flourished (Hardey 1998, p. 9). This meant that the object body could be subject to experimentation and detailed study (Leder 1984). In relation to the mind however, the separation resulted in a positioning of the mind outside the body (Grosz 1994). This dualistic notion of mind and body has led to a devaluing of bodily intelligence and a separation in research of body and mind. Only one study in the review period focused on women's sense of embodiment during breast cancer, the study conducted by Thomas-MacLean (Thomas-MacLean 2004b). This study is important because it brings together the body and the mind in the experience of illness. One reason for the limited research into the experience of embodiment/disembodiment in breast cancer may be that it is a relatively new concept in the field of research.<sup>7</sup>

### **b. Scales and surveys**

Much of the psychological research into the nature of breast cancer in young women has been conducted via surveys or questionnaires. A problem with this form of research is that the responses do not reveal contradictions or ambivalences on the part of the responders (Burman & Parker 1993, p. 8). Within survey research, contradictory responses are viewed with mistrust as they threaten the integrity of the data and are therefore discarded. However, attitudes are not fixed; they can, and do, change from day to day, moment to moment. In addition, an alteration in the wording of a question can result in different responses (Potter & Wetherell 1987). The value of survey

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<sup>7</sup> Merleau-Ponty, a French philosopher, described his theory of the body and embodiment in his essay titled *The Phenomenology of Perception*, which was translated into English in 1962. (The Fontana Dictionary of Modern Thought, 1988, p. 265).

research into advanced breast cancer in young women is therefore limited as the context in which the disease is lived is absent. Qualitative research, such as that conducted on the lived experience, offers us an insight into this context.

The medical research community, especially in the field of breast cancer research, does not generally hold the use of personal experience in studies in high regard. These stories are seen as lacking in objectivity and rationality. However, from a feminist viewpoint, the foregrounding of personal stories makes them visible to all, thus countering the tendency for the scientific method to silence women, rendering them invisible and hence powerless (Wilkinson 2000a). Locating breast cancer outside the biomedical arena is necessary so that the voices of young women living with advanced disease can be heard.

### **c. Interpretation**

Within a positivist paradigm, women's experiences of living with advanced breast cancer are categorised and transformed into language suitable for publishing in research journals. The women themselves become invisible during this process and their experiences of grappling with a terminal illness are absent. In contrast, the studies conducted within the interpretive paradigm focus on individual accounts. Rather than viewing these subjective experiences as suspect, as an objective researcher might, these experiences become resources upon which researchers can draw (Banister et al. 1994).

However, the stories told by young women living with advanced breast cancer are not identical copies of the lived experience being described, just approximations. When a young woman tells her story, this story is not without its own history or context as these stories are influenced by the existing discourses of this time (Hardin 2003a). The ability to examine the social and cultural context of the story goes beyond many qualitative methods mentioned thus far. Revealing how a particular version of a story came to be told in the first place is the task of discourse analysis. A number of the studies conducted on the media have involved discourse analysis. It is on these that I now focus.

## **6. Research studies conducted on the media**

Scientific knowledge is not only reproduced through textbooks, but is represented to the public primarily through a wide and intertextual range of visual and print media. (Stacey 1997, p. 144)

So writes Jacqueline Stacey in her cultural analysis of 'her' experience' of cancer. The previous section critically examined research that has been conducted on (advanced) breast cancer in young women over the last 10 years. As attested to by the above quotation, the scientific knowledge that informed these research articles also weaves its way through our visual and print media. Contrary to some writers (Corbett & Mori 1999), this information does not travel in one direction only, from medical journals to the media, for lay views on health and illness also inform what, and the way in which, scientific research is conducted (Petersen, A 2001). As Fowler explains,

News is not a natural phenomenon emerging straight from 'reality', but a product. It is produced by an industry, shaped by the bureaucratic and economic structure of that industry, by the relations between the media and other industries and, most importantly, by relations with government and with other political organizations. From a broader perspective, it reflects, and in return shapes, the prevailing values of society in a particular social context. (Fowler 1991, p. 222)

The majority of the lay public does not read research reports in order to obtain information about health and illness, but they do take notice of information that is contained in other more popular forms of print media. This chapter extends the critical review of the literature by examining the research that has been conducted on the mass media and breast cancer during the same ten-year period. The rationale for exploring the 'various organs of the mass media' (Seale 2003, p. 514), magazines, television, newspapers and so on - is that they are important in shaping values and beliefs of the society in which they operate – that is, they have an ideological function (Clarke 2004). In addition, in many countries the mass media is a leading source of information about health issues such as cancer prevention and screening mammography (Grilli 1999; Rees & Bath 2000). Young women diagnosed with breast cancer draw upon this information, sometimes rejecting it, in order to explain their illness to themselves and to those around them. Therefore, this literature review would not be complete without examining research studies conducted on the media. However, before moving onto a review of these studies, I will outline a categorisation scheme that I found useful when reviewing articles in this area.

### **a. Three broad areas of research**

Research studies conducted on breast cancer and the media can be grouped under three types of broad inquiry - production, representation and reception (Keppler 2004, p. 105). Production studies are those that focus on the influence of media and/or government organisations on how the news is produced (p.515). Production studies in the area of breast cancer and the media might involve questions of how breast cancer action groups influence the content of articles such as information on mammography or how government health policy might influence the inclusion of particular content in articles. Production studies are few in the area of breast cancer while representation studies are far more numerous. Representation studies focus on the exploration of the actual media message itself (Seale 2003, p. 515). In the area of breast cancer, such studies include the exploration of linguistic devices such as metaphors used or the dominant discursive constructions within the texts and/or the recurring content or themes. Questions within this area of inquiry could include how are young women with breast cancer constructed within the media, or how are messages about breast cancer incidence at odds with the statistics? The third area of inquiry includes those studies that focus on how audiences receive media messages. Rather than being passive recipients of information, audiences are active in this reception process (Seale 2003, p. 516). Questions from within this area could include how do ordinary women with breast cancer understand and respond to media messages about the need for screening mammography, or how do these women respond to the messages about young women diagnosed with breast cancer? Like production studies, reception studies in the area of breast cancer are also limited in number perhaps because they are difficult to design.

Having outlined a potential categorisation scheme, I now add that the boundaries between these three broad categories are rarely so clear-cut (Seale 2004). Therefore, it is perhaps more helpful to structure this section of the review according to content headings such as personal responsibility, inaccuracies in reporting, young women, an epidemic, celebrities, and issues of sexuality and gender. The majority of the studies described below, unless otherwise indicated, are representation studies. In addition, all of the studies cited are of studies of written texts rather than visual images<sup>8</sup>. However, the use of visual images, such as photos, drawings and film, are unique topics for

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<sup>8</sup>Studies, such as those by Pitts (2004) involving the internet have not been included in this review. I acknowledge however that this area is also receiving increasing attention from scholars.

investigation and are gaining popularity within the sociological domain (Harrison 2002).

### **b. Breast cancer and the media**

Magazines and newspapers have already been the focus of considerable media research, in particular research into the portrayal of women with AIDs (Sacks 1996), women with depression (Gattuso, Fullagar & Young 2005) and women and health (Roy 2008). Several studies have explored the representation of breast cancer in the media, both in Australia and overseas (Andsager, J & Powers 2001; Bonner & McKay 2000; Lupton 1994a; McKay & Bonner 2002, 2004; Reyes 2005; Schwartz & Woloshin 2002; Seale 2002; Sooyoung Cho 2006; Wilkes et al. 2001).

All studies reviewed, except one (Corbett & Mori 1999), were conducted within the qualitative domain. In addition, the most common method of analysis in these media research reports has been content or thematic analysis which has allowed the tracing of breast cancer reporting over time. However, as Lupton suggests, this research method is 'limited to documenting "what was said" rather than "how it was said"' (1994b, p. 38). Several of the studies cited here used discourse analysis to uncover the operations of latent meanings within the various texts.

### **1. Personal responsibility and blame**

Deborah Lupton conducted one of the earliest studies on media representation and breast cancer in Australia. She analysed the discourses or representations of breast cancer in the Australian press from 1987 and 1990, a time when screening mammography was widely introduced throughout Australia (Lupton 1994a). She discovered that there were three prominent discourses guiding the reporting during this time; the discourse of femininity, whereby breast cancer was linked to a woman's reproductive choices, the discourse of medical technology in which the answer to breast cancer could be found, and the discourse of responsibility whereby the individual women were responsible for preventing breast cancer through correct lifestyle choices (Lupton 1994a). Several other studies have also found that this latter discourse has informed the media's reporting of health and illness (Crabble & LeCouteur 2006; Gattuso, Fullagar & Young 2005; Roy 2008). The concept of personal responsibility is

also a major theme in the wider research conducted on women and breast cancer (Adams 2007; Kastner 1998; Wilkinson & Kitzinger 2000).

According to Roy (2008, p. 465), personal responsibility underpins the discourse of healthism. Healthism is a belief that the responsibility for health is a person's moral responsibility, and to do this, a person needs to follow a set of prescriptions that will contribute towards good health and well being (Crawford 1980). If these prescriptions are not followed and illness develops, then the person only has him/her self to blame. However, the responsibility for breast cancer is beyond individual women. Locating the responsibility in such a manner ignores the responsibility of the wider community in which women live to the problem of cancer's causation and treatment. Locating the responsibility for survival within each individual woman leaves her with the need to make 'right' treatment choices (Klawiter 2000). The requirement to make the 'right' choice supposes that there is a 'right' and rational choice to be made and suppresses the fact that there could be other alternatives (Klawiter 2000, p. 351). Locating the responsibility for survival within each individual woman supports a blame-the-victim mentality (Wilkinson & Kitzinger 2000). If women, in their attempt for prolonged survival, do not try hard enough to follow the correct diet or exercise regime, then they are to blame if breast cancer returns. Victim blaming is not restricted to Australia or other Westernised countries. Im found in her study of breast cancer amongst Korean women that victim blaming was also a feature of Korean culture (2000).

Clarke extends Lupton's earlier work in the field of breast cancer and media research. However, rather than just focussing on breast cancer, Clarke compared and contrasted the portrayal of three cancers (breast, prostate and testicular) in the print media (magazines and newspapers) from 1996-2001 (Clarke 2004). In relation to breast cancer, Clarke found that articles on this topic far outweighed those on prostate or testicular cancer. However, unlike Lupton's findings where the individual was portrayed as being solely responsible for her health and therefore her illness, Clarke found that in the sampled publications, breast cancer was seen as not just a disease of individual women, but of extended family members as well. Breast cancer was called a family curse ('a traitorous family' p. 545) or a family legacy, and thus seen as a disease not of an individual woman but of a family of related women' (Clarke 2004, p. 543).

This study is relevant to this review because breast cancer occurring in younger women is more likely to have a familial genetic component than breast cancer in older women.

This shift from one of individual responsibility to that of a community of related people reflects the change in the thinking and talking about health and illness over the past decade (McKay & Bonner 2004). For Rose, this shift is part of an individual and his or her wider community's reclamation of power and responsibilities, previously held by politicians and governments (Rose 1999). As a result of the shift, new ways of governing oneself have arisen and newspapers and magazines have played their part in spreading 'new procedures for understanding oneself', that is new ways of controlling oneself (Rose 1999, p. 90). For example, Bonner and McKay explored breast cancer reporting in three popular Australian women's magazines from 1999-2001 (Bonner & McKay 2000). They found that during this time, the reporting mainly focused on the reduction of personal risk through self-control and self-management strategies such as exercise and diet (Bonner & McKay 2000). While the personal responsibility for one's health was still evident in this research, this responsibility has shifted to include an ethical and moral dimension that Rose has described as a 'new ethical politics' (Rose 1999, p. 2).

## **2. Inaccuracies in reporting**

### ***a. Media versus research accounts***

The media do not always record medical news faithfully. Sometimes there are discrepancies between the popular accounts of research findings and the original scientific publication (Moyer et al. 1995). For example, Moynihan, Bero and Ross-Degnan discovered that in the reporting of the side effects and benefits of three popular drugs, pravastatin, alendronate and aspirin, only half of the newspapers mentioned their potential significant side effects (2000). At times, there are also differences in the reporting of breast cancer between newspapers and magazines. Women's magazines tend to have more personal stories and, while both sources present information on prevention and treatment, news stories tended to focus on funding for breast cancer research (Andsager, J & Powers 1999).

***b. Young women***

The media also tends to overemphasise events that, although they are serious, are relatively rare (Lupton 1994b). For example, during 1995, Shiel collected the majority of Australian newspaper and magazine articles that mentioned the term ‘breast cancer’ in their content (1999). She found that young women with breast cancer, and not older women (the majority of those who develop breast cancer), dominated these articles. Again, in an Australian telephone survey exploring the knowledge and perceptions about breast cancer, only 6.6% of the women interviewed (out of a total of 2935) were able to say that it was women over the age of 60 who were most likely to be at risk of developing breast cancer. Most (87.2%) said that women between the ages of 30-50 years were most at risk (Paul et al. 1999). Similarly, Marina and Gerlach (1999) found that the average age of women who featured in selected women’s magazines (1987-1995) was 40.5 years. This inaccurate perception may well be due in part to the increasing portrayal of celebrities with breast cancer in the media. The studies mentioned above were all conducted towards the end of the 20<sup>th</sup> century. One would suppose that this aspect of inaccurate reporting would have ceased; however the over emphasis on younger women was also found in a recent American survey (Survey 2006). In addition, a recent study of cancer in Australian television news found that there was an over-representation of reports on breast cancer in young women (MacKenzie et al. 2008). Bowel cancer, which kills more people in Australia than any other cancer was under-represented (MacKenzie et al. 2008, p. 157). The researchers suggested that this bias in reporting could skew public and political awareness of the burden of cancer within our society. Government bodies may be persuaded by public opinion to fund areas of cancer research that carry a lesser burden in terms of human suffering.

Criticism has been aimed at the media for some time now for misrepresenting the proportion of women who get breast cancer (Gigerenzer 2002b; Shiel 1999). Over representing young women (and their experience) is in part because they are more newsworthy than older women, adding to the discourse of tragedy discussed in Chapter 6. A simple example of this misrepresentation follows. In 2001, an article appeared in the *Daily Telegraph*, a Sydney tabloid, talking about the psychological stresses that many women face after breast cancer. The article related the experience of 11 women who were reported to be surviving breast cancer (Patty 2001c). Five out of the 11

women were older than 50, i.e. 45%, and yet to truly reflect the current Australian statistics, this figure should be at least 70%. Four of the 11 women were younger than 35 years of age i.e. 35% of the cohort. However, the current incidence rate of breast cancer in women under the age of 40 is less than 6% (Australian Institute of Health and Welfare Australia & Australasian Association of Cancer 2008). From this article, it appears as though breast cancer is nearly as prevalent in young women as in older women. On a sub textual level, this type of article conveys a confusing message to the wider community.

### *c. An epidemic?*

Breast cancer incidence has increased in Western countries. In Australia, the latest figures from the National Breast Cancer Centre indicate that one in eight women will develop breast cancer at some stage before the age of 85 (Australian Institute of Health and Welfare and National Breast Cancer Centre 2006). In contrast, in 1996 the incidence rate was one in 12. Much of the documented increase has been attributed to the introduction of screening mammography and is therefore not really an accurate reflection of a 'real' increase in breast cancer incidence (Australian Institute of Health and Welfare 1999). However, this increase, either real or manufactured, is not an 'epidemic' as has been described by the media in the USA (Lantz & Booth 1998). Lantz and Booth looked at the trends of reporting of breast cancer in magazine articles between the years of 1980 and 1995. They used content analysis to examine how the increase in breast cancer incidence has become an epidemic and a social problem in the eyes of the media. Using a sample of 91 articles, Lantz and Booth found that an 'increase in incidence was commonly portrayed as a mysterious, unexplained epidemic occurring primarily among young professional women in their prime years' (1998, p. 907). In addition, they found that the articles implied that it was the women themselves who were to blame for this increase due to lifestyle choices such as a delay in having children, having no children at all, the use of contraceptives and other lifestyle factors that have been linked to breast cancer causation. The discourses of responsibility and femininity were also found in breast cancer reporting in Australia (Lupton 1994a). Lantz and Booth surmised that the portrayal of breast cancer as an epidemic taps into society's need for order and control over the chaotic disease that is breast cancer. The use of the epidemic discourse therefore leads to moral panic. The epidemic discourse

also is a vehicle for the social control of women who have been liberated by the feminist movement during the 1960's. As a result of this liberation, women now carry the seeds to their own destruction through the way that they choose to live their lives (Lantz & Booth 1998, p. 917). This portrayal also reinforces a blame-the-victim mentality.

### **3. Celebrities**

The success of media campaigns in increasing the participation rates of screening mammography has meant that the media will continue to be used to spread public health messages. Furthermore, young celebrities with breast cancer also keep the disease in the public eye. Famous people, tragic tales and statistics are considered by journalists and editors as extremely newsworthy items (Fairclough 1995).

Within the review period in Australia, several young famous women have been diagnosed with breast cancer: Actor Belinda Emmett, Jane Steele the wife of cricketer Glenn McGrath and, more recently, the singer Kylie Minogue. Their individual struggles with treatment and recurrence have become a very public matter. This relationship between celebrities and increasing media attention is not a phenomenon restricted to Australia. Researchers Corbett and Mori (1999) in their examination of the relationship between public events and media coverage over a 36-year period (1960-1995) found that in 1974, media coverage of breast cancer showed a marked increase (Corbett & Mori 1999). This was the year that Betty Ford (wife of President Ford) publicly announced that she had undergone a mastectomy for breast cancer. More recently in Australia, in May 2005, Kylie Minogue was diagnosed with breast cancer. She was 36 years old at the time. The news of this event was widely published both in Australia and overseas and in the few weeks following this disclosure, there was a 20-fold increase in the news reporting of breast cancer, and bookings for mammograms rose by 40% (Chapman et al. 2005). This increase in mammography screening has been termed by these authors as the 'Kylie effect' (Chapman et al. 2005, p. 249).

Kitzinger, in her earlier study of child abuse, developed the notion of templates (2000). A template is a previously formed shortcut to understandings and judgments on a topic. A template contains stereotypes that can be overlaid onto new situations, simplifying interpretations, making immediate understandings possible. We can see a media template at work in celebrity stories of young women with breast cancer. For example,

in 1998 Belinda Emmett, an Australian celebrity, announced she had breast cancer. The news coverage of her experience set up a template into which other celebrity stories could be slotted. In 2005, doctors diagnosed Kylie Minogue's breast cancer; as media audiences, we can immediately recognize and remember Kylie's story as another example of an already existing story – one involving Belinda Emmett.

While the use of celebrities has been useful in raising community awareness, there is a downside to such sensationalised reporting. Ordinary women who are living with a diagnosis of breast cancer often find this coverage frightening (Rees & Bath 2000). In addition, newspapers use ordinary women in articles to engage readers and as Roy suggests, they help create norms 'against which individuals are judged and against which they police themselves' (Roy 2008, p. 8). This policing activity resembles Foucault's notion of disciplinary power (Foucault 1995). The use of celebrities will ensure that breast cancer in young women remains in the media's eye for some time to come, in spite of its rarity.

#### **4. Gender, beauty and breasts in the media**

*A woman's body is the battlefield where she fights for liberation. It is through her body that oppression works, reifying her, sexualising her ... (Greer, G 1999, p. 106)*

As a society, we are preoccupied with breasts; a woman's breasts are a symbol of femininity and sexuality. It is within these breasts that cancer occurs, striking at the very heart of a woman's sense of identity and embodiment. As Saywell, Beattie and Henderson state, '(w)omen's bodies, especially young women's bodies, make breast cancer newsworthy' (2000, p. 38). Therefore, it is not only the use of celebrities that continue to make breast cancer a news item, but also the use of young women's bodies.

Within the media, several studies have explored the construction of young women's bodies and breasts in the context of breast cancer, (Lupton 1994a; Potts 2000a; Saywell, Beattie & Henderson 2000). For example, Saywell, Beattie and Henderson (2000) explored media coverage of breast cancer in a selection of UK newspapers over a three-year period. Like other studies, they found that the newspapers over-represented breast cancer in young women. They also found that the printed articles sexualised breast cancer by locating the disease within a particular site in the female body – her breasts.

This location is problematic because it disempowers a woman with breast cancer and reduces her to a commodity for ‘male gaze and masculine consumption’ (Collie & Long 2005, p. 850).

No other cancer receives the same media attention. As one study participant (a press officer) stated, ‘... it (bowel cancer) is not going to make the best magazine story with pictures of bowels ... hardly the stuff catwalk models are going to get involved in whereas breast cancer is ... a much more sexy subject’ (Saywell, Beattie & Henderson 2000, p. 42). Rarely do pictures of mastectomy scars or flat-chested women feature in newspapers. Women cover up the scars that stigmatise them; the newspapers are no different. Stacey suggests that this cover up is part of a women’s need to keep her femininity together, a ruse that requires a great deal of energy and effort (1997, p. 71). Returning to the Saywell study, the newspapers also portrayed (young) women with breast cancer as living a tragic tale of sacrificed motherhood. This construction was reinforced when a number of the young women featured in the study chose to forgo breast cancer treatment to ensure the health of their unborn children. By making this sacrifice, the women were, in effect, signing their own death warrant. Other studies have also found constructions of sexualised breasts within the stories of women with breast cancer (Langellier & Sullivan 1998).

### **5. Feminism, media and breast cancer**

Feminism in its various forms has long been interested in breast cancer as a topic. Feminist research has striven to validate personal experience, previously hidden from the public eye and to critique the political structures that are embedded in the ‘personal’. For some writers, breast cancer is considered to be a feminist issue (Potts 2000b). Challenging the discourses of individual responsibility for one’s health and illness and that of personal blame is at the heart of much feminist research (Wilkinson 2001).

Clarke’s study, mentioned earlier, found that women with breast cancer were portrayed as being emotionally vulnerable and fearful, while doctors were portrayed as masculine, objective and rational (Clarke 2004). In contrast, Seale, in his analysis of cancer stories in news reports, found that women and men shared a common pathway in the pervasive ‘striving against all odds’ story (Seale 2002, p. 107). He concluded that both genders saw cancer as something that could be controlled to some degree. However, he did find

that women were more likely to be shown to be skilled in the area of emotional labour, drawing upon other women for support, while men tended to be stoic in the face of cancer and did not show the same level of distress. This representation of men and women along the lines of gender stereotypes provides a narrow focus that excludes other possible interpretations of emotions in men and women.

## **6. Other writings on breast cancer**

The biomedical literature sanitises the traumatic legacy of breast cancer diagnoses and the struggle of ongoing survival for the young women concerned. Autobiographical accounts on the other hand - photos, poems or stories - reveal to all the trauma and stigma of living with a disease that leaves a female body scarred and forever altered. Thus far, I have not mentioned the numerous first person accounts that appear almost daily on bookshelves all over the country. While examining personal stories might reveal both the personal and social meanings of having been diagnosed with breast cancer (Kleinman 1988), a review of such publications - except for those represented in the newspapers - is beyond the scope of this chapter. Suffice to say that access to such autobiographical accounts enables us to connect with other women on a very intimate and personal level. In addition, these stories usually feature 'ordinary' women and sit alongside the media representations of celebrity figures. Newspapers do publish first person accounts from time to time, such as the story written by Ruth Picardie (Picardie 2000). It is these latter stories that have formed part of the data for this study.

## **7. Summary and limitations of breast cancer in the media**

As this review has shown, research on breast cancer in the mass media has been extensive; however few (apart from Rees and Bath (2000) have explored the reception of these messages with a sample of young women who are actually living with breast cancer. In summary, the literature review in this area of media research has shown that many of the studies have revealed a bias towards personal responsibility and victim blaming. In addition, many of the studies have highlighted the inaccuracies in reporting, including the difference between media accounts and research reports, the over-representation of young women, the use of celebrities and the representation of breast cancer as an epidemic. Finally, it is the use of young women's breasts and bodies within the media in particular, and in representations in general, that has sexualised this

disease, reinforcing gender stereotypes within society and contributing to the oppression of young women living with breast cancer.

Much of the research into breast cancer and the media, both in Australia and overseas have used content analysis as a way of discovering commonly occurring themes (Sooyoung Cho 2006). Content analysis is valuable in tracing trends over time, allowing comparisons to be made. However these studies are limited in that they do not extend their analysis into how breast cancer in young women came to be reported and spoken about in the way it has (Lupton 1994b). In addition, content analysis can give us clues as to what young women living with advanced breast cancer believe in relation to their illness and ongoing survival (Wilkinson 2000b), yet fail to examine the political landscape in which such beliefs are forged.

Researchers sometimes use a discourse analytic approach alongside content analysis. Discourse analysis delves beyond common occurring categories within textual accounts and examines the political and historical contexts in which these texts were written. Discourse analysis examines the systems of belief that shape conversations about young women with advanced breast cancer within the media and in society (Lupton 1994b, p. 39). Discourse analysis helps to answer questions about who benefits from advanced breast cancer being spoken of as tragedy or a personal responsibility and who is silenced in this process. It is to this area of discourse analysis which I now turn.

### ***8. A discourse analytic perspective***

The knowledge of breast cancer is socially constructed from a number of institutional sites (Woodward 1997). These sites include medicine, psychology and the media. Within these sites, not all ways of knowing are given equal credit. For example, Fosket's study explored the construction of knowledge within the lived experience of women with breast cancer (Fosket 2000). She found that the dominant biomedical knowledge, supported and perpetuated by the 'gaze', dismissed the women's own ways of knowing. This dismissal of knowledge was most notable in the area of early detection. Biomedical knowledge struggles to incorporate or acknowledge the resulting knowledge that women derive from their own lived experiences. Foucault (1973) argues that it is the clinical 'gaze' that socially constructs diseases. In the case of breast cancer, the clinical gaze locates the 'truth' of the disease within the body of the women

concerned. It is the 'gaze' that locates the lump within the breast and the 'gaze' that detects recurrence.

My study moves beyond the current studies cited in this review in that its analysis is organised in the inter-textual elements between media representations of advanced breast cancer in young women, professional medical literature and the stories of young women living with the disease. As such it combines both a reception and representation type of inquiry (Seale 2003). In addition, Kroenke has stated that 'young women comprised a distinct population that differed in their response to breast cancer than did older women ...' (2004, p. 1853) and therefore warrant specialised attention.

Advanced breast cancer as a socio-cultural phenomenon has been less studied than cancer in general. The research on advanced breast cancer in the medical and allied health literature has focused mainly on its terminal phase, psychosocial interventions, the effects of acute treatments and symptom management, clinical trials, quality of life and the support needs of the woman and her family. In her book titled *Teratologies: a cultural study of cancer*, Stacey (1997) examined some of the contradictory discourses that surround a person living with cancer. She juxtaposes her own experiences of having had cancer alongside the biomedical accounts of disease and alternative medicine's view of illness. I intend to extend Stacey's cultural analysis of cancer to include advanced disease and young women, an area she does not explore in any detail. The importance of this analysis can be found in the following quotation:

Awareness of the subtextual meanings of discursive accounts of health and illness is important in understanding the context in which lay health beliefs are formulated and expressed. (Lupton 1992 p. 148)

My rationale for using discourse analysis rather than quantitative analysis or some other form of qualitative analysis is that these other forms of research restrict how we come to understand the world around us (Parker 1999c). Meanings are not fixed in any pre-defined category that I can discover and hold firm. Rather, any meaning that I draw upon to make sense of my world, breast cancer included, is set against an ever-moving cultural terrain that involves shared, conflicting and contradictory systems of meaning. For Parker, the investigation of this culturally shared system of meaning that we employ

is a qualitative endeavour (Parker 1999c). It is in within this particular milieu of research and discovery that this thesis is located.

**9. Implications of this chapter**

From this review of the contemporary research literature on young women with advanced breast cancer, what are missing are studies that focus on young women living with advanced disease. Specifically what are missing are studies, which examine the social and political context in which this disease occurs. This is the aim of my research - to fill this gap.

## CHAPTER 3: THEORETICAL PERSPECTIVES

### **Introduction**

In the previous chapter, I outlined the dominant themes that appeared in research into advanced breast cancer in young women. I showed how positivism has largely driven the research in this area. While positivism is important in the management and treatment of breast cancer, other theoretical positions have something to offer as underpinnings for the research process. The aim of this chapter is to outline the theoretical framework of poststructuralism within which this thesis is located. Firstly, I differentiate structuralism from poststructuralism and then locate poststructuralism within the broader term of postmodernism. I then explore the theoretical position of poststructuralism and its key concepts before moving onto a discussion of Foucault's concept of power. Next, I discuss the work of Kristeva and Lacan and the implication of their writings for this thesis. Finally, I outline some of the limitations of poststructural theory and describe its beneficial application to the question of young women diagnosed with advanced breast cancer

### **1. Structuralism**

Poststructuralism is defined in relation to the term from which it is derived, namely 'structuralism' (Crotty 1998). The poststructural view of language differs from the related theoretical position of structuralism. Within structuralism, language contains a formal structure that is available as a source of exploration for a researcher. Ferdinand de Saussure (1857-1913) is an early structuralist, often referred to and quoted. He viewed language as containing particular signs that are shared by a community of people who speak the same language (Audi 1999). It is through this structure of language that signs acquire their meaning (Fowler 1991). Signs are made up of two elements, the first being the image used in the text (*signifier*) and the second being the meaning that the image has for a particular community (*signified*). For example, *advanced breast cancer* is the image or word used in the text and is therefore the signifier. *A non-curable disease* is the signified and is the meaning that our society readily attaches to the term *advanced breast cancer*. Both these elements join together to make the sign. The sign derives its value from the position it has within the language system as a whole and yet only gains meaning through a system in which it is

differentiated from all other signs (Audi 1999). Meaning is therefore relational, with the link between the signifier and the signified only ever an arbitrary one (Danaher, Schirato & Webb 2000). How does the sound element of *advanced breast cancer* relate to an *incurable disease*? How does reference to one bring to mind the other? The link between the two terms depends on the systems of meanings that operate in a particular culture at one point in time (Seale 1998b). Consequently, from a structuralist perspective, the words we use and the activities in which we participate only make sense when they are related to other words or circumstances. Therefore, to understand the term 'advanced breast cancer', I have to relate it to other words I have at my disposal such as 'early breast cancer', 'neoplasm', and 'terminal illness'.

Structuralism may be able to explain the rules of the language system but it cannot account for why some people use the rules in one way and not another. Nor can structuralism give reasons for why some words have many meanings or how meanings change over time (Weedon 1987). Structuralism can give us facts about a text yet, from a poststructuralist perspective, there are no facts, only varied interpretations. From a structuralist's perspective, language is a stable and fixed structure while when viewed from the perspective of poststructuralism, language is unstable and fluid (Ward 1997). Structuralism therefore leaves many questions unanswered.

## **2. Postmodernism or poststructuralism?**

Postmodernism is a term that has been used widely within architecture and literature and several variations exist (Ward 1997). Its key features are as follows: an acceptance of fragmentation and discontinuity, a suspicion of grand narratives and science and a rejection of history and progress (Muir Gray 1999; Sarup 1993). The terms *postmodernism* and *poststructuralism* are often used interchangeably to mean the same thing. However, as theoretical traditions they share some common features as well as differing on a number of points. They are similar in that they both rest upon political foundations and have arisen out of major shifts in world historical structures (Lemert 1992). They also share a similar focus on how social reality is represented and the use of a deconstructive process to explore these representations. They differ in that the focus of poststructuralism is generally language, while the focus for postmodernism is culture. And yet these two concepts are often difficult to separate (Grbich 1999).

Poststructuralism is often considered a specific aspect of the broader concept of postmodernism (Crotty 1998).

### **3. Poststructuralism**

Poststructuralism is not a single theory, but a group of theories that make problematic the link between human beings, the world in which they live and how meanings are made and spread (Belsey 2002). The theories that have assisted in the shaping of poststructuralism as a theoretical tradition include (but are not limited to) Ferdinand de Saussure's structural linguistics, Louis Althusser's understanding of ideology and structural Marxism, Jacques Lacan and Julia Kristeva's psychoanalytic theories, Jacques Derrida's writings on deconstruction, and Michel Foucault's insights into discourse and power/knowledge. While these theorists and their writings give rise to different forms of poststructuralism, they all share some basic understandings of language, meaning and subjectivity (Weedon 1987). These concepts are central to poststructuralism and therefore require further explanation.

#### **a. Language**

Language is central to our culture (Fuery & Mansfield 2000). As individuals, we are born into a language that is shared with others. This language operates within the social and cultural networks in which we live. Therefore, when we use language to explain, communicate or retell that experience, it is an experience that is located within a particular history and context (Allen & Hardin 2001). When young women talk about their experience of living with advanced breast cancer, they do not speak of a private and individual experience, 'but rather public understandings that are given voice through this individual experience' (Hardin 2003a, p. 538). The idea that personal experience is dependent on and located within a wider framework of public understandings is important in this thesis.

The core of poststructuralism is its focus on language. As Belsey writes,

(a)fter food and shelter ... language and its symbolic analogues exercise the most crucial determinations in our social relations, our thought processes, and our understanding of who and what we are. (2002, p. 6)

Language is not a neutral or passive medium in which our thoughts and happenings are communicated, but a place in which our understanding of the world and our place in it are aggressively shaped (Tonkiss 2004). Furthermore, language does not reflect a pre-existing reality. Reality is not *out there* somewhere, just waiting to be discovered and reported on (as in the literature review of Chapter 2); rather, it is shaped in language.

Language, from a poststructural perspective, can be explained by using the Saussurean terms for a sign - the *signifier* and the *signified* (Allen & Hardin 2001) The words 'dash' and 'cash' represent eight marks on this paper; they differ by only one syllable or one mark. These marks are the *signifiers*, while what the words mean is the *signified*. From a poststructuralist perspective, the *signified* or the meaning of a word always points to an endless chain of other *signifiers* rather than to a pre-determined meaning. For example, looking up the word 'cash' in a dictionary only leads us to other definitions and links, one *signifier* calling forth another and so forth. Therefore, words or marks on a page can only ever be made sense of by reference to other signifiers (Allen & Hardin 2001). Consequently, a sign has no elemental meaning of its own; meanings are always deferred. A redirection from one signifier to another in our search for meaning implies that there is a constant referral process going on. As Crotty states, '(in) our search for meaning ... we are sent to difference and meaning is deferred' (Crotty 1998, p. 207). Derrida coined the term 'différance', meaning both to differ and to defer (Belsey 2002, p. 83). Derrida insisted that 'différance' was not a concept or a word, but a process (Ward 1997). Therefore, the meaning of any sign exists only through its differentiation. For example, *advanced breast cancer* only means incurable because *early breast cancer* means curable.

Derrida's ideas are important because he raises an awareness that people always think and act from a particular position; no two positions are ever the same. In addition, he raises the idea that there is no single truth or objective viewpoint on the topic of advanced breast cancer in young women. Consequently, the interpretation of any text is always open to an infinite array of possibilities within a system of meaning (Ward 1997, p. 116).

### **b. Language and meaning**

From a poststructural perspective, meanings vary depending on the context in which the words appear. Meanings are neither final nor fixed; they are fluid (Belsey 2002, Grbich, 2004 #527) and they always have the potential to refer to something else (Ward 1997, p. 212). Meanings are also related to discourses (Grbich 2004). For example, the meaning of the term *cure* for a young woman with advanced breast cancer depends on the discourses available to her at a particular point in time. It may be that, if viewed from within the discourse of biomedicine, she might see cure as unattainable given the statistics on disease progression. If, however, she views cure from within the discourse of self-responsibility, she may see it as her duty to try every treatment possible, thinking that if she just tries hard enough, cure will be attainable. Therefore, another meaning of cure may be produced. The young women living with advanced breast cancer are caught up in the middle of this battle for meaning.

### **c. Language and subjectivity**

Language is more than just the contested ground in the production of meanings. As the next quotation attests, language is also where our sense of ourselves is constructed.

Language is how social organisation and power are defined and contested and the place where our sense of selves, our *subjectivity*, is constructed. (Richardson 1998, p. 349), original emphasis

The question of who is the subject has remained a core issue for philosophy for hundreds of years. The question of ‘who are we’ - that is, what is our subjectivity - is tied up with our understanding of ourselves as people. We have particular characteristics and attributes, such as height or an ability to swim fast, that lead us to say “I am just made this way” as though there is something fixed within our inner beings that is unaffected by the outside world. This is an Enlightenment view of subjectivity, a knowable and definable entity (Fuery & Mansfield 2000). However, the question of who is the subject is not quite as simple as it might first appear. One's sense of self does not arrive at birth already formed. It is something an individual acquires as s/he ages through the interaction with the world around them, and yet it is more than a product of this socialisation process. Power produces subjectivity and as Kendall and Wickham state, ‘the formation of subjects is part and parcel of power’s productivity (1999, p. 52).

Poststructuralism has much to say about subjectivity, especially in the writings of Michel Foucault. His insights on this topic are important. For Foucault, how human beings come to understand themselves as subjects occupies much of his writing.

The goal of my work during the last twenty years has not been to analyse the phenomenon of power, or to elaborate the foundations of such an analysis. My objective, instead, has been to create a history of the different modes by which, in our culture, human beings are made subjects. (Foucault 1984, p. 7)

The different ways human beings are made subjects has a profound impact on the world, for the process by which this occurs determines how as subjects we are treated and in turn treat others (Danaher, Schirato & Webb 2000). In Foucault's earlier work, the idea that the self is passive or innate, produced by powerful discourses, is a pervasive thread running through his writings (Smart 1995). While these forces still limit and control individual possibility to some extent, his writing progresses to the point where the subject does have some choice (albeit limited) in the types of self he or she will be, and the ability to change that self when it is no longer appropriate (Danaher, Schirato & Webb 2000, p. 152). It was the exploration of Ancient Greek society in Foucault's later work (Foucault 1978, 1990) that opened up the way for Foucault to understand the subject as being active (Fairclough 1992a). It is this later view of the self with its possible agency that I find useful as I ponder the forces that limit and control a young woman's possibilities and subjectivity.

There are three main ways to achieve subjectivity (Foucault 1997a). First, there are the classification practices that turn human beings into objects. For example, young women with breast cancer are classified as either having early breast cancer or advanced breast cancer based on a histopathology report. The second way that subjects are made is by dividing practices. This is where young women with advanced breast cancer are separated from those with early breast cancer. Medicine considers them to be in a category of their own. This division stigmatises these women and brands them as *non-survivors* or *non-curables*. The third way that subjects are made is through self-subjectification practices whereby human beings learn to identify themselves in particular ways and thereby turn themselves into subjects (Foucault 1997a). Young women with advanced breast cancer often identify themselves as incurable.

#### **d. Subjectivity and positioning**

A subject position allows a person to view the world from a particular perspective and this position is made accessible from within a discourse<sup>9</sup>. For example, within the discourse of survivorship, there are a number of conflicting or alternative positions that could be taken up by the young woman concerned. One position could be that of the survivor who has struggled against all odds to become the victor over disease. The person who takes up this position in a discourse has agency or power to do this (Parker 1992). Another position available to the young woman with advanced breast cancer could be that of a 'non-survivor', a victim of life's circumstances, reliant on some sort of a hero to stall the progression of the disease. If two people are living out a version of the survivorship narrative, they will position themselves and each other according to the conflicting subject positions made available by the discourse of survivorship. Davies and Harre suggest that,

(w)ith positioning, the focus is on the way in which the discursive practices constitute the speakers and the hearers in certain ways and yet at the same time is a resource through which speakers and hearers can negotiate new positions. (1990, p. 62)

The negotiation of new positions does not have to be intentional; it can occur at the level of the unconscious. The important point here is that a discourse and its practices can be a resource from which we all can draw upon to make sense of our worlds and position ourselves in certain ways. Although these contradictory subject positions can exist between numbers of individuals, they can also co-exist within the same individual (Davies & Harre 1990).

#### **4. Language and discourse**

Language is located in discourses (Weedon 1987, p. 41). A discourse is a group of statements about 'what is possible to know, to do and to be' (Seale 1998a, p. 12). These statements differentiate one discourse from another. In breast cancer care, there are a group of statements about young women that are perpetuated by certain practices such as patient notes, professional cancer journals, treatment protocols and interactions between the women and their doctors (Grbich 1999). Such practices are linked to other practices within society and together they make up the order of discourse in a particular

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<sup>9</sup> Not the same as 'roles' which are prescribed ways of acting and behaving (Willig 2001).

area (Fairclough 1992a). The links between discursive practices are not fixed; they are always provisional (Malson 1998, p. 27). Furthermore, certain discourses allow us to see some things and not others, and these same discursive explanations influence our understanding of ourselves and our ability to discern what is ‘true’ from what is ‘false’ (Danaher, Schirato & Webb 2000, p. 31). As Miller states,

(w)e enter into discourses as we go about the practical activities of our lives. The discourses are conditions of possibility that provide us with the resources for constructing a limited array of social realities, and make other possibilities less available to us. (Miller, G 1997, p. 33)

The most influential discourses in society have specific institutional locations – in medicine, in psychiatry and so on - and these locations are sites of struggle (Pringle & Watson 1992, p. 65). A young woman’s experience is open to competing discourses that arise from such institutions. Therefore, each young woman with advanced breast cancer is subject to an array of often-conflicting discourses.

However, discourses are more than ways of thinking about something, more than something that refers to something else in the formation of meaning. Discourses are

... practices that systematically form the objects of which they speak. Of course, discourses are composed of signs; but what they do is more than use these signs to designate things. It is this *more* that renders them irreducible to language ... and to speech. It is this ‘more’ that we must reveal and describe. (Foucault 1972, p. 49)

It is this *more* of discourse that Foucault refers to above that I am seeking to reveal and describe in this thesis.

### **a. Discourse and Foucault**

There are many theorists who have helped to shape poststructuralism. Michel Foucault is one such theorist. While he is generally considered to be a post-structuralist, some of his earlier works, in particular *The Order of Discourse* and *The Archaeology of Knowledge*, show evidence of structuralism; (Foucault 1972, 1981). Structuralism provided Foucault with a systematic and precise way of analysing history and gave him the idea that meanings in and of themselves do not actually ‘mean anything’; they only make sense when they are related to other ideas or events (Foucault 1972). These earlier works of Foucault mentioned above focus on language and how subjectivity is

shaped in discourse (Crotty 1998, p. 204). However, he favours poststructuralism in his later writings on power.

In his later work, Foucault shifted from linguistic determination to the view that individuals are constituted in power relations, power being the ultimate principle of social reality. (Sarup 1993, p. 73)

History and the ability of an historical excavation to reveal ‘where we are standing in the present’ fascinated Foucault (Lloyd & Thacker 1997, p. 21). For Foucault, examining the present directly is not possible, for it slips away as soon as we focus upon it. Therefore, the past is our only link with the present. Hence, a number of Foucault’s studies focused on the histories of prisons (Foucault 1995) and mental institutions (Foucault 1988a) in order to shed light on present day social and cultural practices. His work spanned many years and contained within it a number of shifts in thinking. For example, his writings concerning the nature of power and the subject towards the end of his life differed to the ideas expressed in his earlier work. I have no wish to outline his entire *oeuvre* but only those aspects that relate to the themes of power/knowledge, discourse, the body and subjectivity.

The production of discourses is controlled by disciplines. Before a discourse can be included in a disciplinary framework, it must face the challenge of scrutiny by the discipline in order to preserve the discipline’s own status and identity. It must act in a way that the discipline sees as the ‘realm of truth’ (Lloyd & Thacker 1997, p. 3) Therefore, a discipline disciplines.

Any academic discipline constantly surveys its own borders, allowing only certain discourses to be included within it, as part of a process designed to maintain its own identity and status: too many aberrant discourses allowed within the portals of a discipline would threaten the boundaries of the subject but would also threaten the principle of order and organisation that maintains self-identity of a discipline. Any discipline disciplines the discourses it allows within it because of a fear of how new and different discourses might disrupt the contours of the subject of study. (Lloyd & Thacker 1997, p. 3)

In this thesis, I am studying discourses that inevitably traverse disciplinary boundaries between nursing, palliative medicine, oncology, alternative and complementary therapies and psychology/psychiatry. Within these academic disciplines, discourses are

often pushing against and crossing disciplinary borders. Medicine constantly surveys its borders and excludes discourses that threaten its self-identity and order.

### **b. Discourse and power**

Power has its part to play in the discourses of advanced breast cancer in younger women. This point is well illustrated by the following quotation.

Discourse transmits and produces power; it reinforces it, but also undermines and exposes it, renders it fragile and makes it possible to thwart it. (Foucault 1981, p. 101)

The possibility that power can be thwarted is intriguing for it suggests that as human beings we might be able to expose and render power fragile through the practices of discourse. Therefore, discourse and power are intimately connected.

Foucault's historical approach to investigating institutions and practices originated in the work of Nietzsche, from whom he borrowed the term 'genealogy' (Ransom 1997). For Nietzsche, institutional and individual practices that make up the society in which we live, engage in battles between opposing wills and hence have their origins in conflict. Conscience and morality originate from these battles. Foucault used the genealogical method in his research, thereby enabling him to uncover the things that were not being said about these institutions and practices – the 'hidden voices' so to speak (Grbich 2004, p. 39). The purpose of such uncovering is to reveal the battles and power plays that make our everyday world seem natural (Ransom 1997, p. 5). As Kendall and Wickham state, genealogy '... rudely flushes out assumptions' (1999, p. 30). Genealogy also views history as chaotic, disordered and discontinuous rather than an orderly unfolding of events (Danaher, Schirato & Webb 2000, p. 101). The genealogical method therefore uncovers relations of power, 'a machine in which everyone is caught (Foucault 1980b, p. 156). No one escapes power's machinery, not even young women living with advanced breast cancer.

### **c. Power/knowledge**

Foucault extends the influence of power to embrace knowledge. The two terms ‘power’ and ‘knowledge’ often appear as one, *power/knowledge*, in much of his writings (Peerson 1995, p. 110). For Foucault, one is inseparable from the other.

(The) ‘power-knowledge relations’ are to be analysed ... not on the basis of a subject of knowledge who is or is not free in relation to the power system, but, on the contrary, the subject who knows, the objects to be known and the modalities of knowledge must be regarded as so many effects of these fundamental implications of power-knowledge and their historical transformations. In short, it is not the activity of the subject of knowledge that produces a corpus of knowledge, useful or resistant to power but power-knowledge, the processes and struggles that traverse it and, of which it is made up that determines the forms and possible domains of knowledge. (Foucault 1995, pp. 27-8)

Power/knowledge is a valuable concept. As a researcher, through the application of this concept I can uncover various historical constructions in the world of advanced breast cancer, the values inherent in palliative care knowledge and practice, and the interests being served by the maintenance of certain power relations. The understandings that I can potentially gain from such a challenge can lead to change and transformation within the field of advanced breast cancer management amongst younger women (Street 1995).

### **5. Features of Foucault’s concept of power**

There are a number of important ideas that are contained within Foucault’s writing on power. These features are that power is productive, that power cannot be possessed, that power produces individuals, and that power engenders resistance.

#### **a. Power is productive**

The first feature of Foucault’s conceptualisation of power is that it is productive and not repressive.

... (power) traverses and produces things, it induces pleasure, forms knowledge, produces discourse. It needs to be considered as a productive network, which runs through the whole social body, much more than as a negative instance whose function is repression. (Foucault 1984, p. 61)

An individual cannot hold power and therefore it cannot be handed from one person to another. For example, it is not possible for the doctor to hand over power to the patient or vice versa, as power is a network of relations running through society.

**b. Power cannot be possessed**

A second feature of Foucault's conceptualisation of power is that it can never be possessed; it is only visible in its operations.

Power exercised on the body is conceived not as property, but as a strategy... (it) is exercised rather than possessed; it is not the 'privilege', acquired or preserved, of the dominant class, but the overall effect of its strategic positions – an effect that is manifested and sometimes extended by the position of those who are dominated ... this power is not exercised simply as an obligation or a prohibition on those who 'do not have it', it invests them and is transmitted by them and through them; it exerts pressure upon them just as they themselves in their struggle against it resist the grip it has on them. (Foucault 1995, pp. 26-7)

From the orientation to power presented above, power is a strategy, a strategy that is exercised both on and through the body and through certain institutions. Therefore, power is capillary-like, extending into all domains of society. It is capillary-like in two ways. Firstly power attempts to govern the minute details of our existence such as our thoughts; and secondly power is not directed from some place on high, but develops from within the crevices of society (Ransom 1997). Power also operates through institutions such as the National Breast Cancer Centre, spreading through the population by means of health monitoring and disease surveillance.

**c. Disciplinary power**

Disciplinary power is a third feature appearing in Foucault's work on power. Viewing disciplinary power historically, disciplines arose out of a need to manage increasingly large numbers of people during the eighteenth century. As a collective, people are unpredictable and hence dangerous. Society must be defended. In the absence of visible punishments (beatings etc), the middle classes needed to develop a means of controlling an unruly 'mob; and disciplines sought to organize this growing populace to reduce the threat they posed. Foucault explored how some disciplines accomplished the aim of making the population less dangerous by organising and training them so as to increase their productivity, whilst at the same time making them politically docile

(Ransom 1997, p. 40). It was during this time that large numbers of people demanded education and training. Armies and hospitals required efficient management procedures in order to control the increasing numbers of people coming through their doors. The need for order and control also extended to individual bodies. Disciplines produce individuals, in the same way that the rules of a 'game' such as tennis produces a type of individual who obeys and plays by the rules of the game (Ransom 1997, p. 49). However, although disciplines 'make' individuals, there is still room for these individuals to change or oppose the forces that shape them. It is this latter ability of the individual that has important implications for young women diagnosed with advanced breast cancer, as I will now explain.

#### **d. Power and resistance**

Where there is power, there is resistance. (Foucault 1978, p. 95)

I am arguing here that the distinct features of Foucault's concept of power (productive, unable to be possessed and disciplinary) enable the exploration of the effect of power on young women with advanced breast cancer and those who care for them in a professional capacity. However, these women are not powerless, although their actions may be constrained by the actions of those around them. There are opportunities for resistance or for 'intransigence of freedom' (Foucault 1982a, p. 221) at the heart of any power relationship. It is these opportunities that I am interested in and how they might possibly come about. It is knowledge that holds the key to understanding the workings of resistance; 'the key role played by knowledge in modern power formations makes knowledge a potential site of resistance' (Ransom 1997, p. 82). On the topic of resistance, Foucault states that,

... the latter (resistances) are all the more real and effective because they are formed right at the point where relations of power are exercised; resistance to power does not have to come from elsewhere to be real, nor is it inexorably frustrated through being the compatriot of power. It exists all the more by healing in the same place as power; hence, like power, resistance is multiple and can be integrated in global strategies. (Foucault 1980a, p. 142)

Resistances are formed at the point where relations of power are practised. New possibilities thus emerge for the resistance of power within the lives of all individuals.

Rather than taking the analysis of power as my starting point, the workings of power can be better understood by analysing resistance and struggle.

### **6. *The shaping of human beings***

The exercise of power practiced by doctors over patients, oncologists over palliative care physicians, medicine over alternative therapies, all have some characteristics in common. First, they are all considered to be 'transversal', meaning that they are not located within a particular nation or political affiliation (Smart 1995). Second, medicine's target is to have power over people's bodies and lives. Third, people direct their opposition towards the power that is exercised over individuals. Finally, the exercises of power are all concerned with the question 'Who are we?' (Smart 1995, p. 135).

Disciplines shape human beings, with or without their consent. To accomplish this aim of shaping human beings, a discipline does not use force, for to do so would invoke sanctions. Disciplinary power achieves its hold on individuals and collectives in three ways: (1) by hierarchical observation, (2) by normalising judgement, and (3) by the examination (Smart 1995, p. 85).

#### **a. Hierarchical observation**

Hierarchical observation is exemplified by the Panopticon structure and surveillance techniques. The Panopticon refers to an architectural structural arrangement taken from the work of Bentham, whereby cells or rooms are arranged in a circular fashion around a central highpoint, usually a watchtower (McNay 1994, p. 93). From this highpoint, everyone can be observed, night and day. Those down below (prisoners) are unable to see the watchers above them and yet they know they are being watched. The prisoners adjust their behaviour accordingly, without coercion or threat, and therefore power functions automatically within this model. The prisoners down below internalise the surveillance practices of those in the watchtower and the individual takes on the same surveillance task, monitoring themselves according to the values of others (Crossley 1994, p. 185).

The awareness of being observed can be alienating as well as pleasing. For Young, a feminist writer, the awareness of being observed is alienating.

“See yourself in wool.” Yes, I would like that. I see myself in that wool, heavy, thick, warm ... But who is this coming up behind me? Bringing me down to size? His gaze is unidirectional, he sees me but I can't see him. But no – I am seeing myself in wool seeing him seeing me ... So I am split. I see myself, and I see myself being seen. (Young, IM 1990, p. 177)

Surveillance therefore leads to a split between the observer and the observer being observed. However, there are hierarchies within hierarchies and those who ‘gaze’ are also being monitored and undergo surveillance. For example, doctors monitor the health of patients, at the same time, clinical practice guidelines and legislations monitor the practices of doctors. Many researchers in the fields of health and sociology have used the concept of the ‘gaze’ to explore the concept of surveillance (Heaton 1999; McKie 1995; Reuter 2002). Other writers such as Armstrong (1983) have extended the gaze to include the practices of health care professionals and the bodies of patients. Surveillance is central to the analysis of technologies of power. In *Discipline and Punish* Foucault writes that ‘our society is not one of spectacle, but of surveillance; under the surface of images, one invests bodies in depth’ (Foucault 1995, p. 217). For Foucault, doctors are agents of medical surveillance that infiltrate people’s lives by such techniques as the monitoring of the body and the use of the confessional, aspects that I will cover later in the chapter.

### **b. Normalising judgement**

The second instrument of disciplinary power is that of normalising judgement. Punishments for non-conformity are metered out and rewards for correct behaviour are given. For example, if a young woman does not want further treatment for her advanced breast cancer, then her oncologist or some other treating physician could potentially refuse to be involved in her ongoing management. She is thus punished for non-conformity. In addition, through the act of confession, she gives greater power to the oncologist to come up with the ‘right’ treatment regime or a particular prognosis. According to Foucault, we have all become confessing animals (1978, p. 59). The use of the confessional also forms part of the examination.

### **c. The examination**

The third instrument of disciplinary power, the examination, is the combination of both techniques mentioned above. As a result of the examination, a normalising ‘gaze’ is formed through which human beings can be classified and judged (Smart 1995, p. 86). The gaze makes an individual an object, highly visible and therefore under the influence of the exercise of power. This gaze is constant, and the ongoing visibility keeps the individual subjected and permits he or she to be treated as objects (Fairclough 1992a, p. 53). Being visible is how discipline affects individuals in institutions such as hospitals and clinics. The examination also enables information about individuals to be kept in registries and files allowing for commonly occurring features in a population to be documented. Through this process of collection and manipulation of records, generalisations about the population can be made leading to averages, norms and percentages being calculated. Consequently, the individual becomes an object, a ‘case’. The examination is very much part of the life of the young women with advanced breast cancer and the normalising gaze positions them as either survivors or non-survivors., thereby producing disciplinary knowledge for the expert.

## ***7. Biopower and governmentality***

The concepts of biopower and governmentality are the result of Foucault’s later work, and are considered to be his more mature approach to the concept of power (Moss 1998, p. 2).

### **a. Biopower**

Biopower is Foucault’s name for a new form of power concerned with the management of life at both an anatomical and societal level (Moss 1998, p. 2). How does biopower work? Firstly, it resembles disciplinary power in its attempt to shape the lives and bodies of individuals in order for them to fit into institutional structures. Secondly, biopower operates through populations with the collection of statistics and demographic characteristics. I am interested in both these aspects and dimensions of biopower, but especially the way biopower works on and through populations in the form of governmentality (Bunton & Petersen 1997, p. 5).

## **b. Governmentality**

Foucault's notion of governmentality is also relevant for this project, for it is how biopower is exercised at the population level. Governmentality is,

... the ensemble formed by the institutions, procedures, analyses and reflections, the calculations and tactics, that allow the exercise of this very specific albeit complex form of power, which has as its target population. (Foucault 1991, p. 102)

Governmentality includes both self-governing strategies, and those activities carried out by the state for the purposes of surveillance and regulation (Lupton & Chapman 1995, p. 9). Governmentality is therefore the intersection between the 'technologies of the self' and the regulation of the society. The idea of governmentality broadens out his earlier workings of power by differentiating between violence and domination. And although power constrains individuals, it also paves the way for the possibility of freedom (McNay 1994, p. 4).

The art of government depends on knowledge, knowledge of the numbers of people being born, the number that are dying, who gets what sort of disease, the calculation of probabilities and survival rates. They convert the world into numbers such as are found in reports and statistics that are housed in state and national registries. The art of government is therefore not concerned with the protection of territory from invaders (at least not in recent times), but with the protection of the individual and the society in which he or she lives so that their health and welfare are secure and protected.

The art of government, as previously described, is a new form of pastoral power. Pastoral power, according to Foucault, is a specific form of governance that uses a technique of power that requires knowledge of its subjects (Nettleton 1997, p. 211).

This form of power cannot be exercised without knowing the inside of people's minds, without exploring their souls, without making them reveal their innermost secrets, It implies a knowledge of the conscience and the ability to direct it. (Foucault 1982b, p. 214)

Therefore, to exercise this form of power, the insides of people's minds must be known and revealed. Experts such as psychiatrists and psychologists can assist in this process of knowing the self by the use of the confessional (Rose 1989). However, knowing the inside of a person's mind is one thing, knowing a person's body is another.

## **8. The inscribed body: the target, object and instrument of power**

The body is the inscribed surface of events (traced by language and dissolved by ideas), the locus of a dissociated Self (adopting the illusion of a substantial unity), and a volume in perpetual disintegration. (Foucault 1977, p. 148)

The body as ‘a volume in perpetual disintegration’ reflects in many ways the body of a young woman with advanced breast cancer where the body is both the sustainer of life, and the container of disorder and death. The women, as they go about their day-to-day lives, grapple with a changing and often deteriorating body. The body that undergoes enormous stress as it deals with the spread of cancer cells also confronts health care professionals. Relief of troublesome symptoms takes up much of this work.

In order to explore the body as both an object and something that is lived, I now draw upon the work of Foucault and Kristeva. The seemingly diverse threads that each offers my project eventually make sense when they are woven together into a theoretical perspective that enables me to ask particular questions within the research process.

The body provides a major focus for Foucault, especially in *Discipline and Punish* (Foucault 1995) and *The Birth of the Clinic* (Foucault 1973). For Foucault, the body is a body upon which rules, hierarchies and cultural scripts are inscribed and reinforced. He argues that bodies are,

... broken down by a great many distinct regimes; it is broken down by the rhythms of work, rest and holidays; it is poisoned by food or values, through eating habits or moral laws; it constructs resistances. Nothing in man [sic] – not even his body – is sufficiently stable to serve as the basis for self-recognition for the understanding other men. (Foucault 1997b, p. 153)

The body is therefore never stable; it is unpredictable and is produced through and within history. The unpredictable nature of the body means that it is the power’s target and instrument, a site for the investment of power. The significance of Foucault’s conceptualisation of the body is that it is the site for potential resistance to power’s capillary pathways (Grosz 1994). Foucault’s writing on the body provides a theoretical thread involving power and the body. I now turn to the work of Kristeva and her radical notion of ‘abjection’.

### **Julia Kristeva and Abjection**

Julia Kristeva's writings are of particular interest to this thesis. Kristeva, a feminist writer, was concerned with the marginalised or repressed in our society – the abject (Tong 1989, p. 230). The value of her work to my project is her ability to link the concept of the lived experience of the body together with its social and cultural meanings (Grosz 1994, p. 192). This linkage does not appear within the writings of Foucault.

Kristeva's (1982) notion of the abject has particular relevance to the construction of identity of young women with advanced breast cancer and those who care for them in a professional capacity.

Abjection ... (is) a terror that disassembles, a hatred that smiles, a passion that uses the body for barter instead of inflaming it, a debtor who sells you up, a friend who stabs you. (Kristeva 1982, p. 4)

Advanced breast cancer involves cancer cells on the march, entering into previously forbidden spaces. The body makes these cells, yet in doing so, signs its own death warrant. Advanced breast cancer contains deviant cells that are at once both part of the body and separate from it (Stacey 1997, p. 78). Deviant cells create horror as the boundary between what is 'me' and what is 'other' becomes blurred. For Kristeva, abjection is 'death infecting life .... Imaginary uncanniness and real threat, it beckons to us and ends up engulfing us' (Kristeva 1982, p. 4). Further she writes, 'it is not lack of cleanliness or health that causes abjection, but what disturbs identity, system and order' (Kristeva 1982, p. 4). Advanced breast cancer certainly does disturb the 'identity, system and order' of the young women concerned. Therefore, using Kristeva's notion of abjection, advanced breast cancer can be viewed as a danger to identity:

Excrement and its equivalents (decay, disease, corpse, etc.) stand for the danger to identity that comes from without: ... society threatened by its outside, life by death. (Kristeva 1982, p. 71)

The anthropologist Mary Douglas has argued that decay is 'matter out of place' and must be subjected to order (Douglas 1966, p. 40). The abject body is also 'matter out of place' and must be subjected to societal control so that order can be maintained. Kristeva uses Douglas' work to analyse the 'structure' of abjection.

## **9. The Unconscious and Emotions**

Truth and knowledge themselves can never be free of emotional underpinnings.  
(Lupton 1998, p. 3)

There is no single truth concerning the nature of advanced breast cancer in young women, nor, as I have already said, is there a single method for gaining knowledge. Emotions, such as the feelings of sadness or despair, are important aspects in the life of a young woman living with advanced disease. They form the basis for her ethical and political responses in society as well as contributing to her sense of self (Lupton 1998). Scientific and objective methods - where emotions are often viewed dispassionately - are inadequate in dealing with the complexity of these emotional responses (Lupton 1998). The importance of psychoanalytic theory to this thesis lies in its ability to delve beneath the rational aspects of subjectivity, the conscious motivation to take up one discourse and not another and to shed light on the unconscious facets of the emotional self.

### **a. Lacan's theory and the unconscious**

Lacan (1901-1981) was a French psychoanalyst. For Lacan, our unconscious is not a collection of biological mechanisms but a series of linguistic signifiers (Blackburn 1996). Like Freud, Lacan looked to early childhood as a crucial time in a child's development. At around the age of six or seven months, a child goes through what Lacan has termed 'the mirror phase' (Lacan 1977, p. 3; Moore 1994, p. 42). The child at some point during this time confronts him or herself in a mirror and is fascinated with the image. The sense of sight predominates over motor skills. Lacan is keen to point out that the mirror does not have to be a literal mirror, but the concept of the mirror is used to convey the idea that around that age, a space outside the child opens up in which the self is recognised as separate from his/her mother. Before this time, a child has no idea of a united self. However, seeing himself/herself in the mirror, the child realises that the mirror image is the 'other' and not the self. The consequence of this realisation is that the idea of a separate 'self' begins to take shape and an image of one's own body develops. It is also during this phase that the child begins to acquire language (Bonney & Wilson 1983).

Lacan's work is complex; however, there are several key concepts that I have gleaned from my reading. The first is the idea that we can never experience the world directly (Hedges 2001). All that I can experience is a mental event - me thinking about an experience - and then interpreting it. For example, when I see a young woman with breast cancer, I do not experience her directly. I see her and I interpret what I am seeing based on images from my previous experiences concerning young women with advanced breast cancer. I recognise advanced breast cancer by its classification and staging systems. My next step is then to give the interpretation a definition that I draw from inside my head and I give the experience language. Someone else viewing the same scene may interpret what was before him or her in a completely different way. My experience of a young woman with advanced breast cancer is therefore an interpretation.

The second key concept of Lacan's theory is that the images and language referred to above are false (Grigg 2008). They are only approximations to the real - they are essentially inadequate in their ability to describe the world. In addition, while we can never really know the world, we can imagine it, and according to Lacan we desperately want it. Desire arises out of the mismatch between what actually exists and what we perceive to exist through our store of language and images. Desire is the motivation for everything; however it cannot be satisfied because we do not know what we want because what is real is unknowable (Sharpe 2006). Our longing to know the real is displaced onto other things such as food or sex, all the time trying desperately to fill the void. Desire for Lacan is not simply the sexual desire referred to by Freud, but a deeper desire that motivates us all. The aim of Lacanian analysis is to 'bring human subjects to recognise and name their desire – the relation of a being to a lack' (Sarup 1996, p. 38).

The last key concept from Lacan's work is subjectivity. Our sense of self, or our subjectivity, is always in the process of construction. The self is not a naturally given, but is a product of one's culture and one's history. Therefore, it is continually shifting and fragmentary (Sarup 1996, p. 14). In order to understand a person's sense of self, I have to consider the biological, psychological and social factors that contribute towards its construction. It is comprised of our conscious realisation of experiences as well as the unconscious and its effects.

Lacanian theory has been used in the field of literary and media analysis. In films, stories or media representations, the reader is constantly faced with occupying differing subject positions that appear in the text; the text therefore positions the reader. The insertion of the self into the text is known in Lacanian terms as *suture* (Lye 2008). Therefore, for Lacan, the self is a construction, formed by culture and history.

The above interpretation of Lacan is necessarily superficial. However, I have come to the conclusion that an understanding of psychoanalytic theories is useful when looking at the way young women with advanced breast cancer (or the health care professionals who care for them) are positioned by particular discourses, a positioning that may have nothing to do with a conscious decision. What motivates us in life - to survive, to form relationships, to be happy or sad - is largely unconscious. By examining the way people speak, whether it is in the media or in our professional journals or the actual words used by the participants themselves, inferences about the unconscious can be made. For as Campbell states, 'psychoanalysis is above all a textual analysis' (Campbell 1995, p. 264).

#### **b. Hochschild's theory and 'emotion work'**

Emotion work is not the suppression of emotions, but rather the formation of a culturally approved emotional response (I *should* be feeling X). Any emotional response, whether conscious or unconscious, is based upon the expected values and norms of the society in which one lives (Lupton 1998, p. 19). Hochschild explained that emotion work was 'the act of trying to change in degree or quality an emotion or feeling' (1979, p. 561). Emotion work is therefore concerned with the management of emotions.

Emotions are managed by certain 'feeling rules' which prescribe the intensity, duration and the type of emotion that can or should be experienced in any given situation (Hochschild 1979). For example, being diagnosed with a terminal illness requires the expression of sadness and not laughter. Our society expects the bereaved person to be sad for a certain period of time, but not forever. Palliative care professionals should not feel disgust when confronted with a fungating breast cancer and nor should they make this woman feel disgust (Small 1996, p. 273). Emotions are therefore socially moulded.

'Feeling rules' are complemented by certain 'framing rules'. Framing rules help us to 'ascribe definitions or meanings to situations' (Hochschild 1979, p. 566). These rules assist us in knowing what particular situations require certain emotions (Small 1996). Different 'feeling rules', for example, are called for in the diagnoses of breast cancer. They will differ depending on the meaning we place on this diagnosis, whether it is labelled 'curative' or 'palliative'. A woman may feel happy or sad depending on the nature of this label.

In this research, the experience of emotions together with its feeling and framing 'rules' will be inevitable for 'emotions pervade the illness experience, both as a cause and as consequence' (Small 1996, p. 270). There is a cost that accompanies 'emotion work'. It has affected the degree to which I was able to listen to the young women's feelings involved in living with a life-limiting illness as well as my capacity to feel the emotions involved (Hochschild 1983, p. 21). Emotion work is especially difficult when there is a sense of stigma involved with the illness or condition. For example, Goffman found that the diagnosis of a mental illness was frequently accompanied by shame and distress for both families and individuals (Goffman 1963). The diagnosis of an incurable disease such as advanced breast cancer also carries with it a sense of shame and humiliation – a stigma. Friends often go out of their way to avoid these women. As Small suggests, such women often need support from health care professionals involved in their care to cope with such alienation (1996, p. 271).

### **10. Implications of a theoretical position**

As with everything, when deciding on a particular approach it is always useful to explore the various sides of the argument and weigh up its pros and cons. The same process applies when exploring a variety of theoretical perspectives that may inform any research process. I am arguing that poststructuralism is a useful theoretical underpinning for my research, yet it is not without its drawbacks; being deemed anti-humanist is one such drawback (Davies, B 2000).

#### **a. Humanism: a critique**

Humanism is a theoretical position that views human experience as the sole source of knowledge about men and women and the world in which they live (*The Fontana*

*Dictionary of Modern Thought* 1988). Several assumptions underpin humanism. First, human beings have value in and of themselves and can exercise a degree of freedom in shaping their own lives. Rational decision-making results in choices. (Davies, B 2000, p. 55). Second, humanism rejects the idea that men and women are expendable and their only use is as a pawn in a political and economic system (*The Fontana Dictionary of Modern Thought* 1988). The majority of the research reviewed in the previous chapter was conducted from within the umbrella of humanism. This research has been vital in progressing the knowledge of early detection and treatment of breast cancer in young women. Third, within a humanist model, stories are true accounts of something real. People (rational adults) can differentiate between true and fictitious stories (Davies, B 2000).

These assumptions are at odds with the theoretical position of poststructuralism. In poststructuralism, subjectivity is the word used to capture the notion of being a person, constructed through and by discourse (Davies, B 2000, p. 55); there are no free and autonomous human beings. In poststructuralism, while there is an acceptance that choices may be made based on rational thought, there is also the recognition that desire may thwart or undermine these same choices. Desires are seen as being inseparable from the various discourses through which each person is constructed (Davies, B 2000, p. 55). Furthermore, from a poststructural perspective, all stories are the result of fiction; fictions provide the basis of a lived reality (Davies, B 2000). This latter point has particular importance in the interview process as I discuss in the next chapter.

A poststructural position rejects the doctrine of humanism. This position sits at odds with my own belief that humans do have value in and of themselves and can exercise a degree of choice over life and its direction. Yet, the terms humanism and anti-humanism are not mutually exclusive. I find that these beliefs can and do exist alongside each other and while I have chosen poststructuralism as a theoretical basis, I am not rejecting humanism nor its assumptions.

### **b. Foucault: a critique**

Although a greater part of this chapter has been dedicated to a discussion of Foucault's ideas on power/knowledge, discourse and the body, I am not suggesting a wholesale

adoption of his work, as there are a number of difficulties with his approach that I will now outline.

First, Potter (1996, p. 87) suggests that if we view discourses as objects, as Foucault would have us do, then the contexts and practices from which they arise can be overlooked and ignored. The fault with this approach to discourse is that discourses are seen as preformed connected objects that can cause things to happen. This idea of cause and effect is reminiscent of positivism. As I have already argued elsewhere, the work of Foucault and other poststructuralists reject the notion of positivism with its optimistic view of progress and scientific growth.

Second, Foucault's work ignores the place of emotions in everyday life (Lupton & Barclay 1997). Feelings and emotions sometimes go beyond language and are hard to articulate in discourse; hence my exploration of emotions and the unconscious. Trying to fit emotions into discourse can leave out the individual experience and uniqueness when it comes to speech and language (Lupton & Barclay 1997, p. 21). By focusing only on power networks, discourses and subjectivity, Foucault has perhaps overlooked the way that health care professionals and young women diagnosed with advanced breast cancer experience the world through their emotions and desires.

Third, Porter (1996) argues that Foucault's conceptualisation of power does not differentiate between degrees of power, and neither does it reveal how structures within society differentiate between different power relations. To illustrate his point, Porter recounts a clash with the British military in Ireland. He shows the military to be agents of repressive state practices, with the legitimate use of force and violence to get what they want. Power for some is therefore repressive and coercive; it is not productive. The possibility of resisting power is there, but the costs may be high. For Porter, to resist answering the questions posed by the military could have meant arrest and further bodily harm. For young women living with advanced breast cancer, resisting further treatment may mean risking alienating their treating doctors. The cost of such action is high as the women may be left without a treatment team.

In the earlier discussion of power, I mentioned that for Foucault power was matrix-like, going in all directions, not just descending. However, as Porter's example above suggests, power does sometime filter down from the top.

(In many instances power comes from above. The degree of power that individuals can exercise is largely dependent upon the position they occupy within social structures. It follows that we need to look at those structures, as well as to individual interactions, if we wish to understand the nature of power. (Porter, S 1996, p. 59)

Certain groups within society can exercise power without appearing to do so by virtue of their structural position within society. By considering that power might sometimes be possessed may help to explain why some inequalities in power relationships continue to exist or why resistance is minimised.

Fourth, while Foucault was against the phenomenological approach for its humanistic tendencies, there are some poststructuralist writers, according to Crossly (1994), who recognise the difficulty inherent in the deconstruction of subjectivity and the need to retain some sense of human agency. I am one of those writers. Many researchers in the area of health have used phenomenology as a philosophical underpinning (Breaden 1997) and its strength lies in its ability to show the world from the point of view of the experiencing subject. Its weakness lies in the over-romanticised version of the self and the centrality given to experience (Atkinson & Silverman 1997). According to Lupton (1997, p. 101), it is the 'lived experience' of the body that Foucault overlooks, promoting instead a docile body caught up in a web of surveillance, subjugated by discourses without recourse to a position of resistance. This is a negative view being promoted here. However as I have explained earlier, this view reflects Foucault's earlier work on the subject. His later work moves from a focus on power and domination to 'technologies of the self, or the way our subjectivities are shaped by our interactions with ourselves' (Foucault 1988b). Foucault does acknowledge, however, that resistance to power is possible, yet he fails to explain the mechanisms by which this might happen. It is in the work of other writers such as Kristeva and Lacan that mechanisms of resistance appear, hence the inclusion of their ideas in this thesis.

### **c. A feminist contribution**

Both post-structuralism and feminism have something to offer my project as they both dispute the claim of a single knowable truth. There are many ‘truths’ of advanced breast cancer in younger women, including those provided by feminism. I am not conducting feminist research as such, yet the question of gender cannot be overlooked, nor its relationship to power.

Foucault’s work has been criticised by many for not examining or even considering such important issues as the oppression of women or other minority groups within society (Grbich 1999). However, McNay (1994) argues that Foucault’s analysis is important when dealing with issues concerning women. Weedon (1987, p. 125) writes that,

(a)lthough the subject in post-structuralism is socially constructed in discursive practices, she none the less exists as a thinking, feeling, subject and social agent capable of resistance and innovations produced out of the clash between contradictory subject positions and practices.

Women, in their everyday acts of resistance, have the potential to produce profound effects (McHoul & Grace 1993, p. 86). In addition, the voices of women with breast cancer are foregrounded within the political arena at present. However, the raising of one voice can lead to the silencing of another; stories of survivors often overshadow stories of those who do not survive.

### **11. Implications of this chapter and conclusion**

Within this chapter, I have discussed the concepts of structuralism and poststructuralism and showed how the earlier structuralist theories were inadequate for an exploration of issues of discourse and power. I have drawn heavily upon the work of Foucault, whilst also acknowledging that there are some gaps in his arguments. In my attempt to cover the areas that Foucault overlooks or does not fully explain, I have explored the work of other writers such as Kristeva, Lacan and Hochschild. It may seem at first glance that I have used an eclectic array of theories, and yet diverse as they might be, they are all connected under the umbrella of poststructuralism. The previous albeit lengthy discussion reveals the philosophical stance behind the methodology I have used in this research.

In conclusion, the ability of poststructuralism to link language, social organisation, subjectivity and power provides the theoretical basis for this thesis. The combination of theoretical perspectives presented above is relatively new in the field of health research.

The implications of this chapter for my research question are this: I am seeking to identify the available discourses in order to understand their influence on the lives and practices of young women with advanced breast cancer. The exploration of discourses and power relationships necessitates an examination that extends beyond individual experience to the sociocultural and political context in which advanced breast cancer takes place.

The next chapter covers the methodological approach of discourse analysis and provides the research context.

## CHAPTER 4: METHODOLOGY AND RESEARCH CONTEXT

### *Introduction*

#### **Every Woman's Lifetime Risk of Developing Breast Cancer is One in 11**

**As Kylie Minogue has discovered, breast cancer can be a younger woman's disease, writes medical reporter Clara Pirani.**

In Australia, more than 11,300 women are diagnosed with breast cancer every year. Often thought to be an older woman's disease, statistics show a different story. In Australia, around 25 per cent of women diagnosed with breast cancer are younger than 49. About 680 women a year under the age of 40 develop the disease ... many women are lulled into a false sense of security that it is an older woman's disease. Young women need to be especially vigilant, because there's data to show that young women are less likely to survive breast cancer than older women. They are more difficult to diagnose and their cancer is often more aggressive." (Pirani 2005)

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A total of 256 (12.5%) patients were aged <35. There was a significantly higher incidence of nuclear grade 3 and medullary histological-type tumors in younger patients compared to older patients ... Younger patients had a greater probability of recurrence and death at all time periods. Although there was no significant difference in disease-free survival between the two age groups in lymph node-negative patients, the younger group showed worse prognosis among lymph node-positive patients ( $p < 0.001$ ). In multivariate analysis, young age remained a significant predictor of recurrence ( $p=0.010$ ). (Han et al. 2004)

Breast cancer in our study population of women less than 30years of age was a highly lethal disease ... The phenomenon of late death after a long disease-free interval is important in the interpretation of data reflecting newer forms of breast cancer treatment. (Feldman & Welch 1998)

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I said to him, am I actually now, what they term as in remission? He said yes you are, and I said all right, so then in 5 years ... I said in 5 years do they then say you're cured? And he said 'you'll never ever hear that, they'll not say that to you'. That really shocked me, I thought, well I would presume in 5 years if it's not come back then everything is OK and I'm 100% cured, and he said 'no, you may as well say you're not actually in remission anymore but, they will never ever say that you're 100% cured, because they can't be positive about that.' (Belinda age 38, study participant)

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These texts, presented here alongside one another, show the attempts of several authors to describe the various 'truths' of advanced breast cancer in younger women. These aspects include the statistics that show that breast cancer is a *highly lethal* disease in

young women; many young women are ignorant of this fact. Additionally, *cure* is not a word that many young women living with advanced breast cancer are ever going to hear. The figures and statistics, presented in this way are indeed disturbing.

In the previous chapter I outlined how poststructuralism as a theoretical perspective, when added to the work of Foucault and others, allowed the creation of a research space that could explore and make visible the powerful and pervasive discourses in society. Although there are many methods I could have chosen to explore knowledge about young women living with advanced breast cancer, the political orientation of the method of discourse analysis seemed the most appropriate to answer the questions I had about the sociocultural construction of advanced breast cancer in young women.

In this chapter I first describe several approaches to discourse analysis and outline insights into poststructural discourse analysis derived from the work of both Parker (1992, 1999a) and Foucault (1972, 1981; 1991). Next, I outline the criteria used to analyse the data. These criteria have been adapted from the steps described by Parker (1992) in his text, *Discourse Dynamics*. I then illustrate the process of data collection and describe the steps taken to ensure the authenticity and integrity of the research findings. Finally, I discuss the ethical requirements and the challenges that arose during the course of the study before finally describing the study participants.

### **1. Approaches to Discourse Analysis**

Discourses, as a set of statements about what is possible to say and think concerning a given topic, have power. This power, as I have outlined in the previous chapter, can be both productive and constraining, and it is one task of the discourse analyst to untangle the workings of power within a text (Parker 1990). Discourse analysis is relatively young within the research world having its origins in the 1960's within the disciplines of linguistics, anthropology, literary and cultural studies (van Dijk 1990). A special feature of discourse analysis is that it does not belong to any one discipline, nor is it a combination of disciplines, like that of Psycho-Oncology. Discourse analysis is multidisciplinary and hence an appropriate tool for exploring knowledge that crosses disciplinary boundaries, between palliative care, oncology, psychology, psychiatry and nursing.

Through the use of discourse analysis I am able to show how the texts (as representations of reality – be it distorted ones) of advanced breast cancer in young women frame the reality for both the women themselves and the health care professionals who care for them. It is the analysis of these texts that is undertaken in discourse analysis rather than the reality the texts are said to represent (Cheek 2000). Certain outcomes, such as the exclusion of one point of view in favour of another, can be produced by the particular way the text is organised and through the particular use of language in the text. Therefore, discourse analysis can assist in making visible that which is usually hidden from view, namely the processes by which certain outcomes or understandings are produced and perpetuated (Tonkiss 1998).

There are two major traditions of discourse analysis, linguistic and poststructuralist (Lee, A & Poynton 2000). The former has arisen from the discipline of linguistics and the work of de Saussure, and the latter from the contestation of the much earlier work of Husserl, Nietzsche, Kant and Hegel (Threadgold 2000). The linguistic form of discourse analysis as outlined by Potter and Wetherell (1994) explores particular language devices such as metaphors and tropes. These devices are grammatical constructions that help redefine reality. For Ricoeur, metaphors are the ‘rhetorical process by which discourse unleashes the power that certain fictions have to redescribe reality ...’ (Ricoeur 1986, p. 7). While the ability of metaphors and the like to redescribe the reality of advanced breast cancer is an important consideration, the perspective provided by this linguistic form of discourse analysis is not a critical one. To be critical, the method would have to attempt to make transparent the hidden - namely the way discourses are shaped by power relations and in turn, shape identities, attitudes and beliefs within society (Fairclough 1992b). As I am wishing to challenge and reveal the politics involved in advanced breast cancer in young women and the way power shapes discourses, a linguistic approach to discourse analysis is therefore insufficient.

However, neither is the method outlined by Fairclough (1992b) entirely adequate for the exploration and analysis of discourses. Although his approach to discourse analysis is considered critical, the method overlooks the link between discourse and power, and the forces shaping subjectivity (p. 13). Fairclough, while outlining the contribution that Foucault has made to the theory of discourse, is also critical of it saying that Foucault’s work is too abstract. While this criticism may well be valid, Fairclough’s textually

oriented discourse analysis, with its focus on such concepts as ‘grammar, politeness and transitivity’ (Fairclough 1992b, p. 235), is also unsatisfactory.

Foucault’s approach to the analysis of discourse lies beyond linguistic analysis and sits within a poststructuralist framework. His focus on power, subjectivity, social organisation and language makes his work a solid starting point from which to explore the discourses of advanced breast cancer in young women. The major insights that are provided by both Foucault’s archaeological (1972) and genealogical works (Foucault 1981, 1995) are used as a matrix to inform the steps of data analysis. These two axes of Foucault’s work are seen as extensions of, and not dissimilar to, one another (Fairclough 1992b). The difference between archaeology and genealogy lies in the fact that the former provides a photograph, a still image of the discourses of advanced breast cancer in young women. The latter provides information on discourses over time, thereby linking the past with the present (Kendall & Wickham 1999). I have used the insights gained from both approaches outlined, seeing them as complementary rather than opposing each other. I also draw selectively from the work of Ian Parker and his ability to bring together an analysis of discourse with the study of power and ideology (Parker 1992, p. xii). Like Foucault, he also conducts his analysis from within a poststructuralist framework and therefore the work of the two authors in the field of discourse analysis is congruent - methodologically speaking. Parker, perhaps echoing Fairclough’s concerns, also found Foucault’s work to be lacking in its ability to ground discourse analysis firmly in reality (Redwood 1999). Therefore, a combination of perspectives is my attempt to ground discourse analysis in a reality and make it more concrete.

I am building on the central tenets of poststructuralism mentioned in the previous chapter, these being that discourses are to be found in texts, that they are intertextual, drawing from the work and meaning of other texts to gain meaning, and finally that they are contextual in that they lie within particular sociocultural and political sites (Lupton 1994c).

## ***2. Insights on discourse analysis***

Foucault’s work contains a number of major insights that are relevant to a discussion on methodology. I have drawn these insights from the writings of Fairclough (1992a, pp.

55-6). The discussion that appears below outlines these; however, I have expanded upon them, adding additional insights from other poststructural writers.

**a. Discourses produce subjects and objects**

Discourses are productive in that they actively construct both subjects and objects. The term ‘object’ refers to objects of knowledge which a particular discipline takes as its focus for investigation and acknowledges within its field (Fairclough 1992b). For example, *psychological morbidity*, a term appearing more and more within the psycho-oncology literature, has become an object of psychological discourse. Discourses therefore produce, reproduce and transform objects of everyday social life. In addition, a discourse produces subjects. Subjects are shaped by discursive practices and in turn, the same subjects reshape those practices. A discursive practice therefore is the many ‘ways in which people actively produce social and psychological realities’ (Davies, B & Harre 1990, p. 45).

**b. Intertextuality**

The word *text* is a common term within the field of literary studies and refers to any representation of reality; it does not just refer to language (Lee, A & Poynton 2000). A text can be any fabric of meaning which is significant for the reader. In this thesis, I have produced a translation of texts, reducing the spoken to the written word in order to subject these words to discourse analysis (Parker 1999a). As I have outlined in Chapter 2, knowledge about young women with advanced breast cancer is spread throughout a number of texts such as conversations, pictures, magazine articles, official publications and visual images such as sculptures, or poems. No doubt, there are many other examples of texts within the field of advanced breast cancer. Contained within the work of any of these texts are traces of other texts; one text always refers to another, just as one discourse always relates to at least one other. Foucault suggests that any text is always caught up in a system of references.

The frontiers of a book are never clear-cut: beyond the title, the first lines, and the last full stop, ... it is caught up in a system of references to other books, other texts, other sentences: it is a node within a network ... The book is not simply the object that one holds in one’s hands ... its unity is variable and relative. (Foucault 1972, p. 23)

The concept of intertextuality has been credited to the work of Bakhtin (1986), yet it was Kristeva who gave it the name of *intertextuality* (Fairclough 1992a, p. 101). For Kristeva, texts are compiled from past texts - artefacts from another era. At the same time, the text reacts to and remakes past texts thereby shaping history and influencing social change (Kristeva 1982, p. 36). Texts are therefore productive; they transform previous texts and help form new ones out of existing discourses.

The importance of intertextuality to data analysis lies in its ability to bring to the fore contradictory and often diverse elements within the text (Fairclough 1992a, p. 104). It is these diverse and contradictory elements within the text of advanced breast cancer in young women that are of interest here.

**c. There is no single meaning of a text**

A text has no meaning in isolation from other texts; meaning occurs on engagement (or not) with other texts. When a young woman with advanced breast cancer engages with the world in which she lives, meaning making occurs as she bumps into the other texts that surround her (Fox 1999). As I read and seek meaning in a variety of texts on the nature of advanced breast cancer in young women, I am constantly led to other texts - be it personal stories or scientific papers - in order to make some sense of the experience. As Parker has stated, discourse analysis allows us to identify *one* truth as opposed to *the* truth, 'held in place by language and power' (Parker 1992, p. 22). Therefore, there is no single or ultimate meaning of a text; any text is a result of human undertakings (Fox 1997).

Within the field of discourse analysis, the examination of texts provides many interpretations. I, as a researcher, have actively constructed the discourse descriptions appearing in this thesis, and these interpretations are only one of any number that could have been made. The knowledge produced is therefore only ever partial.

Representations are always produced within cultural limits and theoretical borders, and as such are necessarily implicated in particular economies of truth, value and power. In relation to these larger axes of power in which all representations are embedded, it is necessary to remind the student: Whose interests are being served by the representations in question? Within a given set of representations, who speaks, for whom, and under what conditions? Where can we situate justice and human freedom? What moral, ethical, and ideological principles structure our reactions to such representations? (Giroux 1992, p. 219)

Therefore, the representations of advanced breast cancer in young women have no meaning other than those that I have assigned to them discursively (Giroux 1992, p. 220).

#### **d. Techniques of power**

The practices and techniques of power (confession, examination, evidence-based medicine, governmentality and disciplinary regimes) are discursive; they shape and constitute the conduct of subjects and the conduct of conduct whereby the strategies and techniques of power rely on the power in language. The technologies of power mentioned above work on bodies, both the individual body and the collective body to effect control, thus rendering the body 'docile'. Power's success can be measured by how well it disguises the mechanisms by which it affects its power (Foucault 1981, p. 86) and the extent to which any thought or practice seems like 'your' idea. In order to explore institutions and organisations in terms of power, I need to examine their discursive practices. These discursive practices are both controlled and constrained by various procedures that limit and allow what can be said, by whom, and on what occasions.

#### **e. Discourses are sites of contestation**

Discourses are sites of contestation; struggles occur in and over discourses. I argued in the previous chapter that the distinct features of Foucault's concept of power (capillary, non-repressive, disciplinary) enabled the exploration of the effect of power on young women with advanced breast cancer and those who care for them in a professional capacity. However, people are not powerless, although their actions may be constrained by the actions of those around them. There are opportunities for resistance or for 'intransigence of freedom' (Foucault 1982a, p. 221) at the heart of any power relationship. It is knowledge that holds the key to understanding the workings of

resistance; ‘the key role played by knowledge in modern power formations makes knowledge a potential site of resistance’ (Ransom 1997, p. 82).

### **3. Steps for identifying discourses**

To outline the steps involved in discourse analysis is a difficult task, as there appears to be no universal method in the literature that describes the steps in a formal sense. Some discourse analysts such as Potter and Wetherell (1994) suggest that practice makes perfect and one only learns how to analyse discourse by undertaking it. This vagueness is hardly helpful for someone intending to conduct research using a discourse analytic method. I have therefore adopted and adapted a number of approaches to the analysis of discourse; the outcome of this process involves three steps; looking for discourses in the text, sorting and coding, and analysing the material discursively. However, the representation of a method as a series of steps does not take away from the complexity of the process, nor are the steps necessarily linear.

#### **a. Look for discourses in the text**

It is impossible to read everything that has ever been said and written about advanced breast cancer and/or represented by visual images, and although there is less written about advanced breast cancer in younger women, covering the extent of the field is still a daunting task. My concern was to include data that gave insight into the problem under investigation and therefore it was the richness of the data that I was pursuing, not necessarily how much material I could accumulate (although I did amass a great deal). In addition, the various cultural sites that inform the experience of being young and living with a non-curable illness, and the discourses that shape them, contain no fixed boundaries or divisions between them. The health care system and the media system blend, and therefore exploring multiple sites makes methodological sense (Phillips 2001).

I collected texts together on the topic of breast cancer in young women and then focused on advanced disease. The data set included the following.

1. The professional research literature from 1997-2008. This literature included journals (251), clinical practice guidelines (2) and medical texts (5). (see page 9 for the description of the culling process)
2. 12 years (1996-2008) of news articles (230) from a selection of major national newspapers, that related to young women and (advanced) breast cancer.
3. Transcripts of focused conversations with 12 young women with advanced breast cancer. I conducted the interviews over an 18-month period from 2001 to 2003. These interviews were one off and not longitudinal.

This data set marks out the field of advanced breast cancer in young women at the beginning of the 21<sup>st</sup> century. I excluded visual images such as paintings, films and other forms of art as these were beyond the scope of this project. I will now outline each of these data sets in turn.

## **1. The professional research literature from 1997-2008**

### ***a. Professional journals***

The journals selected for analysis covered the period from 1997-May 2008. These years represent tremendous growth in the research into the prevention and treatment of breast cancer and the national statistics show evidence of improvements in mortality and survival rates amongst women diagnosed with advanced disease.

I used two major citation databases called the 'Web of Knowledge' and Ovid. These two databases link together the following citation indices: the Web of Science, Social Science, Arts and Humanities, Current Contents, Journal Citation reports, ERIC, CINAHL, MEDLINE, and PSYCHLIT. I searched for articles that referred to *breast cancer* (both advanced and early) and *young women* in their content. I combined this search with the term *breast neoplasm* and *premenopausal women*. I discarded articles that related to risk factors, diagnosis, screening techniques and cancers other than breast cancer. I concentrated only on those articles that featured young women who already had breast cancer. The search was limited to articles written in English. Nine hundred and fifty-six (956) articles were initially identified that related to young women with breast cancer; however, after the culling process only 251 articles remained. **Appendix 1** contains a chronology of article titles and content areas.

### ***b. Medical texts***

The medical texts chosen for analysis were those recommended to medical students by Flinders University on the subject of oncology and internal medicine<sup>10</sup>. There were five of these texts and all were edited books.

1. Harrison's Principles of Internal Medicine, (Fauci et al. 2008)
2. Oxford Textbook of Medicine (Warrell et al. 2003)
3. Davidson's Principles and Practice of Medicine (Boon & Davidson 2006)
4. Cancer: Principles and Practice of Oncology (DeVita, Hellman & Rosenberg 2005)
5. ABC of Breast Diseases (Dixon 2000)

### ***c. Clinical practice guidelines***

In addition to the formal research literature, I have included in the data set two clinical practice guidelines. Clinical practice guidelines are 'systematically developed statements to assist practitioner and patient decisions about appropriate healthcare for specific clinical circumstances (Dwyer 1998, p. 292). In 1995, the Commonwealth Government released a National Health Policy recommending the development and implementation of best practice guidelines. Since then, there have been approximately 15 published clinical guidelines covering a wide range of conditions - from the management of early breast cancer to the management of diabetes in young people. The clinical practice guidelines relevant for analyses were the *Management of Advanced Breast Cancer* (National Health and Medical Research Council 2001a) and the *Management and Support of Breast Cancer in Young Women* (National Breast Cancer Centre 2004).

## **2. Newspapers**

Newspapers are a fertile ground for the production and perpetuation of discourses. To analyse the content and discourses of the national newspapers, I subscribed to Newstext, a company that archives news material electronically. I searched and retrieved the articles via the Internet. While this method certainly saved a great deal of legwork, the illustrations that often accompanied articles were missing from the text, although a description of the picture or caption was included. I included only the Australian

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<sup>10</sup> Personal communication

newspapers that were archived by the Newstext Company. Included were both metropolitan and some rural newspapers. The actual list of the newspapers, together with their readership figures and coding schema can be found in **Appendix 2**.

I searched the newspapers using *breast cancer* as a key word in the first instance. To narrow the search fields, I then selected the terms ‘breast cancer’ and ‘young women’ as key terms. The search term *advanced breast cancer* yielded too few articles and therefore the more general term *breast cancer* was used. From May 1996 to May 2008, 1005 articles were isolated. I rejected articles that referred to breast cancer prevention and articles covering events whose sole purpose it was to raise money for breast cancer research. The newspapers did not differentiate between early and advanced or late breast cancers. Two hundred and thirty articles remained for analysis after the culling process. Nearly a third of those articles appeared during the month of October (73/230), the month dedicated to breast cancer awareness.

I examined newspapers firstly because of the power the media possesses to represent things in a particular light. They are influential in shaping attitudes and beliefs involved in cancer care as well as being shaped by these same forces. Secondly, newspapers are the social scaffolding around which young women with advanced breast cancer construct their accounts (Hardin 2003b). The heading of each of the newspaper articles appears chronologically in the **Appendix 3**, together with their content areas.

### **3. Interviews**

The story is not just a story. (Hardin 2003b, p. 543)

Both qualitative and quantitative researchers use the knowing subject as a starting point for the research process (Prior 1997). For example, epidemiological research gathers statistical information within a particular population to discover trends and disease patterns. Epidemiologists do this by conducting large surveys and gathering specific information about individuals. However, once the individual characteristics are gathered, the knowing subject is then discarded and the individual’s information is reconstructed in the search for a ‘pattern’ or an ‘effect’. In many qualitative research

projects, the aim is often to gather the individual's perspective on a particular phenomenon (O'Connor 2006).

It may be tempting to think that the world of advanced breast cancer exists only in the consciousness of the individual woman experiencing the disease. However, the world of advanced breast cancer can also be found in the social world of human connections. According to Foucault (1972, p. xiv), knowledge of this world can only be accessed by discovering its 'discursive rules' through which knowledge is produced. It is these 'discursive rules' that enable the 'author' to speak with authority on the subject of advanced breast cancer (Prior 1997, p. 65). Therefore, following Foucault's example, I am focusing on the discursive practices through which knowledge is produced and given form rather than on the knowing subject. The interviews are examples of discursive practices (Burman & Parker 1993).

My primary interest in the interview accounts therefore, was not so much on how the participants' experienced living with advanced breast cancer (although these experiences are important). Instead (or as well as), I was interested to know how these views came to be expressed in the first place, for what reason and for whom. As Hardin states:

It is important to recognise the influence that dominant social and cultural discourses have on the articulation of individual accounts. Commonalities in data gathered from multiple individuals and sources exist because individual accounts originate from broader cultural and historical discourses. (Hardin 2003b, p. 537)

An advantage in using a poststructural approach to interviewing is that it has enabled me to question how an account came to be, and what function it served. These questions would be normally be silenced during a sorting and coding process (Hardin 2003b).

### ***The interview process***

I interviewed 12 women recently diagnosed with advanced disease. I recruited the participants through personal networks, cancer councils and breast screening clinics. The sample was therefore purposive. An interview guide was constructed from the review of the public and professional literature on advanced breast cancer (**Appendix 4**). The participants' definitions and interpretations concerning the impact of advanced breast cancer were sought; the diagnosis and prognosis was used alongside their beliefs

and perceptions of the effects of treatment, information resources, support and survival. I followed the participant's lead when discussing the above topics. In a few cases, the areas touched upon in conversation were too sensitive for the women concerned. I therefore followed the participant's lead and did not pursue the topic further. The interviews were *focused conversations* as described by Street (1995). I focused each conversation on the particular issues and understandings of living with advanced breast cancer.

I taped all the interviews with the participants' permission and later transcribed them. The transcriptions were translations of what the participants said, and not an exact replica of the interactions that occurred (Willig 2001). I kept the transcriptions in a locked facility in accordance with NH&MRC guidelines for the storage of research material. Information concerning the participants appears in **Appendix 5**. This tabled information is not meant to contribute to the construction of these young women's identities; the categories do not capture the essential nature of who these women were and are (Willig 2001). A description of the participants appears at the conclusion of this chapter

#### **b. Next step: sorting and coding**

The next step was to sort and code the material collected in the three data sets. The coding process resulted in the identification of common themes. While these themes are not discourses, the process helped me to select the relevant sections of the texts for further exploration. This selection process also meant that there were numerous aspects that I did not analyse (Willig 2001). Inductive analysis was used to sort and code the data, as there was no predetermined coding frame that I was trying 'fit' the data into (Braun & Clarke 2006 892). The generation of the themes occurred using an active six phase process as outlined by Braun and Clarke (2006, pp. 87-93). These phases however are not necessarily linear.

1. The first phase involved familiarising myself with the data. I read extensively on the topic of breast cancer in young women, and read and reread the transcribed interviews, professional medical literature and newspaper articles. I analysed the three data sets separately. During this phase, I noted phrases of interest and jotted down initial ideas. For example, I noted that many of the newspaper

articles used highly emotive language in their headlines such as *Young hit hardest by breast cancer* (*The Mercury* 22/10/01), *The scourge of women* (*Courier Mail* 26/10/1998) and *Surviving with the enemy* (*The Australian* 7/2/1998). I also noted within the medical research literature how often probabilities were used to explain the chance of recurrence or the survival benefit of one treatment over another.

2. The second phase involved the generation of the initial codes. These codes identified a particular feature of the data. I systematically worked through all three data sets, noting interesting ideas, tensions and inconsistencies. These codes were developed and managed using NVivo, a qualitative software programme.

#### **An example of coding from the newspaper articles**

Data extract	Coded for
Jane Poynts is determined to make people aware that breast cancer is not just an older women's disease. She should know – at just 33, she had a mastectomy and was faced with the life-and-death issues that only younger victims of breast cancer know - if I die, who will look after my children? (Olsson 1998).	<ol style="list-style-type: none"> <li>1. Young breast cancer patients are victims</li> <li>2. Tragedy leaving children without a mother.</li> </ol>

### An example of coding from the research literature

Data extract	Coded for
An accurate prognosis is necessary not only to determine the natural history of the disease but also to establish the appropriate treatment. A better prognostic stratification of patients is important so that patients can receive treatment at an earlier stage of the diagnosis and to avoid unnecessary risk to those patients who do not need additional treatment (Guerra et al. 2003, p. 323)	<ol style="list-style-type: none"> <li>1. Prognosis is about prioritising treatment.</li> <li>2. Prognosis can be calculated</li> </ol>

### An example of coding from the interview accounts

Data extract	Coded for
I said in 5 years do they then say you're cured? And he said 'you're never ever hear that, they'll not say that to you'. That really shocked me, I thought, well I would presume in 5 years if it's not come back then everything is OK and I'm 100% cured, and he said 'no, you may as well say you're not actually in remission anymore but, they will never ever say that you're 100% cured, because they can't be positive about that.' (Belinda, study participant).	<ol style="list-style-type: none"> <li>1. Cure not a word that is used in advanced breast cancer.</li> <li>2. Probabilities determine cure.</li> </ol>

3. The third phase of analysis involved the searching for themes. This phase began once I had collated and coded all the data. I then placed all the coded data under the headings of the developing themes. Some of the initial codes went on to become themes and some codes amalgamated under other codes. I used an initial mind map to cluster codes under thematic headings. Themes did not have to be common to be identified as such; themes could also represent areas that were uncommon but pivotal to the experience in one way or another.

4. The fourth phase involved generating a ‘thematic map’ (Braun & Clarke 2006, p. 87) of the analysis. The themes identified in phase 3 underwent a refining process. I reread all collated data under a thematic heading to ensure that it formed a coherent pattern. I had to code some data again as it had been missed in the earlier code identification.
5. Defining and naming the themes occurred during the fifth phase. All the themes, together with their sub themes, that were identified during phase 4 were defined and named, detailing what was interesting about these themes and why.
6. The sixth and final phase involved writing up the results of phase five. Demonstration of the process of sorting and coding from the three data sources appears in **Appendix 6**. The initial thematic analysis mapped the variations within and across the three data sets. These themes, together with their sub themes, appear on the next page.

### Themes and sub themes

Data set	Professional publications	Newspapers	Women's stories
<b>Theme 1: Control of uncertainty</b>			
- prognosis calculations	yes	yes	yes
-survival/non survival	yes	yes	yes
- death hidden	yes	no	no
<b>Theme 2: Women responsible for their survival</b>			
-alternative/complementary therapies	yes	no	yes
-thinking right	yes	yes	yes
<b>Theme 3: Time's effect</b>			
-the imperative to increase time	yes	no	yes
-out of step with time	no	no	yes
-loss of a future time	no	yes	yes
<b>Theme 4: A tragic loss</b>			
-women are victims/heroes	no	yes	no
-motherless children	no	yes	yes
- loss of a future	no	yes	yes
<b>Theme 5: A body affected</b>			
-a thin body	no	yes	yes
-an object body	yes	yes	yes
-a disintegrating body	yes	yes	yes
- a female body	yes	yes	yes

The process of sorting and coding the gathered material provided a descriptive picture of the field of advanced breast cancer in young women over time. Yet these themes are social constructions. In addition, the common themes I have identified within the data sets are common because these are the discourses that are currently circulating in our society. We have all been exposed to the same circulating discourses and consequently there will be repetitions, in the accounts of young women living with advanced breast cancer, in the newspaper articles and in the professional literature (Hardin 2003b). These repetitions construct a 'truth' and the power relationships involved in such a construction become a usual occurrence in our society.

The process of sorting and coding the seemingly unwieldy amount of material was aided by the use of a qualitative software program QSR NUD\*IST Vivo (NVivo, version 1.1). This particular program was able to store and retrieve large amounts of data. Unlike some software programmes, the use of NVivo enabled me to preserve the rich and multifaceted nature of the texts, and did not reduce the data down to a number of commonalities. This preservation meant the texts became dynamic documents, fluid and flexible. As Richards (1999, p. 415) has stated, '(r)ich data means dynamic documents that grow as understanding grows, situations are revisited, insights inform, and links are drawn between data and ideas.' Therefore, NVivo was especially suited to the process of poststructural discourse analysis.

There is a growing amount of literature that debates the pros and cons of computer programmes used for qualitative analysis (Barry 1998; Grbich 1999). I am aware that there is a dark side to the technological innovation of computer assisted analysis (Seidel 1991). However, I found NVivo to be helpful in the storage and retrieval of data as well as in the initial process of data analysis and theme identification. First, I read all of the documents and broadly coded phrases and sentences with similar content. This coding involved the process of labelling aspects of the transcripts, allowed for sorting the information into categories and storing these categories as nodes (Bandara 2006). I read and re-read the documents at least four times and sometimes material that was initially coded under one node was reassigned into a different category. This step of code identification occurred during the sorting and coding process mentioned above.

### **c. Final step: analyse the material discursively**

Step 2 analysed all the texts descriptively and somewhat superficially. Yet, the six phases of thematic analysis were necessary in order to reveal the variations and patterns in the data. It also helped to identify the absences or silences within the texts. However, the process of coding and theme identification is not discourse analysis. What this initial analysis does not show is the contexts in which advanced breast cancer in young women takes place, nor does it reveal the reliance between individual accounts (Hardin 2003b). In addition, the process of thematic analysis develops broad categories and hence makes unclear the complexities and differences in the texts. It also hides the social and cultural locations in the data (Hardin 2003a).

Returning now to the insights derived from Foucault's work together with those of Parker (1992), I am now in a position to outline the questions that I asked of the data. As I approached the texts, I continually placed what I was reading in quotation marks: 'Why was this said, and not that? Why these words, and where do the implications of the words fit with different ways of talking about the world?' (Parker 1992, p. 4). For example, I examined the use of the phrase *epidemic of breast cancer*. Why was the word *epidemic* used and not another word? What connotations does the word *epidemic* have? Who speaks authoritatively about advanced breast cancer and what enables them to do so? What and who is absent in such an account? I considered these and other questions as I approached the data.

The identified discourses were generated using an adaptation of the process outlined by Parker (Parker 1992, pp. 6-20), which he based on the work of Foucault. Parker's original process involved 20 steps, and I have collated and reduced these to nine. This reduction in the number of steps was an attempt to simplify a very complex process. However, I believe that I have retained the main points of Parker's approach to discourse analysis.

### **1. Name objects**

It was necessary to systematically analyse objects that appear in the texts, the rationale being that discourses form these objects (Parker 1999b, p. 97). As I identified the objects, the discourses framing them began to take shape. I looked for nouns within the texts and asked 'what could these nouns signify?'

For example, the objects in the professional research literature were as follows.

- Doctor (category of person that dictated treatment, conveyed prognosis)
- Young women (category of person for whom aggressive treatment is intended, marker of development with 'young' being a significant marker)
- Breast (body part)
- Body (an object to be made docile)
- Mind (an object, lesser in status to the body)
- Disease-free survival (a category in which young women are rarely placed)
- Prognosis (a statistical calculation to predict survival)

- Survival (outlined in terms of years, five year survival is the aim)
- Cancer (aggressive, indiscriminate, lurks)
- Youth (being young is a risk factor)
- Treatments (response to these determines survival)
- Pathologist (category of person who decodes micro-cellular pathologies)
- Psychological morbidity (an illness state characterised by anxiety and depression)
- Time (treatments are about gaining time)
- Death (physiological state - absent)

Identifying the objects within the texts enabled me to get a first glimpse of the discourses at work. However, the edges of the discourses are still very faint.

## **2. Name subjects**

Next, I located the subjects within the texts and identified what position or role did they have to take on in order to hear what was being said? (Parker 1999b, pp. 98-9). Some of these subjects have already been identified as objects in the previous list.

- General practitioners (category of person to whom young women present to initially).
- Young women (category of person at a certain point in development, differentiated from older women)
- Pathologists (category of person who stages cancer)
- Psychologists (category of person charged with identifying psychopathology)
- Surgeons (category of person charged with extracting cancer from the body)
- Oncologists (category of person for whom research reports are intended)
- To hear what is being said, a young woman is drawn into the biomedical discourse, yet she does not have the knowledge to interpret the statistics, as she is a non-medic. She is also seduced into the discourse of individual responsibility
- To hear what is being said, a surgeon or oncologist is also initially drawn into the biomedical discourse and subsequently into the discourse of numeracy in order to make predictions

- To hear what is being said, a pathologist is drawn into the discourse of visibility in which the ‘truth’ of the cancer is revealed at the level of the cell (Stacey 1997).

### **3. Rights and responsibilities of subjects**

Next I outlined the rights and responsibilities of the subjects within the text and the network of relationships that position the young woman in relation to health care professionals (Parker 1992). For example, a young woman has the responsibility of following her oncologist’s advice and guidelines concerning treatment and follow-up. In relation to the young woman, the oncologist or treating doctor must present the best treatment options. These treatment options must be evidence-based. If she (the patient) is unable to choose between them, then the doctor has the responsibility to decide on the best course of action. The oncologist also has a responsibility for surveillance in the months and years to come, monitoring the cancer’s progress. In relation to the writers of the text, the young woman must seek advice early from the medical professionals. She must also follow instructions.

### **4. A discourse refers to other discourses**

This step involved mapping the different versions of the social world that live along side each other in the texts. The step necessitated the placing of the texts along side one another and looking for the interplay between the texts – that is their intertextuality. Parker writes that ‘discourses embed, entail and presuppose other discourses to the extent that the contradictions *within* a discourse open up questions about what other discourses are at work’ (Parker 1992, p. 13) (emphasis in original). For example, the professional literature invites other medical professionals to engage in prognostic calculations. The wording of the research articles assumes that the reader is in charge of a young woman’s management and care and has knowledge of histopathology. The category of the patient is gendered. As a result of this step, I identified several relationships at work within the professional texts: biomedical, paternal, psychological and numerical.

This step enabled me to isolate the discourses at work across the various texts. I was then able to name the discourses, which brings me to the next step.

## **5. Label the discourses**

It is now necessary to choose appropriate terminology for the discourses identified. The main discourses that I identified in the texts from the three data sets are as follows.

### **1. Numbers rule: the discourse of numeracy**

- a. Prognosis (Numbers define prognosis) [Theme 1]
- b. Survival is more than a number [ Theme 1]
- c. Numbers impose an individual responsibility to survive by
  - i. complementary therapies [Theme 2]
  - ii. thinking right [Theme 2]

### **2. Discourse of tragedy**

- a. Victims/heroes [Theme 4]
  - i. Battle metaphor [Theme 4]
- b. Mother-less children [Theme 4]
- c. Not enough time/Loss of a future time [Theme 3]
  - i. Medicine attempts to extend time [Theme 3]

### **3. Discourses of the body [Theme 5]**

- a. the thin body
- b. the declining body
- c. the object body
- d. the gendered body

The discourses identified above are not new discourses. We are already familiar with them because ‘the history that bears the discourses as “objective” phenomena is also a history that bears us as subjective beings’ (Parker 1999b, p. 102). In addition, the identified discourses are my responses to the various texts and are therefore my creation. The discourses are not objects separate from me, as I am implicated in their development and promotion (Parker 1999b).

## **6. Locate the discourse in a time and place**

Once I had named the discourses, I then located them in time, tracing their emergence, and noting how they have changed over the years. This step is similar to that described by Grbich as being from ‘the outside looking in’ (2004, p. 42). For example, the

discourse of numeracy includes the history of probability and statistics. The discourse of tragedy includes a history of dramatic forms and features that have subtly changed over time. The discourses of the body involves the history of the body in Western society and its emergence as disciplined body in a consumer society

### **7. Identify institutions at work**

Discourses and discursive practices (patient notes, medical journals, interview accounts, media releases) support and reinforce institutions (Parker 1992, p. 17) and therefore, in the process of analysis, it is necessary to identify which institutions are being reinforced when this or that discourse is used. For example, the discourse of numeracy reinforces the institution of medicine. It adds weight and legitimacy to the discipline by providing certainty in the face of advancing disease. The discourse of tragedy supports the institution of the media by sensationalising accounts of young women living with advancing disease. The discourse of the body reinforces the institution of both the media and medicine by providing a canvas over which these institutions can assert their influence and control.

In addition, this step involved identifying which institutions are attacked or subverted when this or that discourse appears. For example, the institution of alternative medicine is subverted or silenced when the discourse of numeracy is used to convey a prognosis in young women with advanced breast cancer.

### **9. Who gains and who loses?**

This next step involves identifying which categories of person gains or loses from the use of the discourse. For example, within the discourse of numeracy, the category of young woman loses its place within the discourse, for the language used by doctors confuses her. Within the same discourse, the category of doctor gains a great deal of prestige and power with his or her ability to foretell the future. This step also involves examining closely who is trying to promote the discourse and who would want to make the discourse disappear. The discourse of tragedy is powerful within our society and gains a great deal with its institutional location within the media. The young women in this study resist the discourse of tragedy, as I shall explain in a later chapter.

## **10. The sanction of oppression**

The final step involves looking at how one discourse connects with another to sanction oppression (Parker 1992, p. 20). How do the discourses of the body connect with the discourse of tragedy and numeracy to control the life of a young woman living with advanced breast cancer? How do these discourses allow dominant groups, such as those in medicine and the media, to justify the present by telling stories of the past and prevent other discourses from making history? These are important questions and represent the political orientation of this thesis.

## **4. The issue of rigour**

Scientific reliability says more about the culture of professional conformity than it does about the pursuit of understanding”. (Kellehear 1993, p. 42)

Issues of validity and reliability are important considerations in both quantitative and qualitative research; however, they are contested issues within the qualitative field. Some researchers advocate the use of different terms altogether to represent rigour in qualitative research. For example, for Sandelowski (1993) the term *rigour* is an uncompromisingly inflexible word that detracts from the flexible, reflexive nature of qualitative research, and terms such as *authenticity* and *trustworthiness* are better suited. However, other researchers consider the exclusion of qualitative research from conventional standards of assessing validity and rigour is tantamount to ‘methodological anarchy’ (Seale & Silverman 1997). Whatever the terminology used, issues of confidence in the results and credibility of the data are important ones to be discussed, for as Perakyla points out, ‘all serious qualitative research involves assuring the accuracy of recordings and testing the truthfulness of analytic claims.’ (Perakyla 1997, p. 216). I therefore used the following criteria of reflexivity, credibility and generalisability to discuss my establishment of methodological rigour.

### **a. Reflexivity**

According to Willig (2001, pp. 10-1), there are three aspects to reflexivity. The first aspect is *personal reflexivity* and refers to an awareness of how a researcher’s values and beliefs shape the construction of meaning during the research process. Therefore, personal reflexivity is about making explicit my socially constructed values and beliefs

at each step of the research process and exploring the impact that these values have on the way I interact and interpret the texts (Grbich 1999). To this end, my thoughts and feelings were not held in abeyance during the research process as would be demanded by some methodological approaches. My prejudices concerning advanced breast cancer in young women were brought into play in the analysis of texts. Gadamer suggests, and I agree, that our prejudices open us up to the world.

Prejudices are not necessarily unjustified and erroneous so that they inevitably distort the truth ... prejudices are biases of our openness to the world. They are simply conditions whereby we experience something – whereby what we encounter says something to us. Gadamer (1975) cited in Bernstein (1983, p. 127)

Therefore, reflexivity alerts readers to what occurred during the research process (Koch & Harrington 1998). It is then up to the reader to ascertain whether the findings are believable or not. I acknowledge that the judgement of this research's quality is therefore dependent on the reader (Rolfe 2006). I attempted to clarify my beliefs concerning the nature of advanced breast cancer right at the beginning of the thesis. My values and beliefs as both a woman and a palliative care professional no doubt affected the way I approached the participants, and interpreted and interacted with the data. There is the potential for my views to dominate any interaction and therefore being mindful of differences relating to power and culture, I approached each interaction with sensitivity and thoughtfulness (Grbich 1999). I kept a professional journal during the candidature of my Ph.D. in order to make visible my thought processes and decision trail at each stage of the research. My interest in the field of advanced breast cancer is central and not to be hidden away nor discounted.

The second aspect of reflexivity is called *epistemological reflexivity* (Willig 2001). This aspect involves questioning the assumptions that have underpinned the research process, assumptions dealing with issues such as the nature of knowledge and the function of language. It also involves asking questions about the actual research process such as how the design of the project and the methodology chosen may have constructed the results. Could I have investigated advanced breast cancer in young women differently and to what effect?

The third aspect of reflexivity is *critical language awareness* (Willig 2001). This is the acknowledgment that the words I have used during the study to try to analyse the

experience of living with advanced disease have shaped those experiences. Therefore, the thematic groupings and the identified discourses are my constructions and do not mirror reality.

### **b. Credibility**

One way of attempting to ensure that the descriptions of discourses were as credible as possible was to give my work to others to read to see whether the material had internal logic to it. I did not use a panel of experts to validate my categories, themes or discourses, as there is no consensus on the nature of the reality of advanced breast cancer in young women. No two researchers are going to discover the same themes or discourses.

An additional way of ensuring credibility of the data is to hand the conversational transcripts back to the participants so that they can verify that the content accurately represents what they said during the interview. Member checking is also one way of showing respect for the participants of a research project (Liamputtong 2007, p. 61). I did attempt member checking in this project; however the young women did not take up this offer due to the emotional nature of the stories and the desire to put the whole experience behind them. Other researchers have also found that giving back transcripts and interpretations places an additional burden on participants (Harcourt & Frith 2008). While I acknowledge that I attempted to give back the transcripts, I also acknowledge that member checking has its limitations. It is felt by others that this process may actually undermine any attempt at trustworthiness (Koch & Harrington 1998). Furthermore, I as the researcher and the participants in the research process had our own separate agendas in the stories that were told. Stories do differ depending on who is asking the questions and the different interests that are being served in the process (Sandelowski 1993).

### **c. Generalisability and representativeness**

The term *possibility* is perhaps a more useful concept than generalisability (Perakyla 1997). It is possible that the various constructions of advanced breast cancer in younger women are generalisable to other populations and sites of practice. There is no reason to think that the results cannot be transferable. It is possible. I did not aim for a

representative sample that was going to provide an overview of a particular experience of living with advanced breast cancer. Instead, I sought to explore how attitudes came to be shaped, perpetuated and legitimised through the use of language (Tonkiss 1998, p. 253). Consequently, I looked for information-rich cases and it was hard to predict the amount of material that I would need to collect prior to the project commencing. Discourse analysis draws upon many and diverse texts, and not just interview material.

Finally, a research project can be considered plausible when

... the work is engaging, and has an internal logic achieved by detailing each interpretative, reflective turn of its makers. This means generating data with the awareness that this process operates in a world of existing alternative representations serving to shape the research product with social, political and critical insight. (Koch & Harrington 1998, p. 888)

By considering the criteria set out above, I believe that this research project and the findings contained within it are plausible.

### **5. An ethical comporment**

A discussion of the ethical requirements of this project involves more than simply a discussion of university committees and research protocols. It also involves the way I conducted myself throughout the course of the study - my ethical comporment, and my relationship with the participants.

Submitting a research proposal to an ethics committee is meant to ensure that the research will follow the long held ethical principles of an individual's right to decide and the sanctity of that individual's decision. The language used in such proposals is impartial and objective, a discourse in itself, that smoothes away the complexities of conducting research with real people. I gained approval for this research from a combined university and hospital ethics committee, yet the members of this committee were not there as I renegotiated consent with the participants or dealt with the difficult nature of interviewing people who know that their lifespan was limited. As Madjar and Higgins (1996) have stated,

Once in the field, carefully developed protocols and undertakings to act in particular ways become more difficult to sustain, impeding not only the research

process but also making difficult respectful, sensitive interactions with research participants and others in the clinical setting. (p. 133)

My strict adherence to the research protocol did not protect me from feelings of sadness and helplessness, nor were they sufficient to guide me through all the contingencies that arose during the conduct of the research. My ability to act as a moral agent relied upon the sensitivity and thoughtfulness with which I approached, not just the interview encounters but the complex web of data as well.

Part of the study required that young women share with me their experiences and perceptions of living with advanced breast cancer. It was perhaps unavoidable that some information was extremely sensitive and emotive for both the participants and me. There were a number of instances where the young women cried during the interview process as they talked about the process of living with a life-limiting illness. I too experienced deep emotions on hearing these stories. Sometimes the interviews needed to be suspended for a period until the young woman concerned felt ready to continue. Indeed, asking people to share their experience carries with it a responsibility to provide adequate support in the form of follow up visits and telephone calls. Whilst I recognised that for some participants the sharing of their experiences was therapeutic and provided a safe forum for discussion, some participants may have required additional support in the form of a trained counsellor. Other writers have also recognised this need for a contingency plan when researching vulnerable groups of people (Liamputtong 2007). I did ask the participating organisations to identify professional counsellors to whom I could refer the women should it be required. This arrangement was part of the contingency plan. However, as it turned out, I did not need to call on their expertise on behalf of the participants. I appeared to need the service (or its equivalent) more than they did as I pondered a world where children were left without a mother, where one partner remains to live on after the death of the other, where desperate searches for cure and survival take place. I managed these feelings of despair and sadness through debriefing with my supervisors, self-reflection and journaling.

It was difficult to foresee all the ethical implications of the study due to the nature of the methodology chosen; yet issues of informed consent, of doing no harm, confidentiality

and anonymity were all addressed. The issue of informed consent requires some further discussion. I recognise that consent is not a single event. I needed to renegotiate this consent repeatedly throughout the course of the project. My original intention was to interview the women several times over the course of the data collection period. However, one day a participant would agree to be part of a conversation and then have second thoughts about further conversations the next time we met. Several of the women said that they did not really want another interview with me down the track as they did not want to be reminded of the things that they had said to me in relation to their survival and present situations. One of these women did say, however, that she valued being able to talk and tell her story, as this was the first time that she had had the opportunity to do so; but she had no desire to repeat the conversation at another time in the future. Therefore, my approach needed to be flexible and reflexive. I had to shelve the idea of following the young women over time.

Confidentiality of the research participants and research settings was assured. Pseudonyms were chosen for both settings and participants in all but one case. One woman, Sue, wanted her real name to appear in this thesis. The audiotapes, transcripts and field notes have been kept in a locked file in a research office and will be kept in such a manner for a period of five years and then erased. To further assist in the process of confidentiality, some details that did not directly affect the story of living with advanced disease were altered or written in such a way so as to not automatically point to a specific person or their family. For example, I changed the number and gender of the children each woman had and often changed their location. Both the information sheet given to participants and consent form can be found in **Appendix 7 and 8** respectively.

### ***6. Description of the Participants***

As I introduce the women, I have used the present tense because at the interview they were all involved in the business and burden of surviving with a life-limiting condition. The majority of these women have since died from their disease.

### **1. Anna**

Anna is made aware of the potentially serious nature of breast cancer through the recent death of a close friend. As a direct consequence, she examines her breasts for the first time in many months. She discovers a lump, which proves to be breast cancer. She is 39 with three young children and a partner. Her diagnosis is given to her over the phone and the manner in which her diagnosis is conveyed is extremely stressful for her. As far as treatment goes, her specialist gives her a number of choices and she finds this array confusing and disturbing. After considerable debate, she chooses to have a mastectomy. The oncologist suggests chemotherapy, which she refuses. She is not offered radiotherapy, or Tamoxifen, and her cancer is oestrogen-receptor positive. (In hindsight, she would probably have benefited from these additional therapies – this opinion is based on a review of the literature). Anna relays to me that during those early months, ‘everything seems to happen very quickly. You don’t get a lot of time to research before (the surgery) ... it is amazing what you accept from a doctor’. She does not realise the importance of her choices until later. Initially, her specialist tells Anna that he does not believe that she will die of her disease. Anna believes him, as she has a grandmother who developed breast cancer in her sixties and is still alive. She finds the positive statement concerning her prognosis to be helpful, at least in the short term.

Over the ensuing five years, Anna feels well and participates in her family’s life and in the life of the small rural community in which she lives. She believes that God will heal her, has healed her. She also believes that her initial cancer resulted from various lifestyle factors and the effect of fear and stress on her immune system. During her 44<sup>th</sup> year she begins to experience low backache, which she dismisses as the result of constant lifting at home, and just before her five-year check-up with the oncologist, she notices a lump on the side of her neck and on her chest wall. Further investigations reveal that these lumps are metastases from the original cancer. After several bone scans, she also finds that the cancer is invading her spine and her hips. Cancer’s return is a shock to both Anna and her specialist.

She is experiencing bone pain the day I interview her and says to me that the frustrating thing about the pain is that it persists and it prevents her from doing many things in her day-to-day life. Her children now do many things for her and she finds this aspect of the progressing disease distressing. At the conclusion of our conversation, she

acknowledges her hope of living and not dying. 'I guess not many people get better from it [advanced breast cancer] but it is possible.' I keep silent.

## **2. Belinda**

Belinda, at 38 years of age, has just entered into a new relationship. She notices a hard lump in her breast. She goes to her GP who, according to Belinda, does not appear too concerned and he orders both a mammography and an ultrasound. The oncologist confirms a few days later that the lump is indeed breast cancer and relays some more information about the nature of the disease to both her and her husband. The cancer is already in her lymph nodes - 'extensive lympho-vascular involvement' and 'high grade carcinoma' are the terms she remembers being used. It is at that moment that Belinda says she realises that her condition is serious. Her treatment consists of a partial lumpectomy, and she says of her surgeon, 'it's so hard to talk to him, so hard to get any information out of him, it's like getting water out of a stone' (P. 55). After the surgery, Belinda has chemotherapy. Radiotherapy is commenced in the middle of the course of chemotherapy. Belinda experiences an intense skin reaction (burn) over her chest wall and only completes 25 of the 30 proposed radiotherapy sessions. She is hospitalized for dressings, pain relief and intravenous antibiotics. I interview her two weeks after her discharge from hospital, nearly six months after her diagnosis of advanced disease. Her periods stop and are likely to remain so due to the treatment. Even though Belinda has a child from her previous marriage, both she and her husband were planning to have more. Early menopause robs them of that choice, although Belinda says that she is relieved with the way things had turned out. Belinda has since recommenced work part time and appears to be getting on with her life in a small rural community, yet realises that she will never hear the words 'you're cured'.

## **3. Carol**

Carol is 27 when she discovers she has breast cancer (she is now 42). After an initial segmental mastectomy in one breast, she finds another new cancer in the other breast. Due to the strong history of breast cancer in her family – her mother also developed breast cancer at the age of 27 - she decides on a bilateral mastectomy and reconstructive surgery. Chemotherapy and radiotherapy follow and eleven years pass during which time Carol feels well. Five years ago, she entered into a new relationship with a man

who has two children by his previous marriage. Shortly after meeting this new man, she begins to have problems with her vision. Breast cancer has reappeared in the retina of both her eyes, and after further investigations, she and her husband learn that the cancer had also spread to her lungs, her bones and her liver. It ‘just popped up everywhere’ she says. That was four years ago. Since that time, she has had numerous courses of chemotherapy and radiotherapy, and surgery to remove her ovaries. The term ‘palliative care’ is initially shocking for Carol, although she has experienced the benefits of effective pain control that a palliative care team has been able to deliver. However, she appears comfortable with the concept during our conversation. She understands that her prognosis is limited, yet does not want to dwell on the numbers or probabilities. She has a strong faith in God and says that she can remain positive most of the time. She and her husband live outside the metropolitan area of a large city.

#### **4. Donna**

Donna discovers her first breast lump when she is just 32. She has a partial lumpectomy, and a few years later a second lump appears in the same breast necessitating a mastectomy. After both operations to remove the breast cancer, Donna has no radiotherapy or chemotherapy. Seven years later, she begins to experience shoulder and arm pain, which she puts down to a work injury. As she is due for a check-up with her surgeon in a few weeks time, she delays having the pain explored until her scheduled appointment. The surgeon biopsies an area on her chest wall, just under her arm that appears suspicious on the CT scan. She is given the ‘all clear’ at this time, yet four weeks later another lump appears on her chest wall, the same place as the biopsy site. Her surgeon refers her to an oncologist who confirms that the cancer has indeed returned; it has now spread to her liver, lungs, sternum and chest wall. These events occur a year before I interview Donna. Chemotherapy appears to work very effectively in reducing the size and extent of the tumours, yet the effect is short-lived. A month after completing chemotherapy, pain and a lump returns similar to the one she had a year ago. The fact that pain has appeared so quickly after chemotherapy seems to surprise her oncologist who initially thinks that the lump is nothing too serious. Donna however knows that something is wrong as these words indicate: ‘When I’d had the chemo and they’ve said everything was fine and I’m saying, things aren’t fine, I know they’re not, something’s happening here to me ... nobody was listening’. Frustration and anger follow. The lump continues to grow, as does the tumour in her liver. Further

chemotherapy and radiotherapy are given yet Donna realises that her cancer is no longer considered curable. She searches for someone to say just how long she has to live, but no one is able to tell her. She now suffers from depression and is under the care of a psychiatrist. She has a husband and two teenage children and continues to work and find support in the small rural community in which she lives.

### **5. Emma**

Emma is diagnosed with advanced breast cancer at the age of 38, just six months before our interview. This is her first diagnosis of breast cancer. Emma finds a large lump in her breast that seemingly appears ‘almost overnight’. Subsequent tests prove that the cancer has already spread to her bones. However, the word ‘cancer’ is never mentioned to Emma in the early stages of her diagnosis. Her disease is referred to as a ‘worrying lump’ or a ‘growth’. First, she has chemotherapy and then surgery, followed by more chemotherapy. Emma finds the words on her admission forms disturbing. The forms state that the reason for her treatment is to prolong her life and not cure the disease. This is new information for Emma. She wants to know what her prognosis is. Knowing this, she says will help her deal with the events she now has to face. Not knowing how long she has left puts her into a sort of limbo land where nothing can be pinned down. She needs to know so that she can begin to grieve. She is beginning to get tired of the ‘best case’ scenario stories: ‘... the surgeon and the oncologist want to give us the story of their best case scenario and that is tiring us out because this best case is somebody else, not me’ (P. 94). Emma is married and has two children. She hopes to see them through as many milestones as possible and is beginning to prepare them for a life without her. She says she is sustained by her faith in God and, like Donna, draws upon the support of the small rural community in which she lives.

### **6. Fran**

Fran is unusual in that she is breast-feeding her 7-month-old baby at the time she discovers a breast lump. The ‘Women’s Weekly’ has just run a story about a young woman who finds a cancerous lump during breast-feeding and this article jolts Fran to check her breasts under the shower one night. She is 36 years old. She has a lumpectomy followed by radiotherapy and an oophorectomy. Yet another lump appears in the same breast before the end of the radiotherapy treatment. She then has a full

mastectomy and chemotherapy. A few months after the completion of this treatment, her specialist discovers metastases in her bones. 'It is the sort (of cancer) that just doesn't go away' says Fran. The cancer remains quiescent for five and a half years, not causing Fran too much discomfort.

Two months before I have this conversation with Fran, she starts getting bad headaches. A tumour has started to grow in her brain necessitating surgery and further radiotherapy. Fran now walks with the aid of a stick and has permanent weakness down her left side. She knows that the cancer is incurable and that it will 'pop' up again somewhere else, and chooses particular treatments with the smallest number of side effects because she lives alone and still has to care for her child. For Fran, the most difficult thing about living with advanced breast cancer is the time consuming nature of all the treatments. She has not wanted to know her prognosis. She has months rather than years to live in my opinion.

### **7. Gena**

Gena is 43 when diagnosed with breast cancer. Her youngest child has just started kindergarten. Her doctor discovers a lump in her breast after she has complained that it (the breast) has been very painful. Her breast cancer is stage III (highly undifferentiated cells, poor prognosis) and she undergoes a lumpectomy followed by chemotherapy and radiotherapy. Three lymph nodes are also found to be involved. She says that she trusts the medical system and does not pursue other forms of healing. Her oncologist commences her on Tamoxifen.

Even though Gena develops lymphoedema subsequent to her treatment, she returns to work, restarts some exercise, and feels that some degree of normalcy has returned to her life. Nevertheless, this feeling does not last for long. Ten months after she completes her treatment, the cancer returns. This event is very unexpected for Gena who never dreams it will return so quickly. Indeed, she is very angry that after all that she has been through, cancer returns. It has now spread into her liver and bones. Further chemotherapy follows. She asks about her prognosis and is told that she has maybe months, but certainly no more than five years to live. She now takes Herceptin and a bone-strengthening agent and mourns the loss of her future.

## **8. Helen**

Helen intuitively knows that she had breast cancer prior to its confirmation. She repeatedly dreams about dying and returns to her doctor for reassurance a number of times. The doctor says that there is nothing wrong with her breast. She is nearly 29 years of age. Eventually the doctor agrees that there is indeed something amiss as by now (six months later) Helen has puckering of her skin when she lifts up her arm. She has a mastectomy and removal of her lymph nodes; 12 out of 20 lymph nodes contain cancer cells. Helen does not want to know too much about her prognosis, as she says 'the less information the better'. In her opinion, too much knowledge creates fear. Her doctors tell her that she has perhaps 2-3 years left and she laughs. She does not believe in this prediction of her survival and has a strong faith that it will not be so.

Well-intentioned acquaintances give Helen books on self-help and healing and she throws them all in the bin. She says she feels very vulnerable during treatment and just after, and she feels that people play on this vulnerability. Stories of older women surviving cancer are not inspiring at all.

The thought that she may not be able to have children is devastating for Helen as it is something she has always wanted. Doctors tell Helen that she will not be able to have children or at least it would not be wise. Yet in July 1998, she has her first baby. Helen's obstetrician wants to discuss her previous breast cancer with her but she says that the obstetrician is not her oncologist and if she wants to discuss such details then here is the name and number to contact. Now, she is not on any treatment for breast cancer. From Helen's perspective, the cancer is gone.

## **9. Inge**

Inge's cancer is diagnosed at an already advanced stage. Initially, the primary site of the cancer cannot be found and doctors therefore classify it as a 'cancer of unknown origin' (very poor prognosis). After several mammograms and scans, her doctors determine that breast cancer is the most likely site of origin. She is 36 years old.

Inge is keen to find out all that she can about the stage of her cancer and her prognosis. However, finding out that her probability of survival is very low, she becomes very depressed. She rings the cancer helpline in order to try to find someone with whom to

talk. However, the woman she eventually links up with is no help as this woman's breast cancer has a much better prognosis than Inge's. She knows that she will die of her disease yet is uncertain when that might be. Her oncologist says it could be months or years off yet. Inge optimistically hopes for a long life.

She has two young children 2 and 6 years old. Her partner also has a chronic illness which means that there are many stresses in this family. Palliative care is a term that she has not yet heard in relation to her ongoing management, and she does not really want to. From Inge's point of view, palliative care means that death is near.

### **10. Jessica**

Jessica, at 40 years of age, tells me that she has had lumpy breasts all her life. During a regular check-up, her GP notices that one breast is lumpier than the other and orders further investigations 'just to be on the safe side.' The following mammogram and ultrasound turn out to be negative. A few days later, she has a fine needle biopsy. The results of this biopsy show that she has invasive breast cancer. Due to the cancer's pathology (Stage III) and after an initial lumpectomy, she returns to hospital for a mastectomy. Cancer has spread to over half of the axillary lymph nodes (poor prognosis). Her treatment protocol includes radiotherapy, followed by chemotherapy, followed by more radiotherapy.

The diagnosis of breast cancer comes to Jessica, as it does to many women, as a total shock. Her breast is not sore, nor does it feel like anything other than the way it has always felt. She feels that she is to blame for not discovering the lump earlier, saying 'I am sort of chastising myself thinking, you know, why wasn't I more observant, but I honestly didn't think that (breast cancer) was likely.'

Jessica realises that her chance of long-term survival is not great, although she does not elaborate on this to me. Jessica, like many of the women that I interviewed, wants to know as much as possible and uses a vast array of resources to get this information; she especially uses the internet. She wants to be able to talk with other young women about their experiences of breast cancer.

Jessica is surrounded by a supportive network of friends and family, which makes her recovery after surgery not as stressful as it can be for some women who do not have this level of assistance. She tells many people that she has breast cancer in the hope that one of them might discover a breast lump earlier than she did. Being positive and having positive friends with a sense of humour is important to her. She especially wants a positive face to be presented to her children and assumes that everything is going to turn out right in the end. She has two children under the age of 10 and is very concerned that the cancer may come back. She reads the information in magazines and newspapers about women and breast cancer; however, it means little to Jessica for as she says, these women are not like her.

### **11. Karen**

A year before I interview Karen, she finds a breast lump and her co-workers urge her to have it investigated. At 36 years of age, Karen thinks that she is too young to have cancer. In addition, she also thinks that women under the age of 50 do not get breast cancer, her reasoning being that all the public health campaigns for mammography screening are targeted at women over this age. She cannot remember what stage her cancer is at diagnosis, as it is not given to her. From her description of the cancer's histopathology, I surmise that it is stage III. Like Jessica and Inge, Karen is hungry for information and she searches the internet and other sources. She wants to know how much time she has, as she wants to use what time is left to her wisely.

Karen has a mastectomy followed by radiotherapy. She remains positive, on the outside at least, for the benefit of those closest to her. Yet on the inside it is a different story; she is full of doubts and worries. Her teenage daughter, once very close, has begun to distance herself from Karen, which is a great source of pain. She wonders if her daughter is worried about what might happen to her if she does not get better or if she too will get the cancer, given its genetic link.

### **12. Sue**

*Sue Tyler wants her actual name to appear in this thesis, not a pseudonym.*

Four years ago, Sue Tyler is diagnosed with advanced breast cancer. She is now 47 and has by her own admission about one year left to live. She wants to be around when she

turns fifty; however this is unlikely given her present situation. She says to me that her story is not the story of a celebrity or a model, but of an ‘ordinary Australian’ who wants to make a difference in the time she has remaining. Her story is not unique by any means. I meet a number of people like Sue during my research, but I am taken with her passion to make a difference to the lives of others.

Since her diagnosis of advanced breast cancer (it has spread to her bones) and subsequent surgery and radiotherapy, Sue maintains that she has not felt ill. Even when she underwent surgery for some collapsed vertebrae in her neck because of tumour involvement, she states emphatically that she has never felt sick in the whole time that she has been living with cancer’s progression. Sue refuses chemotherapy. I ask Sue what in her opinion is it about chemotherapy that means a shorter lifespan for those who have it. She considers chemotherapy to be a poison and the side effects of the treatment are the things that kill, not the cancer itself. She says, ‘try getting that into the media and they want nothing to do with you’. Apart from refusing chemotherapy, Sue attributes her survival to the fact that since her diagnosis, she has taken control of her life. She no longer mixes with people who have a negative approach to life. She has jettisoned those around her who have not been able to cope with her diagnosis and prognosis. This has meant that she feels very much alone and isolated. Sue knows her condition is terminal and she speaks openly about her impending death.

It is difficult after describing the women above to move on to the technical and necessary summary/conclusion of the research’s methodology and research context. I acknowledge that the stories are deeply moving. As the reader moves through the next three chapters containing the results and the discussion, their names will reappear repeatedly, keeping their stories alive, which I hope will pay tribute to the women’s generous contributions.

## **7. Summary and Conclusion**

In this chapter, I have outlined some approaches to discourse analysis and argued that the poststructural approach to discourse analysis was an appropriate one when looking at the various ‘truth’s of young women living with advanced breast cancer. I have described the three data sets used in data analysis and the steps I undertook to unravel the multiple threads of the discourses at work in the area of cancer care, the media and

in the young women's narratives. I have also explored issues of rigour, which involved considerations of reflexivity, credibility, generalisability and representativeness. I addressed several ethical issues that related to anonymity and confidentiality before closing with a description of the young women who participated in the study.

Within the field of discourse analysis, the examination of texts provides many interpretations. I as a researcher have actively constructed the discourse descriptions appearing in this thesis and these interpretations are only one of any number that could have been made. Consequently, the knowledge produced is only ever partial.

Representations are always produced within cultural limits and theoretical borders, and as such are necessarily implicated in particular economies of truth, value and power. In relation to these larger axes of power in which all representations are embedded, it is necessary to remind the student: Whose interests are being served by the representations in question? Within a given set of representations, who speaks, for whom, and under what conditions? Where can we situate justice and human freedom? What moral, ethical, and ideological principles structure our reactions to such representations? (Giroux 1992, p. 219)

Therefore, the representations of advanced breast cancer in young women have no meaning other than those that I have assigned to them discursively (Giroux 1992, p. 220).

In conclusion, discourse analysis from a poststructural orientation is an extremely complex and diverse method. In this chapter, I have discussed various approaches to the analysis of discourse and provided a description of the steps involved. I explored how these women take up, negotiate, reject or embrace discourses that arise from both the professional and the public domain. The next chapter begins the process of outlining the discourses that are apparent in the texts of advanced breast cancer in young women.

## RESULTS AND DISCUSSION

After collecting and developing codes for the pertinent data relating to young women with (advanced) breast cancer, I conducted a thematic analysis and found five main themes that appeared common across the three data sets. These themes were the control of uncertainty, young women responsible for their survival, time's effect, a tragic loss and a body affected. The results of the discourse analysis saw these five themes being incorporated into three discourses: the discourse of numeracy, the discourse of tragedy and discourses of the body. The initial themes provided a descriptive picture of young women diagnosed and living with advanced breast cancer, and the discourses illuminated the forces that were at work within the various texts.

The resulting three discourses were not the only ones that could be seen operating within the data; others were also present. For example, the overarching discourse of science dominated both the newspaper articles and the medical literature and often the stories of the women themselves. However, throughout its construction, the discourse of science constantly referred to and relied upon the discourse of numeracy for its display of power. Therefore, the discourse of numeracy, while a subset of the powerful and pervading discourse of science, provided a more focussed discussion on a discourse's effects. Likewise, the discourse of tragedy draws upon the broader discourses involving time and mothering. In addition, the discourse of the body referred to and drew upon the discourse of individual responsibility and the discourse of consumerism. Indeed, it was often difficult to disentangle one discourse from another. Consequently, while I have presented the discourses in individual chapters, the discourses overlap and merge, belying their separateness.

As I will now illustrate, although the discourses of numeracy and the body were by far the most dominant within and across the three data sets, the discourse of tragedy bridged these two, providing a pathway from one discourse into the other. I begin the discussion of results with the discourse of numeracy, as it was the most dominant within the professional medical literature. The next chapter discusses the discourse of tragedy, as it was the most dominant force at work in the newspaper articles. Finally, I present the various discourses of the body. These were dominant across all three data sets, but were particularly strongest in the interviews. I have combined the results together with the discussion of the discourses' significance, as it seemed appropriate to do so.

## CHAPTER 5: THE DISCOURSE OF NUMERACY

### *Introduction*

Probabilities are in every case artefacts, created (but not arbitrarily) by instruments and by well-disciplined human labor. By now, an economist, doctor, or psychologist who cannot comprehend statistical arguments involving variances and probability values will work less effectively on that account. This is not because the world is inherently statistical. It is because quantifiers have made it statistical, the better to manage it. (Porter, T 1995, p. 213)

In the previous chapter, I argued that discourse analysis was an appropriate method to explore the various knowledges currently being drawn upon within the public media to make sense of young women living with advanced breast cancer. I located this method within a poststructuralist framework in which discourses are to be found within and across texts.

In this chapter, I focus upon the concepts of probability, prognoses and survival as these concepts emerged from the initial analysis of newspapers and review of the literature, and they are objects within the discourse of numeracy. First, I provide a brief and selective history of numbers. Second, I illustrate - through extracts from the analysed newspapers, professional journals, medical texts and clinical practice guidelines - the several constructions involved in the discourse of numeracy. Third, I compare and contrast these constructions as they bump up against the young women's narratives. Finally, I show how this discourse shapes and regulates the young women's experiences at both an individual and a wider social and cultural level.

In the medical-scientific worldview, the discourse of numeracy plays a significant part. Numbers, as the components of the probability equation, are one of the ways that doctors convey the risks of various treatments and their likely outcomes to patients. For example, treating specialists now recommend that pre-menopausal women with oestrogen-positive tumours undergo ovarian ablation as it provides - or at least is thought to provide - a 10% increase in survival (National Health and Medical Research Council 2001b). Doctors discuss with their patients the probability of disease recurrence and death, tentatively at first, and then with increasing certainty as the biological

signposts show that cancer is on the march. Yet probabilities, like numbers, are artefacts of human endeavour.

Young women living with advanced breast cancer have lived with these percentages and probabilities during the course of their illness. Over time, they become aware that their chance of long-term survival is remote, yet each of them hopes to be among the few to be still alive in five years time. In this chapter, I argue that probabilities make little sense to them for their chance of living and dying with an incurable disease is already 100%. Probability has become a certainty.

While numerical representations are a significant part of the discourse, the discourse is more than numbers; the following concepts are also part of its fabric.

- *Probability* – Likelihood or a chance, something that is stronger than possibility but falls short of certainty.
- *Prognosis*- A foretelling or a prediction; a forecasting of the probable course and termination of a disease; a portent or omen.
- *Survival* - living beyond the life of, or continuing longer than another person, thing or event; an outliving; the act, state, or fact of surviving.
- *Non-survivor* – a person who does not outlive another; someone incapable of surviving changing conditions or misfortunes.

(Macquarie Encyclopedic Dictionary 1990)

### **A brief history of numbers – from the outside looking in**

Mostly, we are all familiar with numbers and the counting and collating of facts. However, the counting of things and the keeping of records are relatively recent phenomena. Initially, only churches kept records of christenings and burials for the state had little need to count anything else (Hacking 1991). However, with the advent of industrialisation (around the 1820's) and with the establishment of towns there arose a great need for the state to keep accurate records for the purpose of efficiency and profit. For example, newly formed companies began keeping records of the number of people employed or the cost of a particular item (Levinson 1963). Because of the state's

interest in its economy, the collection of numbers grew exponentially into statistics on plagues, deaths, crime rates, suicide and other human events (Hacking 1991). Finding patterns in such an array of information has helped to simplify it, make it more predictable and somehow less chaotic.

In medieval times, the treatment of sick people depended mostly upon the outcome of a few observations and/or anecdotal evidence. Implicated in disease causation were such things as bad humours and evil spirits. Scurvy for example was believed to be a contagious disease for over 250 years, that is, until 1754 when James Lindt discovered the link between the lack of oranges/lemons in the diet and scurvy's symptoms (Everitt 1999). A few years after James Lindt's observations (1780), Laplace a mathematician, teamed with the chemist Lavoisier to examine respiration in guineapigs. The experiments at times gave conflicting results which the men explained away as 'errors', concluding that there were some events within the experiment and within the unfortunate animal itself that just couldn't be controlled. They believed that it was solely due to their ignorance of the confounding events that led to the difference in results (Gigerenzer et al. 1989). If they could only control these unknown events, then the results of future experiments would be identical and hence predictable (Hacking 1991). The controlling of confounding variables is part of the workings of modern statistics.

Today the use of statistics underpins the randomised controlled trial, the utopia upon which the foundations of evidence are based and recommendations for clinical practice made. Clinicians are loath to use lesser forms of evidence (personal opinion or subjective judgement), as the professional community views these with suspicion (Everitt 1999). The medical community also uses statistical tests to calculate 'cancer specific survival', an estimate of how soon the cancer might return or more significantly, how soon the cancer might cause death (Anderson, T 2002). Within the field of palliative and cancer care, discussions of 'how soon the cancer might cause death' play a major part of the clinical encounter. Even if the woman does not ask "how long have I got to live", like the large animal in the room that no one is talking about, the length of possible survival is on everyone's mind (Christakis 1999).

### **1. In the professional literature**

The discourse of numeracy reigns supreme within the professional literature in all its forms. It appears as actual numbers, as percentages in probability equations, as statistical tests that support one hypothesis over another, and as words. Firstly, here are some examples of the discourse at work within the medical texts.

#### **a. Medical texts (n=5)**

Apart from certain bodily discourses, the discourse of numeracy was the main discourse identified within the five medical texts examined. I have organised the discussion under the headings of treatment factors, staging and prognosis and survival as these topics contain pivotal information for the young women diagnosed and living with advanced breast cancer.

#### **1. Treatment factors**

This first extract comes from *Harrison's Principles of Internal Medicine* (2008), required reading for many graduate entry medical programmes in Australia at this time<sup>11</sup>. The paragraph provides information on treatment factors and their effect in advanced (metastatic) breast cancer. The information relates to all women and not necessarily younger women with breast cancer.

Nearly half of patients treated for apparently localized breast cancer develop metastatic disease. Although some of these patients can be salvaged by combinations of systemic and local therapy, most eventually succumb ... Between 10 and 25% of patients have so-called locally advanced or stage III breast cancer at diagnosis. Many of these cancers are technically operable, whereas others, particularly cancers with chest wall involvement, inflammatory breast cancers, or cancers with large matted axillary lymph nodes, cannot be managed with surgery initially. Although no randomized trials have proved the efficacy of induction chemotherapy [chemotherapy given prior to surgery], this approach has gained widespread use. More than 90% of patients with locally advanced breast cancer show a partial or better response to multidrug chemotherapy regimens that include an anthracycline. Early administration of this treatment reduces the bulk of the disease and frequently makes the patient a suitable candidate for salvage surgery and/or radiation therapy. These patients should be managed in multimodality clinics, if possible, to coordinate surgery, radiation therapy, and systemic chemotherapy. Such approaches produce long-term disease-free survival in about 30 to 50% of patients. (Lipmann 2008, pp. 521-2)

In this extract, women may be 'salvaged' from their disease, but most eventually 'succumb'. The fact that most will die is hidden by the percentages given and the

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<sup>11</sup> Personal communication

promises of 'long-term' survival. Having a 30 to 50% chance of long-term disease-free survival is not exactly great odds for a young woman living with advancing disease.

The next extract is talking about the benefits of receiving a particular treatment for the spread of breast cancer to the bone. The bone is one of the commonest sites of metastasis in breast cancer (Dickson, Pestell & Lippman 2005).

The skeletal morbidity was significantly reduced in the patients receiving pamidronate; however, there was no significant difference in survival or objective bone response rate. Not until 6 months was a difference observed between the two groups, at which point the curves diverged, with an upward shift of the placebo group's skeletal event rate curve, though the curves for both treatment groups maintained the same [downward] slope. (Brown & Healey 2005, p. 2580)

Although skeletal morbidity may be reduced with the administration of this drug, the woman receiving it is going to die of the disease. Within the professional medical literature, survival rates are commonly represented as a curve and representing them as such, make the survival predictions come alive. As the survival curve inevitably slides down towards the y-axis (zero axis), the longevity of the group diminishes - a distressing picture for those health care professionals and young women actually viewing this information.

## **2. Staging and prognosis**

The discourse of numeracy has a powerful effect especially in the area of staging and prognosis. The staging process is important to the discourse; for how the cancer 'looks' at the cellular level determines the treatment and hence its prognosis. It purports to be an exact science and yet allocating a woman to one category or the other depends on the expertise of the pathologist and his or her ability to allocate correctly. Human error and uncertainty do not appear in the pathology reports. Doctors read these reports, interpret them and, if asked, provide a prognosis.

Correct staging of breast cancer patients is of extraordinary importance. Not only does it permit an accurate prognosis, but in many cases therapeutic decision-making is based largely on the TNM (primary tumor, regional nodes, metastasis) classification ... Comparison with historic series should be undertaken with caution, as the staging has changed several times in the past 20 years. The current staging is complex and results in significant changes in outcome by stage as compared with prior staging systems. (Lipmann 2008, pp. 519-20)

Correct staging permits an accurate prognosis. An accurate prognosis means that the treating physician can make correct decisions regarding treatment and the right treatment permits extended survival. The calculations that make prognoses possible are based upon various mathematical formulas such as the Nottingham prognostic index. This particular index takes into account various chronological (tumour size, number of involved lymph nodes) and biological factors (histological grade) relating to the cancer itself. This index is the most widely used prognostic indicator within the medical arena. It is calculated in the following manner, 'Nottingham prognostic index =  $(0.2 \times \text{size}) + \text{lymph node stage} + \text{grade}$  (Miller, W, Ellis & Sainsbury 2000, p. 76). The age of the woman is not taken into account in this prognostication and yet young age is probably the most significant prognostic factor.

Patient's age is also an independent prognostic factor. Very young women with breast cancer have a poorer prognosis than older women. If the hazard ratio of 1.0 describes the outcome for women 40 to 45 years and 45 to 49 years of age, then it is 1.8 for women under 30 years, 1.7 for those 30 to 34 years, and 1.5 for those 35 to 39 years. (Wood et al. 2005, p. 1423)

The *hazard* refers to the probability of dying and a *hazard ratio* compares the probability of dying between two groups of people (Beswick, Cheek & Ball 2004, p. 392). In the above paragraph, the chance of dying of breast cancer is being compared in two groups of women, those under the age of 40 and those over this age. A women with breast cancer under the age of 40 has a 1.8 greater chance (or odds) of dying when compared to older women with breast cancer. The language of mathematical certainty is being juxtaposed here with the language of chance and luck - an unsettling alignment.

### **3. Survival**

Angiogenesis is the formation of new blood vessels and cancer cells secrete certain growth hormones that promote and support this process. Angiogenesis enables cancers to grow and metastasise and it is this ability that eventually leads to death. The discourse of numeracy informs the paragraph below with its suggestion that the process of angiogenesis can be quantified and with this number, additional authority can be added to the prognostic equation.

Studies of metastasis have suggested that quantification of tumor angiogenesis and deposition of specific extracellular matrix proteins may be of supplementary value in

prognostication with traditional lymph node biopsy measurements. (Dickson, Pestell & Lipmann 2005, p. 1412)

Being able to count things such as the number of new blood vessels assists in the foretelling of future events and hence the length of a young woman's survival.

Inflammatory breast cancers are particularly aggressive and though rare, occur most often in young women around the time of pregnancy and/or birth (Rodger, Leonard & Dixon 2000). Here is another example of the discourse of numeracy as it relates to survival.

The reported outcomes for treatment of inflammatory breast cancer show overall survival rates at 5 years of 35% to 56%, and at 10 years of 35% to 51%. Disease-free survival rates have been reported at 5 years as 35% to 49%, and at 10 years as 34% to 38%. Although these results are poor, it is important to recognise that there is a small, but real, fraction of patients who enjoy long-term survival with contemporary combined modality treatment. (Wood et al. 2005, p. 1453)

The prognosis of young women with inflammatory breast cancer is dismal as the above percentages attest. Even though the numbers convey a sense of tragedy, we can derive some comfort from knowing that a few women do survive in the long term. Yet, what about the young mothers who die, leaving young children behind? This paragraph hides the implied tragedy behind the certainty of numbers.

### **b. Professional medical journals (n=251)**

The discourse of numeracy is again strongly evident in the medical journals. For a start, only 12 out of the 251 articles (5%) used qualitative analysis of some sort in the research design. All the remaining articles were driven by quantitative analyses involving mostly sophisticated statistical tests. Therefore, as it did in the medical textbooks, the discourse appears here under several guises, such as statistical tests, probabilities and percentages. Apart from hazard ratio calculations mentioned above, statistical tests are also used to calculate confidence intervals and *P* values, tests that give us confidence in the reliability and validity of the data being presented. Probabilities are often given as percentages and are helpful when making comparisons between one treatment and another (Anderson, T 2002).

The topics of survival and prognosis featured heavily in the professional journals. These two concepts accounted for nearly 42% (105) of the content in the 251 articles collected over the research period. In contrast, articles on treatments accounted for only 24% (61) of the content. Discussion of new and different treatment regimes did however increase during the last half of the data collection period – from 18 (1997-2002) to 43 (2003-May 2008). This increase perhaps reflects medicine's growing confidence in being able to treat breast cancer in young women. Christakis' research on prognosis and pneumonia supports this last statement (Christakis 1999). Christakis found that as pneumonia began to be more successfully treated with the discovery of antibiotics, less and less space was allocated to the discussion of prognosis in the medical literature. As the condition became more treatable, different treatments dominated the space where previously prognoses had been. Whatever the reason, more and more space is certainly being given over to discussions concerning the benefits and survival advantages of particular breast cancer treatment regimes.

### **1. Treatment factors**

Baud and his colleagues looked at the association between chemotherapy response and survival amongst young women with early breast cancer. They followed 603 premenopausal (and therefore young) women who had undergone chemotherapy prior to having either radiotherapy and/or surgery. They divided the women into three groups based on age; group one were less than 35 years of age, group two were between 35 and 40 years of age and group 3 were older than 41 years of age. This is what they found;

Objective and complete clinical response rates were significantly higher in the youngest patients (below 35 years:  $P=0.005$  and  $P= 0.001$ , respectively) in stark contrast to a particularly poor outcome of this subpopulation. Five-year local recurrence rates were 31% in the youngest patients, compared with 26% and 16% in groups 2 and 3 respectively ( $P= 0.0007$ ). Group 1 also had a significantly higher 5-year metastatic relapse rates (41% versus 35% and 28%;  $P= 0.007$ ) and 5-year survival figures were 70%, 82% and 84% for groups 1,2 and 3 respectively ( $P= 0.002$ ). (Braud et al. 1999, p. 392)

Young women with breast cancer, irrespective of its stage, have a particularly poor outcome. We can be confident in the merit of this statement because of the way the evidence has been presented in the above paragraph. A  $P$  value represents the strength of the evidence for either accepting or rejecting a null hypothesis. A low  $P$  value means that we can reject it. In the paragraph above, the  $P$  values are quite low, indicating that

we can be fairly confident that the hypothesis holds 'true'. Another way of putting it is to say 'how likely are the results to have arisen by chance'. A *P* value of  $< 0.05$  is the same as saying that there is a 5% chance that the relationship between age and prognostic factors occurred by chance (or luck) (Greenhalgh 1997). A *P* value of 0.05 is commonly accepted as the cut off point between chance and certainty. There is no empirical reason for the cut off point to be 0.05 - it is simply a convention.

Tamoxifen given after chemotherapy has been found to increase disease-free survival (DFS) in premenopausal women, but only for those women who have an oestrogen (ER) positive breast cancer who also suffered from chemotherapy-induced amenorrhea.

Tamoxifen improved DFS in the ER-positive cohort (hazard ratio [HR] for tamoxifen v no tamoxifen =0.59; 95% CI, 0.46 to 0.75;  $P < .0001$ ) but not in the ER-negative cohort (HR = 1.02; 95% CI, 0.77 to 1.35;  $P = .89$ ... Patients with ER-positive tumours who achieved chemotherapy-induced amenorrhea had a significantly improved outcome (HR for amenorrhea v no amenorrhea =0.61; 95% CI, 0.44 to 0.86;  $P = .004$ ), whether or not they received tamoxifen. (International Breast Cancer Study Group 2006, p. 1132)

*P* values have been mentioned in the preceding paragraph, however we now see both *hazard ratios* (HR) and *confidence intervals* (CI) being added to the discussion on the survival advantage of one treatment over another – additional statistical tests that provide us with a sense of certainty in the midst of chaos.

The next extract from a journal article repeats the findings of many of the studies in the area of young women - certain adjuvant treatments appear to extend the length of a young woman's life. By removing her ovaries and giving her tamoxifen, she has a greater chance of overall survival. The study reported here randomized young women with operable breast cancer to either an adjuvant oophorectomy and tamoxifen for five years group, or to an observation and this combined therapy on a recurrence group. The results were as follows;

Five-year disease-free survival (DFS) probabilities of 74% and 61% (95% CI for difference, 7% to 21%) and overall survival (OS) rates of 78% and 71% (95% CI for difference 1% to 21%) were observed in the adjuvant and observation groups. Ten-year DFS probabilities of 62% and 51% (95% CI for difference, 4% to 22% and OS probabilities of 70% and 52% (95% CI for difference, 6% to 34%) between adjuvant and observation groups, respectively, were observed. In the subset of estrogen receptor-positive patients, 5-year DFS probabilities were 83% and 61%, and 10-year DFS probabilities were 82% and 49% in the adjuvant and observation groups, respectively. (Love et al. 2008, p. 253)

Again, the numbers given as percentages convey a feeling of certainty. Chance has no place within the science of breast cancer treatment and yet it is all about chance. However, treatment regimes are not the only place in which numbers rule; numbers also infuse tumour characteristics and their prognostic significance.

## 2. Staging and prognosis

The next journal extract comes from a study that compared the tumour characteristics of younger and older women. Pratrapp and Shousa (1998) found that P53, a measure of tumour aggressiveness, was more common in women under the age of 50 years.

In invasive ductal carcinoma (191 cases), p53 positivity was significantly related to high tumour grade (7% in grade I [1/14], 19% in grade II [2/105], and 43% in grade III [31/72];  $p < 0.0001$  [I-II vs III]), p 53 positivity was also significantly related to the presence of extensive (more than three) axillary lymph node metastases (p53 positivity being 22% in node negative tumours [40/178], 18% in tumours with three or less positive nodes [6/33], and 61% in tumours with more than 3 positive nodes [11/18];  $p = 0.0033$  [second vs third group]). Both features were also significantly more common in the younger age group. (Pratrapp & Shousa 1998, p. 35)

The discourse of numeracy is evident in the numbers and percentages in the above paragraph. This discourse frames the biological factors that herald limited survival in younger women. It locates the source of the poor prognosis within the individual tumour characteristics of each woman.

We have known for some time now that certain genetic mutations such as BRCA1 and BRCA2 are risk factors for the development of breast cancer at a young age and these cancers tend to run in families. Another genetic mutation has been discovered called *CHEK2\*1100delC* and this mutation appears to be implicated in breast cancer's recurrence, especially in younger women. Again, numbers overwhelm the information in the paragraph and the source of the poor prognosis is located within the genetic material of individual women.

We detected a *CHEK2\*1100delC* germline mutation in 54 patients [young women] (3.7%). *CHEK2\*1100delC* carriers had a two-fold increased risk (hazard ratio [HR]. 2.1; 95% CI, 1.0 to 4.3;  $P = .049$ ) of developing a second breast cancer and they have worse recurrence-free survival (HR, 1.7; 95% CI, 1.2 to 2.4;  $P = .006$ ) and worse breast cancer-specific survival (HR, 1.4; 95% CI, 1.0 to 2.1;  $P = .072$ ) compared with noncarriers. The poor disease outcome of *CHEK2\*1100delC* carriers could not be explained by the increased risk of second breast cancer. (Schmidt et al. 2007, p. 64)

Young women with this particular mutation have a poorer prognosis than women without it. Again, numbers give us confidence that the results have not been arrived at by chance and that rigorous checks and balances have been put in place to ensure the study's methodological rigor. Long-term survival is not for these young women.

### 3. Survival

Young women diagnosed with advanced breast cancer hope for a long life. The stage at which they are commonly diagnosed reduces this hope considerably. Again, we see that percentages and probabilities shape the outcome for young women diagnosed with advanced disease.

Patients younger than 36 years were more likely to present with a palpable mass (87% versus 55%,  $p < 0.001$ ) and ... had larger tumors (median 2.0 cm versus 1.5 cm,  $p < 0.001$ ), more nodal involvement (50% versus 37%,  $p = 0.022$ ), more nodes involved (median 1.0 versus 0,  $p = 0.010$ ), and were more likely to be diagnosed with stage II or III cancer (60% versus 43%, overall  $p < 0.001$ ). Young patients' cancers were more poorly differentiated (80% versus 44%, overall  $p < 0.001$ ), estrogen receptor-negative (52% versus 31%,  $p < 0.001$ ), aneuploid (70% versus 49%,  $p = 0.013$ ), and had higher S-phase fractions (59% versus 29%,  $p = 0.001$ ) ... Cumulative 5-year local and distant disease-free survival were significantly worse for patients younger than 36 years ( $p = 0.011$  and  $p = 0.044$ , respectively) ... Patients diagnosed with breast cancer before age 36 differ from older patients in numerous respects. (Gajdos et al. 2000, p. 523)

In this example, numbers expressed as percentages point to a grim picture for the young women diagnosed. Complex mathematical equations hide behind these percentages together with the fact that the majority of young women will eventually die of this disease. Numbers hide the tragic nature of survival for these young women.

These next statistics come from a research study that looked specifically at survival in breast cancer. It repeats some of the information presented above; however, this time the word *death* is actually mentioned.

Women aged 80-89 had a 25% higher risk of death at five years than women aged 60-69 after adjusting for time period of diagnosis and spread of disease. Women aged 20-39 years had a 13% higher risk of death at five years than women aged 60-69 after adjusting for period of diagnosis and spread of disease. (Supramaniam et al. 1998, p. 11)

Variables such as disease spread and period from diagnosis can be *adjusted for*. The language of statistics infuses these predictions; 'disease-free interval, low median survival rates, survival up to 40 months, 69%, 51% ...' There is no hint of chaos or the

uncertainty of prognostication in any of the above paragraphs, nor the emotional cost of such foretelling.

### **c. Clinical practice guidelines (n=2)**

National health organisations within Australia, such as the *National Health and Medical Research Council*, have developed clinical practice guidelines based on a systematic review of evidence in order to provide clinicians with information and guidance to assist them in decision-making. The guidelines are widely disseminated across the professional community of care providers within Australia and are therefore highly influential. Two such guidelines are relevant to the care of young women living with advanced breast cancer. Both guidelines (National Breast Cancer Centre 2004; National Health and Medical Research Council 2001a) included in this data set repeat many of the treatment factors already mentioned (p. 135) therefore I will not repeat them again here. However, the subjects of prognosis and survival discussed in these documents provide additional evidence of the workings of the discourse of numeracy.

#### ***Prognosis and survival***

In the ‘advanced breast cancer’ guidelines, the section referring to the outcome of advanced breast cancer talks about prognosis as relating to a period of time in which the cancer is no longer evident.

Prognosis in the presence of metastatic disease relates powerfully to the disease-free interval following diagnosis and management of the primary tumour. Early relapse is associated with a low median survival rate of less than a year, while a disease-free interval of five years may result in a survival of up to 40 months. (National Health and Medical Research Council 2001a, p. 18)

Early relapse equals *low* median survival. A *low* median survival rate is defined here as being less than a year’s duration. Advanced breast cancer in young women carries with it a ‘low median survival’ irrespective of whether it relapses or not. In addition, 40 months may not seem like ‘high median survival’ for the young women whose lives are being counted.

The ‘advanced breast cancer’ guidelines, as do many other cited works, define survival as being disease-free after a specified period, commonly five years. The likelihood of survival is expressed as a probability;

Women with localised breast cancer at diagnosis had an 89% chance of surviving for five years after diagnosis, those with regional spread 69% and those with metastatic disease 13%. (National Health and Medical Research Council 2001a, p. 17)

The language of chance weaves its way through the paragraphs. Chance is a calculated probability, devoid of luck and yet, given the probability mentioned above, one may need 'luck'. Here, the uncertainty of living with a life-limiting illness is being quantified to make it less chaotic, more certain.

The clinical practice guidelines relating specifically to younger women state that the five year relative survival for women aged between 30 to 39 is nearly 80% compared with 86% in the 60 to 69 aged group (National Breast Cancer Centre 2004). Because of the high recurrence rate amongst younger women diagnosed with breast cancer, chemotherapy is now strongly recommended.

Clinicians should advise younger women that the benefit of chemotherapy is greater the younger the woman's age. Chemotherapy [given after surgery] will reduce the risk of recurrence by about one-fifth in women aged 60 to 69 years, but nearly two-fifths in women under the age of 40. (National Breast Cancer Centre 2004, p. 22)

Chemotherapy *will*, not *may*, reduce the risk of cancer returning. The guidelines are definite about this outcome. I interpret the above paragraph to mean that 40 out of 100 young women will not experience a disease recurrence if they have chemotherapy. The figures do not reveal the stage of cancer the women needs to be at to experience the survival advantage of adding chemotherapy, nor the significant morbidity and mortality rates of this treatment. The guidelines are only presenting part of the picture, yet are using numbers to support their argument.

To sum up thus far, the discourse of numeracy spreads tentacle-like (cancer-like) throughout the sampled professional medical literature. Numbers define the likelihood of a particular treatment working; they shape survival curves and the odds of living and dying. Living with advanced breast cancer can be deemed a *hazard* for the young women concerned.

## **2. The newspapers**

Like the medical journals and clinical practice guidelines referred to above, the media also uses the discourse of numeracy to shape and perpetuate information about breast cancer in young women. However, rather than in the more exclusive world of disease research and treatment, it does so within the public arena. Over half (56% or 129/230) of the articles reviewed used numbers to frame arguments and convey information about breast cancer in young women. Unlike the professional medical literature, the newspapers did not differentiate between early and advanced breast cancer in the population of younger women.

### **a. Staging and prognosis**

The first example begins with the title, *Young breast cancer attack plans*<sup>12</sup>. The content of the article involves a campaign to have free mammograms available to all women under the age of 40. At present in Australia, free screening mammograms for this age group depends on a person's family history. In this article, the journalist uses the Australian actor Carmen Duncan to rally support for the campaign. It is debatable whether young women benefit from screening mammograms due to the density of a young woman's breast tissue (Lucassen, Watson & Eccles 2001). Half way through the article an expert voice appears in the form of a state cancer council, followed by the then chief executive officer of the National Breast Cancer Centre. These two experts cite probabilities to lend weight and authority to the counter argument to have free screening mammograms available only for the older age groups.

New research by the NSW Cancer Council reveals 51% of women aged between 20 and 39, who are diagnosed with breast cancer, have an advanced tumour, which is difficult to treat. This compares with 38% of all women with breast cancer, many of whom have access to mammograms, which can detect cancers earlier. But breast cancer experts said there would be little benefit in mammograms for women under 40, who made up a small number of the total diagnoses and whose breast tissue was too dense for an accurate reading to be taken. National Breast Cancer CEO, Sally Redman, said 700 of the 10,000 breast cancer diagnoses each year were in women under 40 ... She said that all women under 40 should examine their breasts regularly and/or have their breasts checked by their GP. (Stock & McGilvray 2000)

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<sup>12</sup> The military metaphor continues and a number of authors such as Susan Sontag (1991) and Deborah Lupton (1994c) have already commented on its use.

The initial two sentences in this article frame one aspect of the tragedy that is breast cancer in young women – that many young women who are diagnosed with breast cancer already have metastases. The professional literature also commented on this poor prognostic indicator (large tumour at diagnosis) but did so without juxtaposing this information alongside the need for young women to be responsible for early detection and hence their ultimate survival. The remainder of the article attempts to control the anxiety and hysteria that often accompany such statistics when younger women and breast cancer appear together in newsprint. We are told that the number of young women who actually get breast cancer is a small percentage of the total (only 700 out of 10,000 or 7%), and even though screening mammography may not help these women detect their cancers early, they can and *should* examine their breasts regularly. One can infer from the above article that if breast cancer is not found early by the young women, then they have only themselves to blame - even though recent research has shown that breast self examinations are not effective in younger women (Spurgeon 2001). Other studies have also found individual responsibility to be a feature of breast cancer reporting (Lupton 1994a). I talk more about this imperative for self-responsibility later in the chapter. In addition, the article does not mention that, percentage wise, more younger women than older women die from the disease. Advanced breast cancer is portrayed here as something that is *difficult to treat*, not something from which a woman might actually die.

### **b. A game of chance**

The discourse of numeracy does not always reveal itself in numbers, such as probability calculations; words also support this discourse. Even though inferring that survival is a game of chance trivialises it, the media have no such qualms. Eighteen out of the 230 articles or 8% used the language of chance and luck to describe the experience of the young women in the articles. Consider this next newspaper headline and extract:

#### **Beaten by the odds**

Fate decreed that Danielle Molloy should have to battle the odds. Her birth alone created family history [she was the first girl to be born in the Malloy family in 84 years]. Then she became a statistical rarity in being diagnosed with breast cancer before the age of 25. And just as she was about to become the first woman in the world to receive a revolutionary new drug treatment which promised to extend her life, she was dropped from the experiment. It was the final blow for Danielle. Her battle was lost ... Breast cancer claims more than 2600 lives in Australia each year and makes up about 17% of all female deaths. Danielle was one of the youngest women to be treated for breast cancer during her time at the Austin Hospital

[Melbourne] but, says Mrs Malloy [Danielle's mother], the hospital was starting to see more and more younger women. (Steene 2000)

Breast cancer is not about playing a game, nor is it about beating the odds. Fate is not fickle in choosing Danielle to die. Breast cancer in younger women is not on the rise, yet from this article, you may be forgiven for thinking so. The promise of a new drug that could extend her life was whipped away from her at the last minute condemning her to a certain death – a needless tragedy. Inserted into the middle of the article are the current mortality rates from breast cancer for women of all ages. Of what do the rest of Australian females die? Placing the percentage into context may make the figures less frightening for young women; after all, the total number of women who now die of cancer of the bronchus and lung (2683) has overtaken the numbers who die from breast cancer (2618) (Australian Bureau of Statistics 2008). In addition, many more women die of circulatory diseases (10,797 deaths per year - mainly ischaemic heart disease) than they ever do of cancer (Australian Bureau of Statistics 2006). Fear and uncertainty infuse the article, in spite of the rational voice of experts citing numbers.

This next newspaper extract is talking about the misconception many people have that breast cancer is a young woman's disease. This error has been attributed to the media's sensationalised reporting of young celebrities with breast cancer. Chapman and his colleagues have termed this phenomenon 'the Kylie effect' (Chapman et al. 2005).

Women are confused about at what stage of life they are at greatest risk of breast cancer. The experts believe the Kylie effect is to blame. The singer's diagnosis at the age of 36 led many women to think wrongly that breast cancer was a young person's disease... The risk of a woman under 50 contracting breast cancer in 10 years is one in 247... After Minogue's diagnosis a surge of women were screened for the disease. Doctors dubbed it the "Kylie effect". Mammography bookings in Australia jumped 40% in the two weeks after her illness was announced... it could panic young women while leading older ones to think that aging is not relevant. (Pountney 2006)

Breast cancer is again being portrayed here as a game of chance. Young women have a 1 in 247 chance of developing breast cancer. Games of chance have been with us for a long time and we are therefore very familiar with this concept.

The incidence of breast cancer is increasing. One in eight women are now at risk of developing breast cancer before the age of 85 (Australian Institute of Health and Welfare and National Breast Cancer Centre 2006). This figure used to be one in 12. In order to illustrate this increase in incidence, the following newspaper article uses a young woman with a young child. The fact that inflammatory breast cancer in young women is rare is overshadowed by the percentages telling us that breast cancer is increasing.

#### **Determined not to be a statistic**

... when daughter Zoe was born a year ago, life couldn't get much better. Six weeks later, Mrs Robinson was diagnosed with inflammatory breast cancer, a rare and aggressive form of the disease more often found in younger women. Mrs Robinson ... is one of a growing number of Australian women being diagnosed with breast cancer. A report to be released today reveals one in eight Australian women will be diagnosed with the disease by age 85, up from one in 12 in 1983. The report by the National Breast Cancer Centre and the Australian Institute of Health and Welfare found 86 percent of women with breast cancer today can expect to be alive five years later compared with 71 percent 20 years ago. Mrs Robinson was lucky her cancer was found before it spread. (Miles 2006b)

The article states that Mrs. Robinson was *lucky* and yet she has inflammatory breast cancer, which is distinctly *unlucky* given what we know about the poor long-term survival of this particular breast cancer type. Mrs. Robinson is already part of the statistics concerning the incidence of breast cancer, how then can she be determined not to be a statistic? Perhaps she is determined not to be one of the 14% of women with breast cancer who will, according to this article anyway, be dead in five years time. Yet, as shown in the extracts from the medical texts, the overall five-year survival for inflammatory breast cancer is significantly lower than that quoted here (35%-56%, (Wood et al. 2005). Lucky or unlucky? It depends on the game being played or the story being told.

The discourse of numeracy is not a new discovery by any means; others have noted its existence. Potter, Wetherell and Chitty have previously identified this discourse within media accounts giving this discourse the name of 'the quantification rhetoric' (1991). These researchers analysed a TV documentary on cancer produced by charities involved in raising money for cancer research. The results of this analysis showed how different groups could manipulate calculations (incidence rates and success of treatment

percentages) to produce differences in success or failures in the research on the treatment of various cancers.

In summary, the media always use personal stories to accentuate the relevance of the topic to the reader. Newspapers use numbers to shape the representation of breast cancer in young women. This medium uses numbers on the one hand to calm and reassure young women that breast is an older women's disease and on the other, to portray breast cancer in young women as a game of chance. I now turn to the interplay of the discourse of numeracy as it travels across and within the actual narratives of the young women concerned.

### ***3. In the young women's stories***

The young women dealing with fear and uncertainty know that their lives are on the line regardless of the numbers. As I illustrate through their story extracts, they struggle with these social artefacts and remain confused. The numeric discourse, with its authoritative certainty, leaves the women with no space from which to talk about the uncertain and chaotic nature of their world.

#### **a. Treatment factors**

What is uppermost in the young women's minds is increasing their chance of long-term survival. They will do almost anything to make this happen, as illustrated by the story in the prologue of this thesis. Decisions regarding treatment often determine the type of outcome and hence it is vital to make the right choice.

Medical specialists diagnosed Jessica with Stage III breast cancer when she was 40 years old. For Jessica, the statistics were in her favour if she had surgery and chemotherapy rather than just surgery alone. However, the age at which she was diagnosed and the advanced stage of her cancer contribute ultimately to a bleak outlook. Percentages were used to persuade her to have chemotherapy - a perceived value-added treatment.

Well he rattled off statistics during one of my visits, and I think what he said was if I didn't do anything I had a 50% chance of ah, I think it was 50, sorry, if I just had the surgery I had

a 50% chance and if I had the surgery plus chemo at that stage I think it was another 20% onto that, so like a 70% chance [of cure]. The statistics are in my favour. (Jessica, P 179)

I wondered how she could think that the statistics were in her favour given that she was living with an incurable condition. The statistics on prognoses certainly were not in her favour, treatment outcomes are by no means that precise, and yet here they were, being conveyed to her as a certainty. Jessica believed that she would be one of the seven out of ten women who would survive, not only the value-added treatment, but would survive into older age, yet her oncologist was talking about response to treatment and not cure.

Having just said that Jessica thought that the odds were in her favour, she does an about face in the next few lines and now tells me that the statistics for her long term survival were *not* in her favour;

Prior to my surgery I had a bone scan and a CAT scan and they were both clear, so I'm reasonably hopeful that you know this is sort of going to fix the problem although I realise the statistics [concerning cure] aren't fantastic. (Jessica, P 275)

In Jessica's mind, there existed a tension between the statistics that showed a limited lifespan and the statistics used to indicate a survival benefit of adding one treatment to another. I remember feeling somewhat confused myself by the end of our conversation and I wondered if Jessica too realised this inconsistency. I am not seeking to reconcile this confusion, however inconsistencies within and between stories are commonplace. The inconsistencies reveal conflicting subject positions, a point I return to later in this chapter.

### **b. Staging and prognosis**

Karen was 36 when diagnosed with her advanced disease. She wanted the certainty that she felt statistics would give her, the single truth upon which she could act. However, uncertainty and confusion are evident in her story extract below. I had just asked her when had she become aware that she could die of breast cancer. This was her reply:

I think when the doctor mentioned something about the survival rate of five years, and I was trying to work out, I said well what does that mean? Does that mean I have got five years to

live or what does it actually mean. I am still really unsure to this day, because all the books I've read, they talk about survival rates all the time?

*What do you understand about your survival rate? (Katrina)*

Not a lot actually. Um, I think once you get past that five years if you are going to make it past that without getting recurrence of cancer you're okay, but if you get a recurrence within that five years well ... (Karen, P 184-191)

A survival rate is the proportion of people still alive after a specified period has passed since diagnosis – commonly five years (Supramaniam et al. 1998). Yet survival rates may be incorrect. I have often heard from patients that they have outlived their doctors' predictions by many months or years. There appears to be a grim satisfaction in proving the medical profession wrong. Therefore, prediction is an inexact science.

Inge's doctor diagnosed her advanced breast cancer when she was only 36. Initially, specialists could not find the primary cancer and so labelled it as a 'cancer of unknown primary'. After several mammograms, her oncologist decided that her breast was the most likely point of the cancer's origin.

I have been told that I am incurable, which means that at some stage, I will die from the disease, and as to how long I have, my oncologist says it could be months or years, he just doesn't know. So many different parameters decide that. Looking at statistics, I think my chances of living five years are only 20% or something, quite low.

*Was that a need in you to find out statistics? (Katrina)*

I looked out of interest more than anything else. I was quite depressed once I found out ...I do find that understanding my disease is beneficial to me but at the same time if you get a lot of information, especially if you read a lot about statistics, that can be a bit depressing. (Inge, P 238)

In this instance, her doctors did not give her the numbers, perhaps because it would have been so difficult to look this mother in the eye and give her the actual figures. Given the research by Lamont and Christakis (Lamont & Christakis 2001), this may well have been the case. Inge found out the information herself and the knowledge understandably distressed her.

Belinda, diagnosed at the age of 38, had an extensive lympho-vascular component to her breast cancer, which is a poor prognostic sign. She grappled with the percentages that indicated that her breast cancer was most likely to return soon:

He does say that it [breast cancer] has a 70% chance of it returning.

*So in terms of prognosis, 70% chance of it returning in 5 years? (Katrina)*

3 [years]

*3, and what do you understand about that? (Katrina)*

Ah, not good. I look at that as if to say, well, I don't look at it as 30%. I look at it as 70 [%], I think 30% is too small, and the rate it had grown, because he said it was fast, it had grown very fast into my lymph nodes, even though I had so much chemo and so much radio, and must have killed everything, but still, I'm still very concerned that it's coming back. (Belinda, P.207)

Belinda chose to view the statistics in a way that gave her the greatest chance of hope. She would rather see her chances as 70% than 30%, and yet both numbers are saying the same thing. Yet, what do these numbers actually mean? Do they mean that in every 10 young women being treated for advanced breast cancer, seven will experience recurrence, or do these figures relate to all women irrespective of age with similar lympho-vascular involvement? Alternatively, perhaps the numbers mean that only 30% of women like Belinda will still be alive in three years time. After all, recurrence, given the stage of her cancer is a near certainty. The percentages do not add clarity to this situation.

The medical profession often uses the five-year mark to indicate cure. Cancer-free at the five-year point is not a certainty for any young woman given the biology of breast cancer. However, there are some cancers that do attract the 'cure' label (testicular cancer and teratoma). Unfortunately, the young women in this project eventually discover that *cure* is not a word for them; they are excluded from this category.

Using the language of survival as equalling cure can lead to a sense of confusion and sadness. The following quote from a book on living with metastatic breast cancer illustrates this point well. The woman asking the question has advanced breast cancer.

... one of the women in my group said that she had a question, and you could see that she was not comfortable raising it... Her question was: 'Are we survivors?' When she said that, all the other women in the room turned away or put their heads down. It was a question that touched them, embarrassed them, something that they had struggled with too. I asked her what she meant by that. She said, 'Well, all you hear about are survivors. I don't know if I am a survivor. I'm alive. But I don't feel like they do. Somehow they are victorious. I am not victorious.' (Mayer 1997, p. 4)

*Somehow, they are victorious. I am not victorious.* These words highlight the struggle and shame that many young women living with advanced breast cancer can face as they go on with their daily lives. They are stigmatised for being a non-survivor in a world that reifies heroism and battle. Susan Sontag (1991) in her writings on the metaphors of illness condemns the use of the military metaphor attached to cancer and the associated need to fight it. Yet the language of battle continues as it is part of our cultural fabric.

### **c. The search for survival: non-conventional therapies**

Young women do not know how long they will live; they do not know to which treatment they will be subjected next nor which of the many symptoms they will experience next. Will it be pain, breathlessness, confusion, or all three simultaneously? They search for certainty in a very uncertain arena and try to control a seemingly chance event by pursuing additional non-conventional avenues that they hope will prolong their lives. Understandably, these young women are desperate to live as long as possible.

Non-conventional avenues are those therapies that often parallel the delivery of conventional Western medicine and at times may even replace them. I am not drawing the usual distinction between alternative and complementary therapies here, but rather I am using the term *non-conventional* to represent the myriad of therapies that cross borders between proven and unproven treatments.

Sue Tyler [her real name]<sup>13</sup> was 43 years old when diagnosed with advanced breast cancer. In addition to surgery and radiotherapy, her oncologist had recommended chemotherapy. Sue refused this evidenced-based intervention. Instead, she attended a ten-day retreat run by Ian Gawler. Twenty-four people attended the course with Sue and after 18 months, only two of them were still alive, Sue and one other. Both women had chosen not to have chemotherapy. She considered chemotherapy to be a poison and the

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<sup>13</sup> Sue wanted her real name, not a pseudonym, to appear in this research.

side effects of the treatment were the things that killed, not the cancer itself. Chemotherapy does indeed have some lethal side effects.

Her non-conventional approach was to eschew chemotherapy and to take control of her life. This control took the form of an organic diet and a positive attitude. The knowledge that cancer was chaotically spreading within her body or that her future was very uncertain was not apparent to me as she calmly spoke of her prognosis. Chaos and uncertainty were being held at bay by her will to think positively and her desire to take control of her life.

A number of other young women I interviewed had also travelled along the non-conventional path. Some used therapies to help them cope with repeated cycles of chemotherapy whilst others used them because they felt betrayed by the medical profession. Gena was one who felt betrayed because no one in her treatment team had mentioned to her the possible benefits that other forms of healing might add to her treatment repertoire.

I think that the oncologist really needs to tell people that cancer isn't just a going wrong, and I know that's not the right term, a going wrong of a physical thing. That it is a multifactorial thing, there are lots of different aspects to cancer and that people do need to take a holistic look at it. A holistic view of it and to see whether there are any other factors that they need to change in their life to help them get better and if not get better in the sense of having a cure, that they can have a better quality of life and to be able to lead as normal a life as they possibly can. And, I truly believe that my quality of life has greatly improved since I have looked at these other sorts of areas and that I have been able to cope so much better physically, mentally and emotionally since I've changed my diet and I've done my meditation and I've gone to some support sorts of things ... It is a life threatening thing and that I may not be here in 5 years time. I still find that very difficult to believe ... (Gena, P. 104)

Gena's cancer was aggressive and kept reappearing. Being in control of her remaining life was important to her and an holistic approach to cancer treatment gave her a sense of calm that had previously been lacking.

Anna's cancer returned when she was 44 years old. This event occurred nearly five years after her initial treatment. Understandably, the recurrence was very distressing for Anna and her family. Like Gena, Anna too had refused chemotherapy, instead using

prayer and naturopathic medicines to keep her well. She saw herself as a positive person and believed that she would be one of the few people who would ultimately survive.

I know of people who have got well and because I'm not a negative thinking person I wouldn't think someone was going to die until they were dead, there's always a chance that things can revert. That doesn't happen often though all the same. (Anna, P152)

There is always a chance, says Anna that her cancer might disappear, yet she died a year later. Sadly, her 'chance' did not eventuate.

Amongst her search for cure, Anna also had hair analysis to discover if she had an overload of heavy metals in her system<sup>14</sup>. Her naturopath advised her to have 'mercury flushing' to draw the heavy metals from her body. This she declined, as it would have meant replacing all her mercury fillings with a ceramic compound – an expensive business. Not to be deterred, she continued her search and found a faith healer overseas whom she said sounded promising. She and her husband visited this healer overseas, leaving their children behind in the care of family members. Anna and her husband saw a number of 'miracles' whilst they were there.

[People] got their hearing back or their sight back, it was amazing and it was what we expected to see and we did, but I guess I was hoping that the lump would be gone from my chest and that the pain would be gone. It's pretty hard coming back at the airport and the kids were waiting and hoping too, and seeing me just the same, you know the arms still swollen, and that was probably the most, was heart wrenching to see the kids reaction and knowing that, not knowing then but knowing later that mum had told [son], well, you know, when your mum's had enough, God will take her home, you know thinking, that's what he'd heard and then he saw his mum come back the same. But God still works in other ways too. (Anna, P 227)

Tragically, the hoped for cure eluded Anna; the lumps did not disappear, nor did the lymphoedema. These visible markers of advancing disease were still apparent, a distressing sight for her children to witness on the couple's return. Neither conventional nor non-conventional interventions gave Anna a sense of calm in the face of uncertainty.

Anna, Gena and Sue were not alone in their search for longevity or control over their disease. Karen went on a vegan and juice diet, however dropped this after a while as the

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<sup>14</sup> Heavy metals are thought to be a player in the promotion of cancer

organic produce was so expensive. She then read about a clinic in Mexico that advertised remarkable cures and wished she had the resources to attend. Jessica visited a naturopath and felt that this therapy and the therapies of conventional medicine were poles apart. She also found the naturopathic treatments expensive and wondered about their benefits in the long term. Helen used prayer and meditation to combat cancer's potential spread and relied on her faith in God. Fran twice attended a clinic in Germany that offered a particular type of heat treatment that was supposed to kill cancer cells. Then, her money ran out so instead she went on a vegan diet. Donna dabbled in dietary cures and meditation. Carol used shark cartilage but stopped after a few months because of its expense. Inge continued on her usual healthy diet and deliberately tried to think positively. Emma relied solely on her faith. Belinda used mega doses of vitamins but ceased due to their cost. On hearing that she needed to stop the vitamins because of the cost, Belinda's therapist said that as a consequence she would be dead within two years. All these women used non-conventional therapies in the search for cure. However, most found the cost prohibitive and stopped after some months of treatment. The search for cure created a tremendous burden for these women, both emotionally and financially.

In summary to this point, within the professional medical literature and the newspapers the discourse of numeracy shaped understandings of prognosis and survival. The medical literature used numbers to establish authority and control over an area of knowledge; newspapers echoed the medical voice and continued to misrepresent the proportion of young women who get breast cancer and portrayed the disease as a game of chance. Paradoxically, the comforting certainty that numbers could engender dissolved when the uncertain nature of advanced breast cancer was brought under the microscope. Confusion and distress were features in the young women's stories. The search for cure placed additional stresses on the young women's lives, yet each of these women felt they had to try to live as long as they possibly could. It was their responsibility and burden to do so.

#### ***4. Discussion: The problem with numbers***

In the previous text examples, I illustrated the various ways that the discourse of numeracy intersected with the lives of young women living with a life-limiting illness and have presented one interpretation of the texts. In answering the question - 'what

effects this discourse has' - I now move the focus away from the individual women to the wider social and political community in which they live.

There are three main effects of the discourse of numeracy: firstly, governments, the media and doctors use the discourse to manipulate people, secondly; it contributes towards making young women living with advanced breast cancer responsible for their health and survival; and finally, it creates an unhelpful division between survivors and non-survivors. However, before dealing with the discourse's effects, I outline some reasons why probabilities are often inappropriate in the health care arena.

### **a. Probabilities refer to groups of people, not individuals**

The main argument against the use of probabilities for discussing treatments and prognosis with individual women is that the numbers refer to groups of people and not to individuals (Gigerenzer 2002a). The individual and his or her unique characteristics are lost in the 'group average'. Each of the young women in this study made decisions based on the numbers derived from population studies; so did their doctors. Yet as the next quote attests, perhaps the predictions were unwarranted.

If the relapse rate in a disease, under given conditions, is  $x$  percent, it does not follow that each patient has an  $x$  percent chance of relapsing, regardless of the course of action he [sic] takes. Each patient either will or will not relapse. Prediction with respect to individuals is unjustified where the data only provide a basis for prediction with respect to groups. (Cohen 1972, p. 101)

A young woman living with advanced breast cancer, will or will not experience a further relapse. In time, she will die, yet until she does, she is 100% alive. Her eventual outcome is often a result of the random processes at work, many of which are unpredictable and uncontrollable at an individual level.

In addition to the fact that probability theory is based upon groups of people, it is also based upon the observation of a large number of events over time. Yet, counting past life events, for example, how many young women die of breast cancer, only exposes a chain of events, not a set of independent observations upon which probability theory is based (Bernstein, P 1996). Consequently, there is wide room for error when interpreting probabilities, starting with the assumptions that underpin the theory.

Probability theory also assumes a level playing field where each young woman starts from the same point in her illness journey; yet this is clearly not the case as there is enormous variation between the individual illness trajectories. For a start, the ages at which the young women were diagnosed with advanced breast cancer varied. Their ages ranged from 29 to 44 and the younger the age at diagnosis, the more aggressive the disease is likely to be (Kroman et al. 2000). Next, all the women except one had given birth. The age at which a woman has her first period and the age at which she has her first child contributes towards the risk of developing breast cancer (McPherson, Steel & Dixon 2000). Increased exposure to oestrogen is thought to be the mechanism behind this heightened risk. Furthermore, all but one of the women was living with a partner. While still controversial, the level of social support has been correlated with increased length of survival (Spiegel et al. 1989) and a partner may contribute to an increase in social support for some women. Finally, three of the women were under the age of 35 when first diagnosed with breast cancer. They may well have been carriers of the BRCA 1 or BRCA 2 genes given their family histories. The pattern of the disease spread may vary slightly between women with this genetic mutation and those without.

Another possible error when interpreting numbers is that as a society we generally do not understand statistical language, and struggle with probability theory (Gigerenzer 2002b). Even though I studied basic statistics at a university level, I have struggled to understand the mathematical language in the books and journals covered during this research. Perhaps the young women are no different; even though they speak the language of medicine, participate in rational decision-making, and are mostly able to recall the probabilities of surviving beyond five years. However, as I have shown, they often do not understand the numbers given to them. Other research has also found numbers to be a source of confusion (Lobb et al. 2003). Misunderstanding numbers can lead to poor decision making concerning treatment and other factors that impinge on the quality of a person's life (Gigerenzer & Edwards 2003). Therefore, probability theory requires caution when being used at the doctor/patient interface.

The National Breast Cancer Centre (National Health and Medical Research Council 2000) recommends that treating specialists refrain from using statistical language when discussing treatment outcomes and prognoses, however, doctors continue to use numbers in a way that often makes little sense to the young women concerned.

Therefore, if prediction with respect to individual women is unjustified, why does it occur? I believe, as others do, that the practice continues because as a society we are uncomfortable with uncertainty, preferring instead the illusion of certainty that numbers engender (Gigerenzer 2002a).

Having now discussed why percentages and probabilities derived from groups of people are unsatisfactory when talking with individuals, I move on to some of the insidious effects of the discourse of numeracy on the lives of young women living with advanced breast cancer.

### **b. The discourse of numeracy can be used to manipulate people**

Apart from contributing to misunderstandings, the way that doctors present prognostic information can also affect the way people go about their decision-making. There are at least two ways that doctors can convey this information; one is via a *relative risk* calculation and the other is by the numbers of *absolute risk* (Gigerenzer & Edwards 2003).

Relative risk refers to the association between a risk factor such as death and a disease such as breast cancer. It is the risk of women with adverse prognostic indicators, such as age at diagnosis and stage of disease, dying within a specified time divided by the risk of women dying who do not have these particular prognostic indicators (Fineout-Overholt & Melnyk 2004). A relative risk is useful at times as it enables comparisons to occur between groups (Supramaniam et al. 1998). However, it has no influence on the chance of an individual young woman dying of breast cancer (Everitt 1999). Alternatively, absolute risk refers to the calculated probability of death occurring (or some other adverse event) like 2 in 1000 (Everitt 1999). It uses no group for comparison.

Numbers convey power; various institutions such as medicine, the media and governments can use them to manipulate people. For example, using absolute risk is preferable when conveying information such as the effects of treatment to a patient, yet relative risks are more commonly used (Skolbekken 1998). Relative risks use larger numbers than absolute risks and hence are more impressive. A doctor may consciously use a relative risk formulation in order to persuade a young woman along a particular

treatment pathway. For example, a study that examined the advertising of mammography screening in 58 pamphlets found that only information on relative risks was used, undoubtedly because the authors of the pamphlets wanted to encourage as many women as possible to participate in breast screening (Slater 1998).

Another way that numbers can be used to manipulate people is in an overestimation or an underestimation of the probabilities involved. Doctors generally overestimate cancer survival, especially when the doctor knows the patient well (Christakis 1999). Alternatively, they try to avoid using percentages at all when discussing prognosis in an attempt to preserve hope within the patient (Gordon, E & Daugherty 2003). This may have been a factor in Gena's case [the cancer of an undiagnosed primary] where percentages did not appear in discussions. Doctors often feel ill prepared for this task especially when their patients demand certainty (Christakis & Iwashyna 1998). It must be a difficult thing to do, to tell another human being that their life is now limited and yet as self-determining consumers, we demand the numbers. Demanding them is one thing, being provided with them is another. For example, Lamont and Christakis conducted a study of 326 patients with advanced cancer and compared doctors' known calculated survival estimates with the survival estimates that the same doctors would give to the patient if the patient insisted on knowing them (Lamont & Christakis 2001). They found that for nearly all (97%) of the patients, the doctors were able to formulate prognoses; however, these doctors would not communicate this survival estimate in around 23% of cases. They also found that the doctors were less likely to be frank with patients who were younger and if the doctor was either very experienced or alternatively, possessed not much experience at all. Their study suggests that doctors would provide, even if young women diagnosed with advanced breast cancer requested it, a frank disclosure in only about a third of the cases, and would consciously under or over estimate or give no estimate at all a considerable part (63%) of the time.

Additional research into prognosis has supported Lamont and Christakis' findings cited above. For example, Barton (2004) analysed 12 transcribed encounters with four doctors in four separate oncology clinics specifically looking at medicine's oral genre and how prognosis was dealt with in communications between oncologists and patients. She discovered that these encounters were arranged in such a way to allow the oncologists to 'do, appear to do, or avoid' tackling the difficult issue of prognosis

(Barton 2004). One of the reasons hypothesised for this difficulty in engaging in prognosis was that it had the potential to disrupt the doctor-patient relationship and the doctor's control over the clinical encounter. Therefore, numbers can be used to control situations in which the medical professional may find himself or herself - especially in the setting of delivering bad news.

To be able to foretell the future is a powerful position to hold and many people living with a life-limiting illness want information on prognosis (Kirk, Kirk & Kristjanson 2004). Yet communicating prognosis and treatment options has not always been a priority for doctors in the past. Traditionally, both doctors and their patients accepted non-disclosure in the management of disease. Currently however, the push towards more individual responsibility for health and illness demands from the doctor a full and frank disclosure so that people can make decisions regarding treatments that may affect the quality of their remaining life.

### **c. The discourse of numeracy fuels the responsibility to survive**

The probability of successful treatment outcomes and ultimate survival depends in part upon the cancer cells responding to a particular toxin. As the numbers show, a response does not always occur. The young women, aware of the failure of their cells to respond correctly, take on the burdensome responsibility to survive and explore a number of non-conventional pathways. They do not have to go far to find encouragement to take responsibility for their health, for popular self-help books on cancer prevention and treatment abound. In this literature, a woman with breast cancer is urged to take control of her life, to eat or not eat certain foods, to think particular thoughts, to undergo this treatment or that treatment regime. The philosophy underpinning these books reflects society's current attitude towards self-responsibility and the women in this research are positioned within this wider cultural understanding.

We are all urged to take control of our lives and bodies, fostering the illusion that we can make our futures certain (Stacey 1997). For those people who live with a life-limiting condition, it is their responsibility - even their duty - to survive as long as possible, to make rational decisions based on the available information about the right treatment to have, the right therapies to follow and the right thoughts to think. To seek unconventional therapies may be encouraged by friends as a duty, but it is also a duty

not to turn their backs on conventional medicine, for to do so would invite censure. Survival is a mighty responsibility, one that must feel burdensome at times and one that places the guilt for dying firmly upon the individual. To blame the individual for not trying hard enough is an easy step to take, and helps to ignore the social and political forces that shape our experience of health and illness.

Medicine offers choices, some of which appear preferable to others. Young women initially choose one pathway, the pathway of conventional medicine, however like the quote below they follow this path and may end up feeling trapped.

In every day life, you will find that your boss, your lover, or your government often try to manipulate you. They propose to you a “game” in the form of a choice in which one of the alternatives appears definitely preferable. Having chosen this alternative, you are faced with a new game, and very soon you find that your reasonable choices have brought you to something you never wanted: you are trapped. To avoid this, remember that acting a bit erratically may be the best strategy. What you lose by making some suboptimal choices, you make up for by keeping greater freedom. (Ruelle 1991, p. 37)

The exploration of non-conventional ways of healing, while not ideal in and of themselves, allowed the women in this research project greater freedom to explore their survival journey. However, the downside of this exploration is that certainty has become a consumer product (Gigerenzer 2002a). The young women feel that they can buy survival by exploring all the possibilities for cure. They related many accounts of their use of alternative practices such as shark cartilage, mercury flushing, heat therapy and faith healing, often at tremendous expense to the women and their families.

In the newspapers, only two articles out of 230 (less than 1%) mentioned alternative treatments (diets) for breast cancer, Atkey (1999), and Plant (2000). The first article was an advertisement for a book called the *Breast Cancer Prevention Diet* by Bob Arnot and the second was a letter to the editor outlining one woman’s experience of cure from breast cancer by eliminating dairy products from her diet. Many doctors treat such claims of cure as suspect because non-conventional medicine’s truth claims are mostly based upon anecdotal evidence and not on randomised controlled trials. Yet several research studies indicate that a vast majority of people diagnosed with cancer do use alternative or complementary therapies and do not tell their treating doctors that they are doing so (MacLennan, Wilson & Taylor 2002). Rather than seeing the use of such therapies as representing people who are taking control of their lives, their use can be

seen as a marker of distress as was the case in the Burstein study mentioned in the literature review (Burstein et al. 1999).

The professions of medicine and non-conventional therapies are often seen as arising from different epistemological bases. Medicine has the weight of an evidence-base behind it while non-conventional therapies generally lack this. Medicine promotes the mind-body split while non-conventional therapies attempt to combine both in their treatment modalities (Mizrachi, Shual & Gross 2005). While many people see conventional medicine and non-proven therapies as opposites, these two professions both contributed to the distress of the young women in this study by reinforcing the push towards the self-responsibility for survival that originated in a search for certainty.

#### **d. The discourse of numeracy forms its object: non-survivor**

We commonly equate survival with cure. In past times, the examination of entrails or the throw of the dice were used to predict the future. Now, probability calculations estimate the chance of cure or the odds of surviving. The term *survivor* has been used since at least since the 17<sup>th</sup> Century to mean the ‘one remaining alive after a disaster in which others perish’ (Macquarie Encyclopedic Dictionary 1990); a definition that has stood the test of time. A survivor generally is someone heroic, who has battled enormous odds in order to live on after others have died. There are examples of such heroism all around us. For example, in 1997, there were 18 deaths from a sudden landslide in a ski resort at Thredbo, Australia. Only one person survived the ordeal. His name was Stuart Diver and now in the Federation edition (3<sup>rd</sup>) of the Macquarie Dictionary (Macquarie Dictionary 2001), there is a new entry; the acceptable slang term for a ‘survivor’ is now a *Stuart Diver*. One of the hallmarks of a survivor today is heroic endurance, such as that demonstrated by this man struggling underground for all those hours. How does this everyday understanding of the word affect those living with advanced disease? Does metastatic spread mean that one has not been heroic enough? Clearly, this is not the case, and yet the young women involved in this research have taken on the mantra - ‘survival at all costs’.

The shape of a ‘normal distribution’ can visually depict what is normal and what is not – all calculated using numbers and the repeated observations over time. The category of *normal* sits in opposition to the category of *abnormal*. Women surviving breast cancer

by the medical definition of survival sit in opposition to those young women diagnosed with advanced breast cancer. This latter category represents a group of people who are considered pathological – non-survivors - not representing the norm of those who get breast cancer and go on to survive longer than five years. It is not that any of the women in this research referred to herself or others as non-survivors, yet the term is implicated because it sits alongside the category of survivor.

Knowing that their lives are limited, the activities that are open to young women living with advanced cancer are very different to those who fit into the ‘normal’ category (Hacking 1991). These women rarely join support groups because of the way that their statistics on survival affect the feelings of others with breast cancer. Other women, usually much older than they are, have better prognostic indicators and hence can realistically expect to survive for a very long time. Young women generally do not find, in these groups, an experience that resonates with theirs; other women are not like them. These young women present a picture to the older women that is threatening. They are incurable and contain the mark of shame – a stigma, and they struggle with the loss of the person they were before their life limiting diagnosis.

A dividing practice according to Foucault (1982a) is one that distinguishes one group from another. People are always the subjects of a dividing practice and we rarely challenge them. The dividing practice in this case is the one that divides the curable from the incurable, early breast cancer from advanced breast cancer, a survivor from a non-survivor. Similar dividing practices have been used throughout history to oppress or privilege groups of people, like men, women, white or black people. Young women living with advanced breast cancer are also marginalised and oppressed. Cancer support services do not recruit young women diagnosed with advanced breast cancer to visit newly diagnosed women in hospital. Only women who have ‘survived’ cancer for a number of years are deemed suitable for such support visits. Being an ‘incurable’ is not the message a newly diagnosed woman wants to grapple with just yet.

The discourse of numeracy, as a dividing practice, positions these women within the disease model of breast cancer; they are to be treated and controlled. The subject position held within this discourse is one of compliance and order and this position threatens to follow them for the remainder of their lives. The young women initially take up this subject position as it connects them to the wider cultural understanding of

self-responsibility. However, they are not passive subjects; they can and do resist the controlling prediction of numbers. However, as I have shown, their resistance takes the form of confusion.

### **e. The discourse of numeracy and the calculated management of life and death**

Numbers are more than just the vehicle for carrying information; they are also social products created to represent a particular version of reality.

Numbers, like reasons, are pawns; they can be summoned to produce any reality we wish to construct. (Natoli 1997, p. 182)

The particular version of reality that numbers are creating is one of certainty, and they are part of the power apparatus of the culture and the institutions in which we live (Hacking 1991). This kind of power has been termed *biopower* by Foucault (Foucault 1978), and it involves both the practices that control the individual body and the practices that control entire populations.

The old power of death that symbolised sovereign power was now carefully supplanted by the administration of bodies and the calculated management of life ... There was an explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of populations, marking the beginning of an era of “biopower.” (Foucault 1978)

The ‘calculated management of life’ covers the use of numbers that categorises and homogenises the knowledge of advanced breast cancer in younger women. It is to this that I now turn.

Biopower’s relevance to this thesis is that as a technique of government<sup>15</sup>, the collection of numbers enables information about individual women to be kept in registries and files allowing for commonly occurring features, such as the length of survival, to be documented. Through this process, statisticians generalise about the population leading to the calculation of averages, norms and percentiles. Consequently, the individual young woman becomes an object, a ‘case’, a number and is allocated (covertly) to the

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<sup>15</sup> Biopower and governmentality differ in that the former involves the process by which individuals are transformed into objects and the latter, the process by which individuals are transformed into subjects. Governmentality achieves its ends through the manipulation of the consciousness of individuals (McNay 1994).

category of ‘non-survivor’. Taking up the position that the numbers create for her, she struggles to survive. However, she also resists the imposition of the non-survivor category.

### **5. Conclusion**

Probability theory has transformed the world of medicine with its accompanying statistics and percentages. Statisticians make decisions based on probabilities, so do doctors and so do the young women with advanced breast cancer who were part of this study. Probability theory has enabled useful comparisons to be made between differing treatment protocols. It provides a vehicle for doctors to disclose bad news to patients and make predictions concerning survival.

For the young women in this study, uncertainty can never be eliminated, no matter how numbers are used. There are too many unknown variables affecting each and every outcome. However, the concept of certainty is seductive, and the young women in this study looked to numbers to give them comfort. They did not find this in their experience with the medical profession, nor did they find it in the newspapers. The numbers that they grappled with confused them, for they, like many of us, are innumerate when it comes to statistics and survival calculations. Yet numbers placed them into the category of non-survivor, a category with which they struggled. In order to try to extend their survival, they became self-responsible citizens and explored additional treatments that placed an enormous burden upon themselves and their families.

The next chapter moves into a discussion of the discourse of tragedy. Whilst exploring this next discourse and its effects, the discourse of numeracy hovers in the background, helping in its construction.

## CHAPTER 6: THE DISCOURSE OF TRAGEDY

### **Introduction**

The language of tragedy surrounds us; words such as *misfortune*, *desperate*, and *victim* infuse our daily speech, so much so that we barely notice their inclusion. Indeed, tragic events are so common in our daily lives that they are easily shrugged off if they do not touch us directly. Yet a tragic event is not the same as a sad one.

We must never confuse tragedy – the tragedy of drama – with the merely tragic. The tragic event, unlike Tragedy, is not marked by inevitability... If we accept, then, that Macbeth's character is flawed by his ambition, we see also that it's this flaw in this character which forces him inevitably to take the steps that lead him to his doom. Whereas the sort of thing we read in the newspapers as being tragic – er (sic), "Man Killed by Falling Tree", say – is never in fact a tragedy ... It's tragic, yes – absolutely tragic. But it's not a tragedy ... (Chepstow 1983, pp. 50-1)

This quote from the novel based on the screenplay, *Educating Rita* by Willy Russell illustrates one of the features of the discourse of tragedy, and that is inevitability. This inevitability makes a sad event tragic. Young women living with advanced breast cancer will inevitably die before their time and this is a tragedy.

Aristotle in *Poetics* (1997) defined tragedy as any incident that calls to mind the emotions of pity and fear - like a young woman living with advanced breast cancer. She is to be pitied because of the incurable and inevitable nature of the disease and feared because of the apparent randomness of breast cancer distribution within the population. I could fall victim, so could you. Mantle-like, fear settles softly on the lives of women of all ages.

The purpose of this chapter is to trace one particular discourse, the discourse of tragedy as it weaves its way through media portrayals, professional journals and into the stories told by 12 young women living with advanced breast cancer. To begin, I illustrate several features of this discourse, representing these features as particular 'acts' that shape tragedy. I then provide evidence of this discourse as it moves across the three data sets. Finally, I connect these individual understandings of tragedy to the broader social and political contexts in which the discourse occurs.

### **Tragedy – a play in four acts**

A tragedy is a special kind of text with which we are mostly very familiar. Shakespearean and Greek tragedies appear as required reading on many school reading lists. Tragedy is also a familiar form in film, television and popular novels. In this chapter, I am using ancient Greek tragedy as an example of one of many tragic forms; yet acknowledge that there are several others.

A tragedy contains several defining features that can be represented as acts in a play. These acts are not necessarily linear and can occur in any order. Nor are the acts stages that a hero must necessarily pass through in order to attain greatness. By referring to tragedy as a play, I am not meaning to trivialise the experience in any way. Representing the discourse in this manner is purely an organising device.

#### *Act I: Enter the hero*

Firstly, in a classical tragedy there is always a hero<sup>16</sup> or a protagonist around whom the action revolves. She is a person who gives the play a sense of dignity because of her moral respectability. Yet she is not out of touch with the affairs of ordinary people; she is a person we can relate to and hence for whom we can feel pity. However, not only are classical heroes decent people, they are also victims (Williams, R 1966).

#### *Act II: A strange and sinister fate*

Secondly, a classic tragedy always involves ‘a strange and sinister fate’ (Jaspers 1965, p. 45) in which a person is left stranded. The tragic hero finds herself in a situation over which she has little control and she is faced with a choice that in reality is no choice at all. Whichever path she chooses, she will ultimately fail. She accepts responsibility for this choice and thereby her fate. The die has been cast so to speak. In addition, the strange and sinister fate hides a fatal flaw that the hero possesses such as pride or a genetic mutation.

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<sup>16</sup> In this chapter, I use the term *hero* to represent both male and female form of the noun and the pronoun *her*.

*Act III: The battle unfolds*

Thirdly, in tragedy there is an unavoidable battle, usually against fate, a law or a god (Boas 1965). Like the choice that is no choice, the battle cannot be avoided; it is going to happen irrespective of the actions or choices of our hero. However, in the process of battle the hero attains both victory and defeat, “in suffering failure, the loser conquers” (Jaspers 1965, p. 49), and in so doing she attains a level of greatness denied to her in life. She is immortalised by her death.

*Act IV: A young life destroyed*

We are surrounded by many sad events in life and yet they are not all considered ‘tragic’ as illustrated by the earlier quote from *Educating Rita*. A sad event becomes a tragedy when there is the inevitable waste of a young life (Scheler 1965). However, in some tragic forms, the loss can also be that of a dream or an idea (Boas 1965).

The several acts of tragedy presented above can be seen in the lives of young women living with advanced breast cancer, as well as in the popular and professional press. Together, they make up the familiar form of classical Greek tragedy.

***Tracing the discourse***

I begin the trace by locating the discourse within the newspapers. Their portrayal of tragedy, in particular the tragic embattled hero, was by far the most influential in perpetuating and promoting the discourse. The evidence of the discourse within the newspapers sets the scene for further illustrations of its machinations as it works its way across the remaining data sets.

***1. Tragedy in the newspapers***

Stories for reporting in newspapers are usually selected according to their newsworthiness on the basis of certain criteria created by the media (Fowler 1991). Death or a life-limiting illness of a young person (especially if that person is a celebrity) is one criterion often used for such inclusion. This criterion is also a feature of tragedy. Nearly a third (70/230) of the articles mentioned the words *tragedy* or *victim* in their content and a further 14% (32/230) talked about *heroes* and *battles*. As readers, we are

caught up in the web of human tragedy that surrounds these people. In our eyes, the young women become heroes – albeit tragic ones.

**a. Enter the hero**

There were many heroes mentioned within the data collection period. Belinda Emmett, an Australian actor was diagnosed with breast cancer, had an occurrence of the disease and died, all within a ten-year time span. For Jane McGrath, wife of an Australian cricketer, breast cancer came back for a third time in 2006 and she finally succumbed to the disease in June 2008. Kylie Minogue was diagnosed with breast cancer in 2004. Belinda, Jane and Kylie are all celebrities and hence are newsworthy items. Their stories within the newspapers raise the awareness of breast cancer within the general population as the next extract attests:

The recent deaths of Linda McCartney and Kim Walters from breast cancer have raised the profile of the disease that kills thousands of Australian women each year. But the news last week that 24-year-old soapie star Belinda Emmett has been diagnosed with cancer has shocked many ... But tragically, young women are also struck down by the disease ... A mistaken complacency had been bred in the community's mind that those who are young will not fall victim. (Coffey 1998a)

Consequently, it is no wonder that many people believe that breast cancer in young women is common even though it is a rare phenomenon. The next newspaper extract reinforces the view that breast cancer in young women is disturbingly 'everywhere'. The article talks about one specific hero - Belinda Emmett.

Breast cancer seems to be everywhere and frankly, its terrifying. No matter how much we hear about the high survival rates if detected early and the marvellous breast reconstruction work that surgeons now do, it is still terrifying. As well as enormous sympathy and, of course, admiration for her guts, the many photographs of the beautiful and tragically thin Belinda Emmett taken at the Logies recently struck fear into many of our hearts. (Singer 2005)

Belinda Emmett battled breast cancer for a number of years. In the end, she became 'tragically thin' yet her thinness only added to her beauty. Mysteriously, her advancing cancer only made her more interesting and romantic, not unlike the tubercular look of the eighteenth and nineteenth centuries in which women with the disease were described

as ‘wan, hollow-chested’, symbolising ‘an appealing vulnerability’ (Sontag 1991, p. 30).

Kylie Minogue received a hero’s welcome after her return to the stage after 18 months of treatment and recuperation.

Kyle Minogue has endured a rough 18 months, but now she’s ready for her homecoming close up ... the Queen of pop has returned. Indeed, you would have had to have been living under a rock not to know it had been a terrible 12 months for the girl from Camberwell. (Bakker 2006)

The newspapers called her a ‘Queen’. Kyle Minogue is of course neither regal nor of noble birth, and yet she is someone we can look up to and admire. From the media’s point of view, she is a hero because of her diagnosis, her celebrity status and her youth and is likely to remain so whether she lives or dies.

#### **b. The other side of the coin: the victim**

Another feature of tragedy is that the protagonist is at the same time both a hero and a victim. The following headlines, often the only part ever read by many of us, sensitises us to the content that follows:

I want \$1.7 m; Cancer **victim’s** compensation claim revealed in court. (Clark 1998)

Uncommon **victim** of a common killer. (Lee, S 1998)

Agony of young cancer **victims**. (Coffey 1998a)

What about love for cancer **victims**? (Gora 2001)

The content of the articles is also peppered with references to victims. This next extract is from an article by Lyn Swinburne who had breast cancer diagnosed when she was only 40 years of age.

The cancer had not spread to the surrounding tissue but she was advised to have chemotherapy because of the size and aggressive nature of the cancer. “Being told I had to have chemo was absolutely rock bottom for me. You see those people on the television. With bald heads, they’re cancer victims. I didn’t want to be a cancer victim. It terrified me”. (Swinburne 2000).

Lyn did not want to become a victim, someone with a ‘bald head’. She, like many of us, had an image in her mind of what a cancer victim looked like. This image was perhaps not unlike the one of Belinda Emmett presented by the media.

Megan Williams referred to next, was another Australian actor although perhaps not as well known as Belinda Emmett. She attained the status of a hero when she revealed her story to the media. We do not hear of Megan and her diagnosis before this revelation, even though the advanced breast cancer diagnosis was some months old when the article was written.

#### **Megan loses swift battle with cancer**

Popular actress Megan Williams’ future was bright when she rang in the new millennium with her family. At 44, her exercise business was flourishing and she was as healthy and stunning as she was wowing audiences as Alice in the popular 70s war-time drama *The Sullivans*. Less than four months later, she was confined to a hospital bed and fed a cocktail of drugs to keep the pain at bay. On Monday, she lost her swift battle with cancer. But even on the brink of death, Megan was thinking of others and decided to tell her story in a bid to protect other potential cancer victims. (Wilson, P 2000)

Megan, whilst a hero, was also a victim, a sufferer from a particular destructive agency (Macquarie Encyclopedic Dictionary 1990). Advanced breast cancer was a sudden diagnosis and she succumbed swiftly. To use the word *victim* is a deliberate ploy by journalists to evoke our emotions. I will return to this point later in the chapter. Other research has also found the term *victim* frequently being used in breast cancer reporting (Shiel 1999).

#### **c. Altruistic endeavours**

Another feature of tragedy already mentioned is that heroes are usually people that we can admire and look up to; they are decent people who are altruistic in their endeavours, like Megan Williams in the previous example. The newspapers latch onto such altruism thereby adding to the tragic tale. For Vicki Nottage, her good deed was to publicly tell other young women not to be complacent about early detection strategies or to think that breast cancer only occurs in older women.

Her own fight for survival is not over, but Vicki Nottage is already going into battle for other young women. Diagnosed with breast cancer in January, Ms Nottage, 35 is calling for an advertising campaign that warns young women not to be complacent about the disease. “Before I was diagnosed ... well, when you thought about breast cancer you thought about older women” ... (King 2001)

The next extract shows how protecting a loved one from witnessing death can be an altruistic act. Robyn Riley, a journalist, is telling the story. She has just finished telling us of her sister-in-law’s death from breast cancer at the age of 35 and now moves on to describe her young cousin’s plight.

My cousin Leanne is another victim [of breast cancer]. Smart, funny and with so much still to do, she put up an equally determined fight right to the end... I was able to be with Leanne the day she died ... As always her mum was at the hospital with her that day, as was Leanne’s partner. Close friends came and went and I sat in a corner, watching ... It was obvious she was dying, yet Leanne refused to be medicated. She wanted to remain alert. And so she was ... She showed no fear, she was serene and accepting ... just before 7pm, Leanne asked me to take her beloved Mum out for a quick bite. Her mother didn’t want to leave. We were gone less than an hour, and returned to her hospital ward just as Leanne died. I think she knew her mother’s heart would break to see her die and with incredible generosity, she chose to shield her from that experience. It remains one of the most generous acts I have seen one human being do for another. (Riley 2006)

Knowing that her death was imminent, this young woman chose to have her beloved mother absent to spare her the pain of watching her child die. This passage is extremely emotive and it is not hard to consider Leanne a hero due to this selfless act. Seale in his studies on newspapers and cancer also found that women said they developed a sense of altruism as result of their cancer experience (Seale 2002).

#### **d. The battle unfolds**

Vicki Nottage enters into battle, one that she herself cannot win. She fights for all the other young women and urges them not to treat breast cancer complacently. Kate Curtin also goes into battle, yet in this instance, Kate’s battle is against the doctors who failed to diagnose breast cancer before it had spread to her liver. Her good deed lay in her intention to allocate any money received from compensation to set up a healing centre for people living with cancer. She was 34 years of age when she died.

Her family said the money had never been the point of her court battle, instead it was the principle of doctors listening to their patients and testing young women for breast cancer that concerned her most ... Her mother said yesterday Kate had intended to use the money from the settlement to establish a centre for healing people “living with cancer” – a phrase she insisted upon ... Kate’s family spoke yesterday of a remarkably brave woman who refused to give in and who was always ready to help others. (Lalor 1999)

No one knows how they will behave when confronted with adversity, yet such a battle carries with it the potential to elevate some people to greatness. The battle of young women living with advanced breast cancer is like that, yet it unfolds as a losing battle. Be that as it may, in the process, the young women attain greatness that ‘carries human possibilities to their extreme’ (Jaspers 1965: 52). For example:

#### **One woman’s battle an inspiration to others**

Jayne Kite has had hundreds of letters in the past four years from women who said her experience with breast cancer had prompted them to undergo regular breast cancer checks. “Some of them have been diagnosed with early cancer at a curable stage and they are grateful,” said the 38-year-old Mrs Kite said yesterday. “If I have played any part in encouraging SA women to undergo a breast check then that’s something wonderful that I have achieved.” The Greenwith mother had been fighting a losing battle with cancer for more than four years ... For the past three weeks she has been taking morphine daily to help overcome the pain from cancer that has spread ... (Hailstone 2000)

In this article, Jayne Kite is battling to raise the awareness that breast cancer can and does occur in young women. She is also battling the courts to have compensation awarded to her because a surgeon failed to follow up on a pathology report that indicated her lump was malignant. The early intervention that may have saved Jayne’s life was denied her and by the time treatment commenced, the cancer cells had already spread beyond the confines of her breast. Her battle in the face of pain and fatigue is seen here as heroic. Her story appeals to us because of the effort it takes for this woman to resist the inevitable. We applaud and admire her and others like her. Her tragic situation is made even more poignant because she is also a ‘Greenwith mother’, a fact that is mentioned in passing.

The next extract talks about Belinda Emmett’s ongoing battle with cancer. Unfortunately, given the cancer’s aggressiveness, it was a battle she could not hope to win.

**Belinda's agony: the cancer she conquered once has struck again.**

Television star Belinda Emmett has been diagnosed with cancer again... her career has been put on hold again to fight a battle for her young life. (Keogh 2001)

Belinda Emmett was fighting for her life. However, not all cancer sufferers like the term *battle* to describe what they are going through. For example, Meredith Billing was 35 years old when her breast cancer was diagnosed. In this next article, Meredith was comparing herself to Belinda Emmett and was considering how long she might have to live.

She lived for eight years and I just remember thinking to myself, is that how long I have too... I don't like the term battling, fighting for things, but [Emmett] obviously fought for a long time, hung in there and I think its very sad. (Tsavdaridis 2006)

Meredith has a grudging admiration for Belinda and her fight against ever decreasing odds. Yet she hopes that her experience will be different.

**e. A strange and sinister fate**

The strange and sinister fate that marks a tragedy as such requires a hero to be inherently flawed in some way. Depictions of young women in relation to breast cancer show our hero to be doubly flawed. Firstly, her young body does not behave as an older one does, especially under x-rays:

Most clinicians agree that mammography is not appropriate for mass screening of younger women whose breast tissue is much denser than that of older women ... Professor Alan Coates, chief of the Cancer Council Australia, said population screening of younger women could lead to an unnecessary number of false alarms and biopsies. "There is no satisfactory way of adequately detecting cancer in the breast of a younger woman with the same efficiency that we can with mammography in older women," Professor Coates said. (Patty 2001b)

Secondly, being young also means that cancer is more likely to return.

Half the women under 35 diagnosed with breast cancer are at risk of the disease recurring after treatment, according to NSW research ... women under 35 have only a 50 percent chance of remaining disease-free after 10 years, compared to an 85 percent chance for older women. Risks of the cancer recurring in other parts of the body were also found to be higher in younger women ...we've worked out the mere fact that being young increases the risk of cancer coming back ... (Patty 2001a)

Therefore, the *mere fact of being young* is the tragic flaw, for being young means that death is more certain.

Young women need to be especially vigilant, because there's data to show that young women are less likely to survive breast cancer than older women. They are more difficult to diagnose and their cancer is often more aggressive. (Pirani 2005)

Young women with breast cancer have little control over their fate due to the inevitability of cancer's return. However, cancer is not the only disease to attract the label of tragedy. The death of a young girl from AIDS also invites stories of tragedy and heroism (Lupton 1992).

#### **f. Loss of a young life**

There were a number of young women who were reported to have died of their breast cancer during the ten years of data collection. Bonnie Tran (1997), Marcia O'Keefe (1997), Jane Kite (1999), Kathryn Curtin (1999), Megan Williams (2000), Belinda Emmett (2006) and Jane McGrath (2008) were some of the featured women who lost their lives. While the loss of a young life is part of tragedy, so too are other losses associated with being young, such as the loss of dreams. For example, Christina Fiddimore was 40 years old when she was first diagnosed with breast cancer. Barely 16 months later, breast cancer returned to her bones. At this point, Christine no longer considered herself 'young and carefree'.

Mrs Fiddimore's cancer came back but this time she was told there was no cure. "It has spread to my ribs and now there are some spots on my left hip ... I felt a huge loss – the loss of no longer being young and carefree, the loss of dreaming about the future, the things I dream about doing in my life but may never achieve." (Tsavdaridis 2006)

Her loss was the often taken-for-granted ability to imagine a future. With the onset of metastatic disease, this imagined future with all its dreams and hopes was dashed forever and she was mourning this loss. Other losses that young women often face are their changes in appearance, their fertility and the potential to have children:

those [young women] who were diagnosed with the cancer had to tackle many problems not faced by older women. These included the possibility of sterility, their changed appearance after a mastectomy, concerns about their sex life and uncertainty over whether they would see their children grow up. “It’s true that women in their 20s are facing different issues to women who are older,” Ms Steginga said. “Age is an adjustment issue in terms of adjustment. A young person in their 20s is really just starting out on life.” (Coffey 1998a)

This paragraph mentions the possibility that young women diagnosed with breast cancer may not live to see their children grow up. It is however, a near certainty for young women with advanced breast cancer. These women will most likely be leaving children behind. This is indeed a tragedy.

#### **g. The tragedy of motherless children**

The tragedy of leaving young children behind to be brought up by someone else is not a feature of ancient Greek tragedy, but it is a tragedy nonetheless. The newspapers repeatedly added to the already tragic tale by mentioning the fact that many of the young women had children and these children were frequently young. For a mother to lose her children and for children to lose their mother is highly emotive territory and used purposely by newspapers to engage our interest and our pity. Consider this next example,

Thirty-six-year-old Kim Tonnet wants the world to understand that any women can develop breast cancer. Two years ago, Tonnet’s life changed forever when a routine breast check and subsequent tests revealed she has four tumours in her right breast and the cancer has spread to her lymph nodes. Tonnett, the mother of the then 12-month-old baby, had visited her gynaecologist to discuss having another child when he found a lump in her breast... “Basically I’ve gone from being 34 years old with one child and the hopes of having more ... but I still look at him and wonder if I will see him graduate from school. (Pirani 2005)

Kim Tonnett’s breast cancer, when first discovered, had already spread. Surely, this is tragedy enough and yet the situation is made so much worse by the mention of a young child. The possibility of not seeing a child grow up is one that haunts most mothers, irrespective of the presence of cancer. It is a sad and distressing situation. So too is this next extract.

Mrs Robinson, 35 had a six-week-old baby when diagnosed with inflammatory breast cancer, a rare and aggressive form of the disease.... Most of the other women she met having chemotherapy were much older. “My head space is being a new mum and life with my child. I couldn’t relate to older women” she said ... For Mrs Robinson, her 10 months of treatment ... has meant she can’t recall chunks of daughter Zoe’s first year. (Miles 2006a)

Inflammatory breast cancer has a very poor prognosis and due to the aggressive treatment, Mrs Robinson has gaps in her memory relating to her young daughter. She finds little comfort in the support of older women with breast cancer due to their differing circumstances.

Newspapers also use the tragedy of motherless children as a political tool to sway government bodies into placing an expensive drug on the Pharmaceutical Benefits Scheme’s list. Herceptin is the latest anti-cancer drug to be brought into the spotlight. It has made a difference to the length of survival for many young women with advanced breast cancer.

Mrs Levanic is not only trying to fight breast cancer, she is also trying to raise \$70,000 to buy a drug [Herceptin] because her cancer specialist believes it is her best chance for survival. She is mum to Tayla, 6, and Joey 12, and is fighting for their sakes too... They are predominantly young women with children. Young women who have been told that their best chance of survival, their best chance of seeing their children grow up, is to have access to this drug. (Riley 2005b)

Without government assistance, Herceptin is too expensive for many women. Withholding such support means that young women may lose their chance of seeing their children growing up and their ultimate survival is in jeopardy. Using the potential death of a young mother provides a persuasive argument. However, the article neglects to mention that not all young women with breast cancer will be able to benefit from this drug due to the expression of a certain growth factor in the cancer cells. Only 25% of women with breast cancer have this feature (Kondro 2005).

#### **h. Summary**

In summary, all the features of a classic tragedy appear in the newspaper articles illustrated above. There is the death of a young woman who heroically battles against the disease, doctors and lawyers. She is admirable in her actions and, although she is

also a victim, she attains a degree of greatness because of her struggle. Finally, she possesses a fatal flaw that inevitably leads to her death. Newspapers are well versed in the tragic genre, and add to the defining features of ancient Greek tragedy the possibility of not being around to watch children grow up. The mention of tragedy is virtually non-existent in the professional medical literature. It is to this that I now turn.

## **2. Tragedy in the professional medical literature**

The discourse of tragedy within the professional medical literature is virtually absent. This absence disturbs the smooth and unproblematic surface of these texts, thereby requiring a deeper exploration. On closer examination, the discourse was only hidden and not completely absent as first thought. While there is no mention of battles, heroes or 'strange and sinister fates', the loss of a young life does feature, as does the implied tragedy of young women dying and leaving children behind. The evidence for this section has been drawn firstly from professional medical journals and texts, and secondly, from clinical practice guidelines.

In this section, I am discussing both the journals and texts together as they appear similar in their discussions of prognosis, survival, treatment effects and pregnancy-related breast cancers.

### **a. A young life lost**

Although health care professionals know of the trajectory of advanced breast cancer (invariably downhill), the nature of its tragedy is rarely spoken of within their professional medical literature. Seventy-five articles out of the 251 (30%) collected for analysis focused specifically on prognostic factors as they related to young women with breast cancer; a further 12% focused on survival issues. The discourse of tragedy is located within these articles as they talk about poor prognostic factors and limited survival for young women with advanced breast cancer. The probabilities that shaped the discourse of numeracy also shape the discourse of tragedy. We observe the numbers and recognise the tragedy implied by them.

The study included 13 women younger than 25 years at diagnosis... Clinically, the average tumor size was 28.78 mm (CI=6.06), with 46% classified as T1, 31% as T2 and 23% as T4d. We found 92.3% to be invasive ductal carcinoma ... 53.8% were SBR grade 3 and 23%

included axillary node invasion... During the follow up period, we observed two deaths and 6 recurrences. Conclusion: Prognosis appears unfavorable among young women (younger than 40 years) with breast cancer. (Paillocher et al. 2006, p. 1618)

The paragraph above describes the tumour characteristics of 13 young women with breast cancer. We know that the size of the tumour correlates with survival, as does its grade and the number of involved axillary nodes. Two women died during the review period and a further six had a recurrence. Recurrence means that the cancer can no longer be considered 'curable'. For young women, these unfavourable prognostic markers indicate the great potential for an untimely death. The discourse of tragedy is woven into the pattern of numbers that inform prognoses.

The next journal extract reinforces the discourse of tragedy within the professional journals and repeats many of the findings already mentioned.

The relative risk of dying was adjusted for expected mortality, which includes death from breast cancer. In some age categories, particularly among young women, this leads to an underestimation of the disease-specific risk because death from breast cancer accounts for up to 15% of the total mortality in young women. Thus the prognosis for young compared to middle aged women is probably worse than we estimated. (Kroman et al. 2000, p. 477)

We know that the prognosis for young women is worse than for older women. This finding has been repeated across many research studies at a population level. The individual tragedy of a young life lost is hidden behind the language of 'poor prognoses'. Here is yet another example of tragedy hidden behind unfavourable prognostic features.

Very young patients tend to have tumors with unfavourable prognostic features: they tend to be larger, metastasize more often to regional lymph nodes, are of higher histological grade and they frequently do not express estrogen or progesterone receptors. In addition, young patients with estrogen receptor-positive disease are at high risk of recurrence and death following chemotherapy in the absence of hormonal therapy. (Aebi 2005, pp. 594-5)

Young women who develop breast cancer, irrespective of its stage, are at high risk of recurrence and death. This is indeed a tragic tale. A young life is often lost in this scenario. The 'strange and sinister fate' is the genetic mutations that bypass the body's

immune defences and the spread of cancer cells throughout the body. Once these mutations have undergone a number of replications, fate takes over. Death is inevitable.

### **b. Tragedy, heroes, battles and victims**

The other features that define tragedy are missing from the journals and textbooks. There are no discussions of battles against great odds or heroes. I searched the selected texts and journals for instances in which the words *tragedy*, *hero*, *victim* or *battle* had been used as these words indicate the discourse of tragedy in operation. The word *tragedy* was almost never mentioned. When it was, it referred to the tragedy of the growing cancer epidemic:

We have all seen the tragic images of death and suffering caused by the infectious diseases that affect millions of people in developing nations each year. Adding to this international public health tragedy are the less visible epidemics of cancer, heart disease, diabetes, and other noncommunicable diseases that are growing at an alarming rate. (Sener 2005, p. 7)

This example refers to tragedy on a large-scale, one affecting millions of people. The effects of such tragedy on the lives of individual people are not mentioned. The next extract uses the word *tragedy* to discuss preventable cancers such as those contracted through occupational exposure:

Occupational exposures to carcinogens are widespread and can result in tragic consequences for exposed workers. Clinicians are in a unique position to identify associations between workplace exposures and human malignancy, and virtually all occupational carcinogens have first been recognized by astute clinicians. Further, occupational cancers are usually preventable, and clinicians can be very effective in triggering preventive activities by industry, unions, and public authorities. (Landrigan 1996, p. 67)

The tragic consequences for workers exposed to cancer-causing agents are presumably suffering and death, although these are not explicitly stated in the article. Yet, we are familiar with this type of tragedy having grown up with the debate around asbestos.

Only one article actually referred to the tragedy of breast cancer in women. The article was titled *Transformation of tragedy among women surviving breast cancer* (Taylor, E 2000). The age of the women in this article was not specified. According to Taylor's research, women with breast cancer move through several phases in their transformation

of the tragedy of breast cancer. Attributing positive meanings to their cancers helped the women to transform the personal tragedy into something lighter and not so tragic.

In contrast to the term *tragedy*, the term *victim* was frequently used, but not in the breast cancer literature. Within the non-cancer literature, there were many references to victims of rape, domestic violence, incest, sexual abuse, bullying, assault, legal malpractice, burns, strokes, disasters, medical error, vehicle accidents, heart attacks, genocide and homicide.

### **c. The tragedy of motherless children**

The tragedy of motherless children, while common in the newspapers, is silent within the professional journals and texts. Only 15 (6%) of the collected journal articles mentioned pregnancy-related breast cancer and its prognostic significance. Nowhere in these articles is there a mention of the possibility that mothers may be leaving their children behind. An example from the journals comes from a case report of a 32-year-old woman who had metastatic breast cancer (bones and lung). She was being treated with paclitaxel and trastuzumab (Herceptin) and, nearing the end of the treatment, she became pregnant. As she was beyond the first trimester (14 weeks), she opted to continue with the pregnancy and with the single treatment of trastuzumab. Labour was induced at 32 weeks for medical reasons (unspecified).

Labor was induced with delivery of a viable female infant ...The infant was intubated for 3 days for surfactant delivery, and after extubation there were no further respiratory complications or other medical problems. The child is now 5 years old with normal growth and development. The mother is currently receiving lapatinib and capecitabine for metastatic breast cancer. (Pant et al. 2008, p. 1567)

What is not said in this article is that this woman has an incurable condition and will die before her time and leave this 'viable female infant' without her mother. Is this situation not a tragedy? Moreover, the medical texts are no different in their discussions of pregnancy and breast cancer. This next extract comes from the text, *Cancer, Principles and Practices of Oncology* (DeVita, Hellman & Rosenberg 2005).

The diagnosis of breast cancer during pregnancy is frequently difficult and is complicated by the engorgement of breast tissue that accompanies gestation. Most breast cancers in pregnant women present as palpable masses ... Breast cancer during pregnancy is usually detected at a later stage and is generally associated with a poorer survival than breast cancer detected in

nonpregnant patients. Metastatic breast cancer during pregnancy is fortunately a rare event. Systemic chemotherapy with AC or CAF can be safely used in most of these patients after the first trimester. Treatment for such patients must be individualized, and psychosocial and family support is essential. (Wood et al. 2005, pp. 1462-4)

Presumably, the psychosocial and family supports are needed because metastatic breast cancer and pregnancy are tragic combinations, although this is not specified.

#### d. National clinical practice guidelines

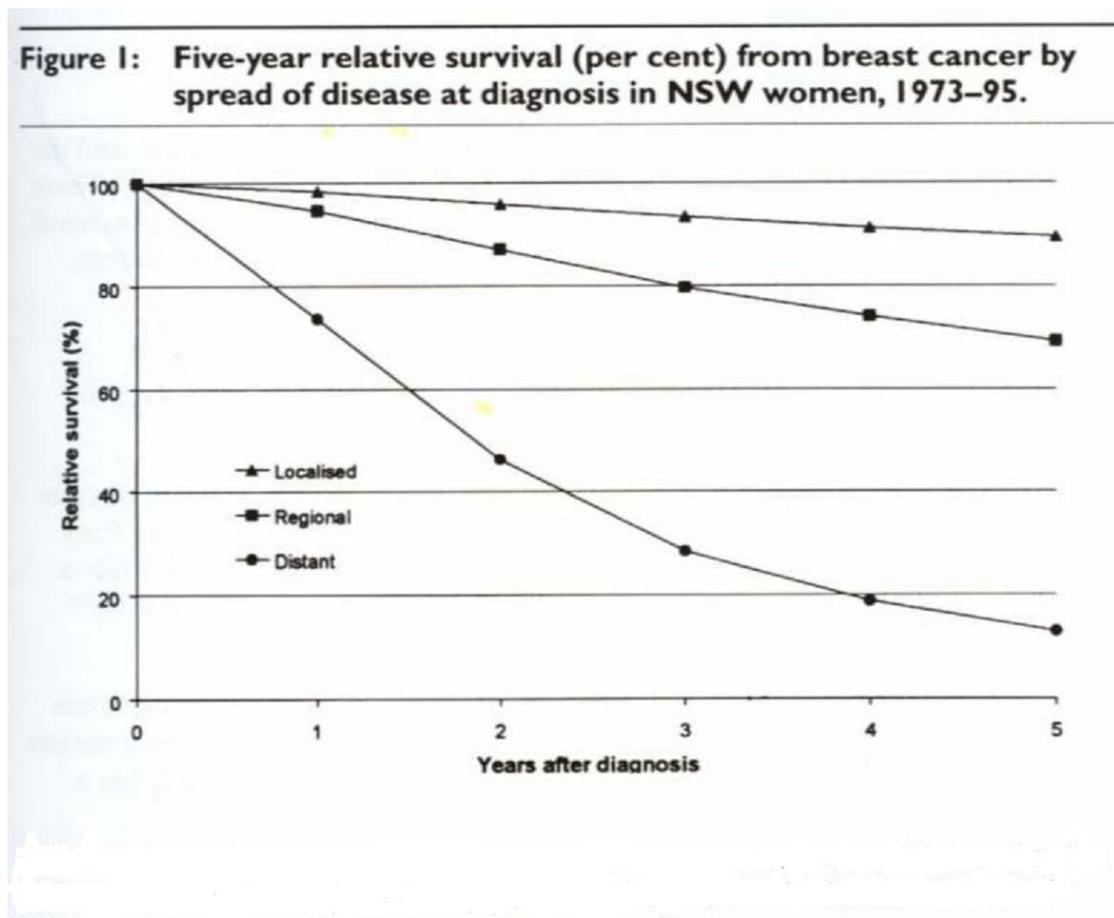
Within the clinical practice guidelines, the human face of tragedy and the inevitability of advanced breast cancer in young women are again masked by the numbers and words used in discussions. For example, in the following table taken from the *Clinical Practice Guidelines for the Management and Support of Younger Women with Breast Cancer* (National Breast Cancer Centre 2004, p. 7), the five year survival rate clearly indicates that younger women do not fare as well as women in the older categories. In addition, the size of the tumour at diagnosis is largest in women under 40 years of age, signalling a poorer prognosis.

**Table 1: Breast cancer incidence, mortality and disease characteristics by age group**

	Age group					
	< 30	30-39	40-49	50-59	60-69	70+
Incidence (% of total)	0.6	5.9	18.6	26.3	21.9	26.7
5-year relative survival (%)	72.4 †	79.8	85.8	85.7	86.1	*
Mortality (% of total)	0.2	3.3	13.8	20.5	19.1	43.0
Cancer size % per age group)						
0-10 mm	12.9	21.4	20.3	26.4	26.3	18.9
11-19 mm	29.0	35.2	34.1	36.7	37.3	34.8
20-29 mm	25.8	23.3	25.6	20.1	21.6	25.3
30+ mm	32.3	20.2	19.9	16.7	14.8	21.0
Nodal status (% per age group)						
Positive	38.2	40.0	38.0	32.2	27.2	20.9
Negative	38.2	42.2	45.3	51.9	51.0	36.5
Unknown	23.5	17.9	16.7	15.9	21.8	42.5

† Proportion reported for women aged 20 to 29 years

The next example is taken from the second of the clinical practice guidelines, the *Clinical Practice Guidelines for the Management of Advanced Cancer* (National Health and Medical Research Council 2001a, p. 17). It provides a more detailed illustration of the relative survival of women when the stage of disease at diagnosis is taken into account. We know from previous studies that a greater proportion of younger women than older women present with metastasised breast cancer (Agnese et al. 2004; Maggard et al. 2003).



The tragedy here lies in the circular mark (the bottom line) that draws our eyes downwards along the sloping line towards death. Similar tables can be found in other medical publications (DeVita, Hellman & Rosenberg 2005; Dixon 2000; Kricke & Jelfs 1996; South Australian Cancer Registry 2007).

The following extract, again from clinical practice guidelines, supports the illustrations above. The words hint at tragedy, but it is not explicitly stated. As they were in the examples above, the experiencing woman is absent.

For many women, distress increases as the cancer progresses. Compared with patients in remission, patients with metastatic disease have significantly more unmet needs in the area of psychological support. (National Health and Medical Research Council 2001a, p. 22)

Young women with advanced breast cancer have *unmet needs in the area of social support*, meaning that they struggle with the fact that they are dying and leaving loved ones behind. Surely this is a tragedy, yet it is not named as such. The closest that the nature of tragedy gets to being overtly mentioned in the guidelines can be seen in the following sentence:

Discussing the transition from curative to non-curative treatment is challenging and emotionally demanding for younger women and clinicians alike, as it involves the consideration of adverse prognosis and facing the possibility of death. (National Breast Cancer Centre 2004, p. 44)

We know that the transition from a curative to a palliative phase of a life-limiting illness is an especially stressful and difficult time for all concerned. The tragedy lies in the adverse prognosis and the near-certainty of death.

#### **e. Summary**

In summary, the professional medical literature does not mention the failure to cure, or the suffering that many young women go through as they experience the treatments for their disease. I am not saying that health care professionals are unaware of the tragic drama being played out within their own practice. They, like the rest of us, are very familiar with this hidden discourse yet perhaps do not recognise its defining or delimiting features in the day to day encounters with these women. Why this might be in uncertain.

### **3. Tragedy in the women's stories**

The discourse of tragedy is evident in the women's stories. Although the women do not call themselves tragic, they do resemble altruistic heroes who are battling against the great odds of dying and leaving children behind.

**a. Altruistic endeavours**

Like the newspapers, the young women living with advanced breast cancer lived out several of the features of an ancient Greek tragedy. Firstly, they wanted to be of service to others. The overwhelming reason they gave for consenting to be part of this research project was in the hope that its findings might be of use to other young women. Belinda understandably was concerned for her daughter.

I'm now concerned for my daughter, and that's why I do these studies, when they ask me about a study, and my first thought, was my daughter, if I could help prevent her getting it or help if she does, help in the treatment or, you know ... (Belinda,<sup>17</sup> P. 319)

Belinda is right to be concerned for her daughter as daughters of mothers with breast cancer often experience a great sense of personal vulnerability and disease inevitability (Raveis & Pretter 2005).

As difficult as it was for Jessica<sup>18</sup>, she made a decision to tell her friends of her diagnosis.

I did find that [telling friends she had cancer] difficult but I made a conscious decision to tell my close friends. I have said to all of them that I don't really don't care who they tell about it for two reasons, first of all, well several actually; it might make someone else go and get a check-up; might flush out someone else who has been through this. (Jessica, P. 227)

Jessica's service to others lay in the hope that her experience might make other young women go for regular check-ups. Karen's<sup>19</sup> service to others lay in her struggle to maintain a positive front even when she did not feel like it.

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<sup>17</sup> Belinda was 38 when her advanced disease was diagnosed. She also has three children under the age of 15.

<sup>18</sup> Jessica was 40 years of age when she was diagnosed with advanced breast cancer. She has two children under the age of 10.

<sup>19</sup> Karen was 36 when she received the diagnosis of advanced breast cancer. She also has two children, aged 10 and 13.

I kept very positive right throughout and people kept saying to me, gee you are looking really well but how you felt on the inside was a different story because it was easy to portray this really positive thing, okay I am going to fight this and feel positive. But on the inside you weren't feeling positive all the time and I guess you put on a bit of a face yourself to get other people through it like your own family members or whatever ... (Karen, P. 117)

Karen came across as a woman who was positively fighting her disease, yet it was a deliberate and difficult choice.

### **b. A strange and sinister fate**

The second defining feature of tragedy being played out was that these women were all the victim of some terrible flaw that was going to lead to their premature and inevitable deaths. However, unlike the newspapers, this flaw lay not in their relative youth but in their immune systems that allowed mutant cells to spread throughout their bodies with aggressive haste. The advanced stage of breast cancer was the outward sign of this flaw and thereby their 'strange and sinister fate', at least in the eyes of the health care professionals involved in their care.

Anna<sup>20</sup> could easily remember the stage of her disease at diagnosis and knew the implications that this stage then had on her ultimate survival. Advanced breast cancer's ominous nature became apparent as she told me this; *it was of a particular aggressive type. The cancer was staged as IIIB (Anna P.4)*. For Belinda in the next extract, tragedy was the knowledge that she had an incurable condition, and like the clinical practice guidelines, she used numbers and probabilities to illustrate what tragedy meant for her.

I said in 5 years, do they then say you're cured, and he [the doctor] said 'you'll never ever hear that, they'll not say that to you'. And that really shocked me. I thought, well I would presume in 5 years if it's not come back then everything is OK and 100% cured, and he said 'no, you may as well say you're not actually in remission anymore but, they will never ever say that you're 100% cured'. (Belinda, P.388)

Belinda may gain remission from her disease, but she will never be cured. This was indeed a shocking revelation for her as it was for many of the women, especially Emma below.

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<sup>20</sup> Anna was 44 when her breast cancer was found to have spread beyond her breast and has three children under the age of 15 years of age.

I suppose one of the things that became obvious - because nothing had ever been very specific about well, we didn't ask for a prognosis, so when we got to fill in the forms and they (the hospital) wrote things like the reasons for this (particular treatment) is to prolong your life ... When you see it written down on a form it sort of hits home and you think, oh so that's what they think they're doing. This is prolonging my life; they're not actually going to cure me. (Emma, <sup>21</sup>P. 84)

Tragedy for Emma lay in the realisation that whatever treatments that she might now receive; they were only possibly going to extend her life. The terrible flaw that allowed breast cancer to spread beyond her breast meant that she would die before her time.

For Inge<sup>22</sup>, the aggressive nature of advanced breast cancer lay in fact that at diagnosis the cancer had already spread beyond the breast, a poor prognostic sign:

We certainly knew right from the beginning that whatever type of cancer that I had it was serious because it had spread already, and so we were dealing with something that was pretty serious ... (Inge, P.44)

Similarly for Carol<sup>23</sup>:

there's heaps [of cancer] in the bones, up and down the spine, there's quite a few (metastases), hips and I had a seizure right out of the blue a year ago and it turns out there's some small ones in the brain as well, so I had to have radiotherapy on those ... (P.20)

Advanced breast cancer is a serious disease with tragic consequences and these young women were aware of this fact. However, while they all possessed a flaw at a cellular and genetic level, they did not consider themselves to be victims. Nowhere in the 12 interviews did the women mention the word *victim*. This was one defining feature of tragedy that they appeared to resist.

### **c. Into battle**

The third feature of tragedy present in the stories is that of being involved in a battle; a requirement of a tragic hero. In this research, battles occurred against the statistics that indicated that each young woman diagnosed with advanced breast cancer would die of their disease. Helen<sup>24</sup> was 29 when diagnosed with advanced breast cancer, her first

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<sup>21</sup> Emma was 38 at the diagnosis of advanced breast cancer and has two children under the age of 16

<sup>22</sup> Inge was 36 at the diagnosis of advanced breast cancer and has two children, aged 2 and 6.

<sup>23</sup> Carol was 38 when her original breast cancer recurred. She has two stepchildren.

<sup>24</sup> Helen has two children under the age of 4.

cancer diagnosis. Her battle was firstly against the statistics that showed she had only two to three years to live and secondly, against the advice that she had received from her oncologist, to refrain from having children. Yet surprisingly, at the time I interviewed her, she had had two children in four years and had successfully breast fed both:

I think that too many facts and such create fear. They (the surgeons) gave me a prognosis of 2-3 years and I laughed at them. Well meaning friends gave me books on self-help and how to heal your cancer and I threw them all in the bin. I was really vulnerable during and just after treatment and felt that people played on this ... I had lots of phone calls from people selling vitamins and minerals and other stuff, I haven't changed my diet or way of life at all though. There is nothing that I can do to cure myself, it has to come from God ... I was told that I wouldn't be able to have children or that it wouldn't be wise. They wanted to take my ovaries out but I said 'no way'. When I did fall pregnant they advised me to have an abortion, and then when I did have my baby they said I wouldn't be able to breast feed. I managed to breast feed both my kids until they were about 14 months old. I have healthy women's checkups now and that's all. My obstetrician wanted to discuss my breast cancer with me but I said she wasn't my oncologist and if she wanted to discuss it with him then here was his phone number ... I refuse to accept that I have breast cancer, not that I am denying the facts but they aren't my truth - do you see what I mean? I made a choice between life and death and I chose life and rejected death. (Helen, P. 67)

I could admire Helen for her courage in the face of the statistics and expert opinion. She had resisted all defining discourses thus far. I found it difficult to imagine the prospect of her long-term survival. Yet, apparent cures from such serious conditions are possible as evidenced by such Australian celebrities as Ian Gawler, Delta Goodram and Olivia Newton-John. Tragedy as we understand it may well lie in Helen's future.

There were many other stories of battles and these can perhaps be summarised by the following extract from Karen's story:

I needed to, yeah, I needed to prepare myself, I needed to say okay I want to fight this, how can I fight it. I needed to find out as much information as I could before I could go and fight it. Like I needed to find out where exactly my cancer was, and perhaps the alternatives to conventional medicine as well. (Karen, P 109)

Karen, as did all the young women interviewed, battled against the inevitability of cancer's progression.

Susan Sontag is well known for her work on the metaphors surrounding illnesses such as cancer and AIDs (1991). She found that the dominant metaphors in these illnesses

used the language of warfare and as a result, cancer has become the enemy we fear. For example, cancer cells *invade*, they *colonise* and cancer treatment *kills*. Cancer is the enemy against which the sufferer must battle (Sontag 1991, p. 65-66). Like tragedy, cancer produces *victims* (p. 59). The term ‘victim suggests innocence. And innocence ... suggests guilt’ (Sontag 1991, p. 97). Young women living with advanced breast cancer feel the weight of guilt for not living a healthy enough lifestyle. In this research, it can be seen that the discourse of tragedy extends the metaphoric language of battle into the realm of the tragic hero. The battle that the young women engage in is not one that will result in a happy ending. They battle against an inevitable decline. Lupton suggests that the use of such metaphorical language produces stigma and discriminates against those who are ill (2003, p. 61). The use of the tragic discourse to describe the experience of young women living with advanced breast cancer may also lead to feelings of shame and result in a young woman’s discrimination.

#### **d. The tragedy of motherless children**

A large part of the tragedy of what it is to be young and diagnosed with advanced breast cancer, at least as far as the young women were concerned, was not the features already mentioned, but rather, tragedy for them lay in the fact that they were going to die and leave children behind. Like the newspapers, this aspect was strongly apparent in their stories:

Anna knew that her death was inevitable; however she hoped her death was far away as she wanted to look after her family for as long as possible;

Nobody wants to die young, there’s a time to die I know that, but for me I want to live because I want to look after my family, there’s other reasons I want to live too, but that’s my major reason, so my decisions have to be carefully made, and doctors can’t always tell you, a doctor can’t always tell what the right decision is, but only help you help to direct you. (Anna, P.353)

What and how much to tell the children are common concerns for people living with a life-limiting illness. Anna struggled with a difficult question from one of her children:

[Child’s name] said “you’re not going to die [of breast cancer], you’re not going to die are you Mum?” you know. So there was a lot of questions [that this child had] ... You know he couldn’t even hardly take a breath of air, and I just felt really sad that it happened to him. (Anna, P. 153)

At the time, I wondered what her answer had been to this child, and like Anna, felt sad that the prospect and reality of death needed to be faced by one so young. The effect of the death of a mother on children has wide ranging and long term consequences (Turner, J & McGrath 1997). For Inge in the next extract, she carefully weighed up the pros and cons of telling her six-year-old son that she had cancer:

[Daughter's name] is two so she is too young to understand, and she just says Mummy's got no hair and Mummy's got a wig, and if I go out with my wig on she'll say 'oh this is Mummy's wig' it's not a secret anyway. Looking after her at times when I'm not feeling very well is difficult because she just doesn't understand, she can't understand that Mummy's not feeling very well, I can tell her that, I can tell her that I am tired but still it's her needs that are most important to her and it's no matter how sick I am, she will still want me to do things for her, she, they just don't comprehend at that age. ... My son has just turned six. It's been a bit more difficult with him. We said initially that I have been sick. We didn't sort of bring up the word cancer initially because he didn't have any idea of what cancer was, and we told him that because I was sick I would have to have medicine that would make my hair fall out and make me tired, so he understands if I stay in bed a bit longer in the morning or have to have a nap in the middle of the day or something, why I need to do that and he is very understanding. He will give me cuddles and he thinks like he will give me a cuddle and say 'now are you better Mum?' cos I give him a cuddle. He says 'now you feel better'. He did ask me one day why I had a sore shoulder and breast. We mentioned the breast because at some stage I thought I might have to have surgery, and he asked me why and I thought the best thing was to be honest and that to say 'Mum has cancer' and that was all he needed to know. He didn't ask me what cancer was, he just accepted the word cancer and that was it. (Inge, P.193)

It may not be too long before Inge's son connects the word 'cancer' with the word 'death'. Children often intuitively pick up that the disease their mother has is serious. They see the effects of treatments; the loss of hair, the oedematous limb, the failing energy and strength and they surmise that not all is well. They are also exposed to media depictions of deaths from cancer and may equate their mother's condition with possible death. Donna was very aware of this fact; *'I think they know, I think they pick up from me, yeah, that I am not well and may never be well. I may never be the mother I was'* (P 152).

Tragedy for Donna was that she could never again be the mother she was and she was beginning to grieve for this loss of her role and her identity. Sometimes children become angry that the cancer has robbed them of the mother they knew and this anger reinforces for the women concerned just what they are losing. This was so for Gena and her children:

If there isn't a physical thing that your children can see they tend to think that you're OK, and it's very hard for them to accept the reality that you're sick and when you are going through the chemotherapy and you are tired and all of those sorts of things and the only way that they really know is by you saying, look I'm too tired to do that or no, I can't do that or whatever. And then they can get angry and bitter about that because then they are unable to perhaps to go places. My youngest daughter in particular wants to have people sleeping over and this stuff and I just can't cope with having extra children in the place at particular times. It's just enough to deal with the 5 of us and all that's going on without having extra people around. So, she would say, I just wish this cancer would go away because I can't have friends over and I can't this and so very sort of egocentric. That's what children are and that makes it very difficult for women, I think in particular to deal with their children and to deal with their cancer because you haven't got a broken leg if you see somebody you can see that they can't get around or but I'm not in a wheel chair you're not in those sorts of things. So when I was wearing my wig, my wig looks very much like my normal hair so unless you actually stopped to think, Mummy is wearing a wig, which kids don't stop to think. It's very hard. Not that you want it to be in their face all of the time either but when it stops them from doing perhaps what they want to do it does make it extremely difficult to explain that to them. I certainly feel for those who have got even younger children where you aren't even able to explain that to them on the very simplest terms. (Gena, P. 125)

Emma looked ahead and saw a future in which she was absent and not able to guide her children. She could see her role and identity as a mother ending and was anxious to prepare her children for this inevitability:

The children have been involved in all of the conversations. We haven't kept anything in secret from them and every now and then they come out with something and it helps to realise how much they've processed with the whole thing. It's hard to know how they really are but they've seen other people die of cancer and they know that's a possibility... they haven't asked me if I am going to die. I've talked a lot about it, I guess I've always been a crammer and so I've talked a lot about, let's do this now and I've got certain things that we want to do together ... things that each one specifically, like the oldest boy, we're getting him organised for the work force and filling him up with the essential things like making sure he can drive and cook and clean and all that. I guess we've been doing that with them anyway but we've extended it now with more of an interest ... so we've made plans to do things together. I talk about it terms of borrowed time, whatever, fairly openly. (Emma, P.151)

While each of the women in this research had a slightly different slant to the nature of the tragedy at work in their daily lives, most of them shared the awful thought that their children were going to be left without a mother to guide them. This thought connected these women to every other mother on earth.

#### **d. Summary**

Like the construction of a garment, the discourse of tragedy gathers its threads as it traverses and informs the young women's stories. Within their conversations, altruistic

heroes can be found who are involved in battles against a strange and sinister fate and, apart from the heroic battle to survive against enormous odds and the fact that they were living with an aggressive disease, they also had to imagine a future for their children in which they were absent. This was the nature of the tragedy they were living.

#### **4. Discussion**

Having provided some examples the discourse of tragedy at work within and across various texts, I now move onto placing this discourse into its broader social and cultural context, specifically looking at its effects on the young women concerned; for tragedy does not appear in isolation, it exists in a world of relationships and human connections.

There are three points I wish to make in this discussion. Firstly, the media through its deliberate use of the tragic genre produces, reproduces and sustains the discourse of tragedy, limiting what can be said and by whom. Secondly, as the discourse intersects with the lives of young women living with advanced breast cancer, it reinforces the unhelpful stereotype of the tragic hero. The women resist this discourse defining who they are and dictating what positions they are able to take up. Thirdly, as the discourse of tragedy plays its way through the various texts, it carries with it certain beliefs and taken-for-granted assumptions about what it is to be young and living with a life-limiting illness in Western society today. These values and beliefs, shaped in part by the discourse of tragedy, are at odds with the realities of the young women concerned.

##### **a. The use of the tragic genre**

One of the mechanisms at work supporting and perpetuating the discourse of tragedy is the newspapers, and to a lesser extent, the professional medical literature's purposeful use of the tragic genre. The word *genre* refers to a particular type or a kind of text which usually shares several defining features (Chandler 1997). I have already outlined the defining features of a particular tragic genre – ancient Greek tragedy. Films can also be classified into subcategories such as mysteries, thrillers or romances. Articles within newspapers can be divided into news, health reports or special feature articles. In drama, there are divisions between tragedies and horror stories. In addition, one genre can spill over into another kind of text or get mixed into another one as in the case of a comic-

thriller. There are no rigid boundaries keeping genres in place so to speak (Chandler 1997).

Newspapers are there to make money, and the more newsworthy the stories are the more likely they are to sell their product. Publishers and journalists use a familiar dramatic form because they know that readers can be relied upon to have the knowledge necessary to interpret the text, thereby making communication more efficient (Chandler 1997). In addition, as the tragic genre is relatively stable over time, newspapers can predict how readers are going to receive the text – in this case with sympathy. Therefore, the tragic genre can also be used in order to predict and control how the readers are going to receive the text.

Furthermore, by drawing on the discourse of tragedy, newspapers and professional medical literature limit other ways that the texts of advanced breast cancer in young women may be read. For example, not all ways of talking and thinking about advanced breast cancer are given equal weight in the articles. The more dominant discourses such as that of tragedy limit or exclude other ways of considering the reality of living with a life-limiting condition. The articles analysed pushed one way of understanding of advanced breast cancer in young women and silenced others, as in the case of the over reporting of young women who get breast cancer. The ability of the news media and its power to influence lay understandings of certain health issues can be seen in the case of HIV and AIDs reporting (Lupton 1992).

The use of the tragic genre also guarantees that the reporting of issues such as young women with breast cancer will remain newsworthy. Using celebrities in the tragic tale adds to this guarantee. This phenomenon can be seen in the recent reporting of Kylie Minogue and her surgery for breast cancer. The reporting of breast cancer in young women had reduced in amplitude since the news of Belinda Emmett's cancer return in 1998, however with another young celebrity falling *victim* (Jane McGrath); it can now be guaranteed to be newsworthy for some time to come. Other conditions do not receive the same media coverage; for example, women dying of heart disease – a major public health issue - is hardly mentioned in our newspapers (Australian Institute of Health and Welfare 2008).

### **b. Effects of the tragic genre**

What effects does the discourse of tragedy, operating as a genre, have on the young women living with advanced breast cancer? I have identified three effects; the first is that the discourse of tragedy reinforces the tragic hero stereotype, the second is that the discourse of tragedy prescribes what emotions can be felt and experienced and third, that the discourse of tragedy has inherent in its fabric the certain values and beliefs that make the world more intelligible.

#### **Effect 1: The discourse reinforces the stereotype of the tragic hero**

As mentioned in the previous chapter, the discourse of numeracy, operating as numbers and probabilities, is one of the ways that both the medical profession and the newspapers attempt to achieve order in the chaotic world that is advanced breast cancer. The discourse operating in such a manner helps us to classify young women with breast cancer into either an early or an advanced category. By knowing the particular category within which a young woman falls, we then know what we are dealing with, what to expect etcetera. This efficiency in communication allows stereotyping to occur (O'Hara 1965).

Stereotypes are conventional and fixed ways of thinking about things and can be very useful. Newspapers use them deliberately, just as they do particular genres. Time and space limitations make it necessary for journalists to use short cuts and we, as readers, make use of a similar understanding of the stereotypes being employed to skim through the story. Stereotyping is similar to Kitzinger's (2000) notion of templates mentioned in Chapter 2. Templates, with their accompanying stereotypes, are widely relied upon in all forms of communication.

Stereotypes are also useful in that they, when used, make events predictable (O'Hara 1965). Using such a stereotype as the tragic hero allows us to predict her behaviour and likely course of events as the disease progresses. However, predictions are usually based upon fictional stories and are therefore fabricated over time. The tragic hero is how we stereotypically think of young women diagnosed with advanced breast cancer. This stereotype has come to stand for a young woman who goes into battle on several fronts - cancer and its progression, the medical profession, the popular portrayals of a cancer death and the downward slope of a survival curve. It has also come to stand for a losing

battle, motherless children, altruism, an inevitable fate and a young victim – all distinguishing features of the discourse of tragedy.

The tragic hero stereotype is reinforced by certain types of narratives that are common in the experience of illness and these are the quest and chaos narratives, identified by Arthur Frank (1995). Chaos narratives are stories of illness in which health can never be regained and life never returns to what it was before diagnosis (Frank 1995, p. 97). Quest narratives on the other hand are stories of how the experience of illness can bring about profound changes in the life of the person concerned (Frank 1995, p. 116). Like Thomas-MacLean's study (2004b) into the stories of women with breast cancer, chaos narratives were prominent in the stories of women in this project. However, quest narratives were also present.

There are two main consequences of such stereotyping. Firstly, by using such a stereotype, the young women concerned arrive at a point in time already classified as a pre-defined group with certain characteristics; they are not seen as unique individuals. Therefore, by grouping all these women together under the heading 'tragic heroes', there is the potential for discrimination to occur. For example, as a health care professional, if I meet a young woman with advanced breast cancer, based on my past experiences and dealings with fiction, I may view her as a tragic hero with its accompanying features and predictable behaviours. If I observe the woman to be not conforming to these predictable patterns I may discriminate against her in some way, such as through distancing or blocking behaviours. Alternatively, I may need to challenge my preconceived view of what it is to be living with a life-limiting illness. Recall Helen's story in which she said that she was already cured of her advanced breast cancer; she was living with an incurable condition and yet resisted its definitional work. My response to that aspect of her story was one of cynicism because of my preformed knowledge of cancer and its biology.

The second consequence of such stereotyping is that the young women, so stereotyped, are under enormous pressure to act in a congruent manner. They are expected to fight a losing battle, do good deeds, succumb gracefully to an inevitable fate. They are expected to live the role of a victim, or, in other words, identify with other popular heroes, such as Belinda Emmett, Jane McGrath or Kylie Minogue, that have been

created and perpetuated by the media. Maybe this identification is one of the ways that they find meaning in what has occurred. However, the downside of identifying with such popular figures is that, for the majority of ordinary young women, it is a very hard image to live up to. It can make them feel inferior and frustrated when an heroic recovery is not part of their reality (O'Hara 1965).

The women I interviewed did struggle with the notion of battle, although they participated in it superficially. It was difficult for them to resist the dominant cultural story that would have them fight cancer no matter what. By participating in it, they then had no space from which to talk about the sheer futility of it all.

Such mythologies [as the tragic hero] encourage us to believe that suffering makes us wiser and serve to heroise those who suffer the most. They leave no room for the futility of the pain the arbitrariness of disease, the unbearable pointlessness of suffering. (Stacey 1997, p. 15)

A myth is a customary story used to explain a particular phenomenon (Macquarie Encyclopedic Dictionary 1990). The story of the tragic hero is a myth. Yet, it is used to explain how it is that some people can become a tragic hero through personal endeavours. The myth of the tragic hero is one of the stories that often influence patients, families and health care professionals' response to cancer (Gray & Doan 1990). However, none of the women interviewed considered themselves heroes, or victims for that matter. They were suffering the loss of an imagined future and were tortured by the notion of leaving children behind. They resisted the myth, the stereotyping and the position of tragic hero that was circumscribed by the texts. It was if they knew that the positions they took up and identified with made up their identity (Woodward 1997, p. 39) and they did not want the identity of a tragic hero. I don't think that it was a conscious decision on their part to do so, as positions and alternative positions within the discourse of tragedy existed before the understandings and experiences of tragic genre were shaped (Willig 1999). As Kress states:

Every genre positions those who participate in a text of that kind: as interviewer or interviewee, as listener or storyteller, as a reader or a writer, as a person interested in political matters, as someone to be instructed or as someone who instructs; *each of these positionings implies different possibilities for response and for action*. Each written text provides a 'reading position' for readers, a position constructed by the writer for the 'ideal reader' of the text. (Kress 1988, p. 107) (Emphasis added)

Resisting the position of a tragic hero created within the texts related to breast cancer has meant that the women have created a different possibility for response and action for themselves.

**Effect 2: The discourse of tragedy and emotional work**

The discourse of tragedy, through its reinforcement of the stereotype of the tragic hero, prescribes what emotions can be felt and experienced in the situation of advanced breast cancer in young women.

Emotionality lies at the intersection of the person and society, for all persons are joined to their societies through the self-feelings and emotions they feel and experience on a daily basis. This is the reason the study of emotionality must occupy a central place in all the human disciplines, for to be human is to be emotional. (Denzin 1984, p. x)

Therefore, the young women and their experiencing emotions are important considerations when examining the effects of the discourse of tragedy. They belong to a group of people who have a heightened sense of mortality. It could be expected that they feel sad or angry that their lives are going to end prematurely. The stereotype of the tragic hero dictates what emotions can be felt in this situation. Yet, these emotions can be controlled through the medium in which they are being conveyed. For example, even though personal stories of young women with advanced breast cancer are reported in the newspapers, the women themselves and their suffering and sadness are referred to impersonally leading to what I believe as a depersonalisation in the way these young women are represented. This depersonalisation is perhaps similar to the disempowerment of women with breast cancer found in Lupton's earlier research on Australian newspapers (1994).

Depersonalisation is a regular feature of an official discourse (Fowler 1991) and the institutions of medicine and the media play their part in sanitising the experience of, and emotions involved, in living with a life-limiting condition so that it can be dealt with by the lay public. And while medical journals are virtually devoid of the tragic, the very nature of tragedy must infiltrate their research and writings to some degree. After all, researchers live in a world where the tragic genre is common. Keeping tragedy sanitised and contained (as does abjection) may be one way that medicine reinforces its boundaries from contamination by subjective knowledge, such as that gained by the

experience of suffering and sadness (Gieryn 1995). Objective knowledge – or depersonalised knowledge - is valued within medicine, however the lay public generally cannot understand it. Knowledge needs to be simplified and translated for the masses. This simplification can protect medical knowledge from being challenged (Petersen, A 2001).

Emotions, from a poststructural perspective, are not simply internal states of an individual, but are constructed at a societal level in and through discourse (Lupton 1998). In the case of young women living with advanced breast cancer, the discourse of tragedy dictates what emotions can be experienced. Apart from reinforcing the tragic stereotype, it does this by the locating of the experience of these young women within the current familiar ‘scripts’ of tragedy. Tragedy always brings forth emotions of sadness, pity and fear because we are familiar with the narrative genre. While we might be numerically illiterate when it comes to statistics and probabilities, we are emotionally literate in the area of young women with an incurable disease.

The young women in this project engaged in what Hochschild identified as ‘emotion work’, which is ‘the act of trying to change in degree or quality an emotion or feeling’. (1979, p. 561). These women were actively trying to manage their own emotions in order to conform to what was expected of them socially. Therefore, the discourse of tragedy has certain ‘feeling rules’ (Hochschild 1979) attached to it. The feeling rules are related to the intensity of emotions, rather than presence or absence of feelings. In order to function in the world, the young women dampened down the emotions of fear and sadness that they exhibited to the outside world. Perhaps in the privacy of their own homes things were different. As the interviewer, I was also engaged in feeling work, struggling with my own feelings of sadness as I sat before these women. We were both following the feeling rules that the tragedy discourse dictates. It is socially expected that tragedy will evoke feelings of sadness and maybe a myriad of other emotional responses, however there is a time and a place for the display of such emotions. It is appropriate that the young women feel such emotions; however, the intensity needs to be at a level that society is comfortable with. It is to be expected that I might feel sad during the interviews, yet not appropriate to overtly show this sadness. In this situation, we were both dealing with an incongruence between our real feelings brought forth by

the story being told and our display of them. Hochschild called this incongruence 'emotive dissonance' (1979, p. 565).

The majority of emotional work in our society today is done by women (Small 1996). Within families, it is usually the woman who engages in the emotional work, providing the nurturing of others, while men are often considered to be less expressive in their emotions. However Deborah Lupton, in her later research on emotions and gender, found that the traditional division between the emotional woman and the unemotional man is breaking down. Men are now expected to be emotionally expressive, especially within the family and women are expected to participate in the paid workforce and display emotions such as anger and frustration (Lupton 1998).

The findings of the link between the discourse of tragedy, young women with breast cancer and their involvement in emotional work supports Clarke's (1999) earlier research in which she found that women with cancer tended to be portrayed by the media as being emotionally labile. In addition, this project also extends the work of Seale (2002) in his research on news reports. His findings indicated that the media at the time were portraying women with breast cancer as being 'skilful emotional labourers' (p. 123). However, this project also deviates from Seale's study in that the women in my study did not emerge triumphant and empowered from their cancer experience. They did not engage in the emotional work brought forth by the discourse of tragedy in order to become new or better women, but rather to survive for as long as they could.

**Effect 3: The discourse of tragedy carries with it certain values and beliefs about what it is to be young and living with a life-limiting illness.**

Stories selected for reporting in newspapers are done so according to a set of manufactured inclusion criteria that are invisible to most of us. These chosen criteria reflect certain values and beliefs of the particular institution or society in which a journalist operates (Fowler 1991). Therefore, journalists do not select stories at random; they are directed to those that meet the criteria set by others (usually editors). And as the criteria for what makes a story newsworthy are never publicised, the power inherent in the media to influence public opinion is hidden within the newspaper articles (Fairclough 1995). The reporting of news therefore contains an ideological dimension.

An ideology is a set of beliefs or a framework through which, when viewed, the world around becomes more intelligible (McCoppin & Gardner 1994). Newspapers use the discourse of tragedy to hide certain dominant interests or viewpoints and these can be used to push a certain way of thinking (Bullock, Stallybrass & Trombley 1988). The discourse of tragedy relies on certain underpinning beliefs about what it is to be young and living with advanced breast cancer in Western society today. These assumptions, drawn from the dominant Western ideology of humanism, focus on the rights and responsibilities of individuals to be in charge of their destinies, to make the most of their potential and, like heroes, surmount difficulties as they arise. Embedded in this humanistic thought is the notion that all life contains a certain order to it and that it is a mother's responsibility to survive for the sake of her children and for the good of society as a whole.

*a. The value of timely order*

Most of us believe there is a 'right' order for things; day follows night, summer follows spring and the old are meant to die before the young. This rightful order when altered throws society into confusion and instils within us a profound sense of unease (Breaden 2003). When a young person dies, it is a tragedy for it is not the way things are meant to be. Heart disease and stroke are often seen as a normal crisis in the process of growing older (Pound, Compertz & Ebrahim 1998) while breast cancer is unanticipated in the young. Young women living with advanced breast cancer are going to die before their time; they will not live to see their three-score and ten, nor watch their children grow into adulthood.

Advanced breast cancer in young women has an uncertain course. Sometimes it kills quickly and at other times, it behaves more like a chronic illness, simmering along quietly for many years. No matter, it is still an incurable disease with death inevitable. Perhaps the tragedy that is breast cancer in young women can be seen as a biographical disruption as described by Bury (1982) where there is a disruption to the young woman's life trajectory and plans for a future. The disruption encompasses 'a recognition of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others' (Bury 1982, p. 169).

The notion of time as having a predetermined order to it comes from looking at time as a lifecycle, where there is a cumulative process of aging until death (Adam 1990, p. 200). Time as irreversible, proceeding from one point to another, represents a linear view of time, a common view in the Western world. However, if we focus only on the loss of a future order of events, such as the birth of a grandchild, then we lose focus on the immediate experience such as the children we have in the here and now. Grosz explains this point succinctly.

But to focus only on the ordering of events, their location in a measurable, overarching time, is to ignore the specificity of the duration of each event, its own unique temporality, the time of each thing or process. (2004, p. 250)

The 'here and now' time has its own special quality that is easily overlooked when concerned about future events. Yet being concerned about future events such as death is frequently necessary and a number of the young women in this project planned for the time when they were no longer physically present. According to Heidegger (1962) we are always future directed, living forwards until the point of death. It is knowing that we are going to die that makes the present so much more precious.

### ***b. The value of motherhood***

To repeat, tragedy is often found in things that have value for us (Scheler 1965). Of great value in our culture is the belief that mothers should be around to watch their children grow up. They are not to leave children behind under any circumstance and to do so summons societal disapproval. As I have shown, the media support this value. One would suppose that societal expectation would diminish in the face of advancing disease, yet from initial research into HIV-positive mothers, this seems not to be the case (Wilson, S 2007).

As seen in the previous chapter, many of the young women searched for cure and longevity, a search that led them into expending a great deal of energy into surviving for their children's sake. Other research has also found that mothers feel obliged to live in the face of advancing disease (Wilson 2007, (Billhult & Segesten 2003). Yet there is not a great deal of other research on this topic. Williams (2007, p.622) suggests the reason that little attention has been paid to mothers living with chronic illness is because of its

emotive and sensitive nature; its tragedy. I certainly found talking with these women about the possibility of dying and leaving children an emotive and sensitive topic.

Within the discourse of tragedy, young women are challenged by the discourse of motherhood and yet they have a strong attachment to it, having invested in it for some time. The position of these women as mothers within the discourse excludes the other positions that they might wish to occupy such as that of lover or sister or daughter. They are positioned within competing demands, both which society endorses. On the one hand, there is the position of motherhood, while on the other; there is the position of the tragic hero. They embrace the position of motherhood, knowing that this position will be accompanied by grief and loss, while at the same time rejecting the position of the tragic hero.

### **5. Conclusion**

In conclusion, like the discourse of numeracy, the discourse of tragedy can never be eliminated. It is so very familiar to us and yet its effects on the lives of young women living with advanced breast cancer are diverse and profound. These women have to battle against a stereotypical view that portrays them as being tragic heroes. They have battled against the prescribed emotions that leave them feeling at odds with the world that they are experiencing. They have to battle against the 'right order' of things, knowing that they are going to die before their time. Finally, they have to battle against feelings of despair and anguish of potentially leaving children behind. This latter battle is perhaps the real tragedy that is advanced breast cancer in young women.

The next chapter explores the various discourses of the body.

## CHAPTER 7: DISCOURSES OF THE BODY

### *Introduction*

If one thing is certain, it is that we all have a body. Everything we do we do with our bodies – when we think, speak, listen, eat, sleep, walk, relax, work and play we ‘use’ our bodies. Every aspect of our lives is therefore embodied. Sometimes we may be more aware of our bodies than others but from the moment we wake, we are to a greater or lesser extent, consciously or sub-consciously relying on our body. (Nettleton & Watson 1998, p. 1)

The body is ‘the location from which all social life begins ... It is the surface on which prevailing rules of a culture are written’. (Gimlin 2002, p. 3)

These two quotes highlight the importance of the body within our individual and social lives. The first quote refers to the way each individual relies on a body for its existence in the world, while the second quote extends that individual bodily existence to the culture in which we live.

Our bodies are more than their physical presences and surface boundaries. They are also the surfaces upon which our cultural rules and norms are inscribed. From an early age, our bodies learn the rules of our culture and society in which we find ourselves and these rules become part of our bodily memory (Young, K 1997, p. 82). We do not need to consult a list of rules on how to dress or behave in certain situations. Our bodies remember.

In this chapter, I focus on several discourses of the body, namely the *object body*, the *thin body*, the *gendered body* and the *declining body*. These four discourses appeared with various emphases across the three data sets. Here I argue that these discourses have a profound effect in shaping and regulating a woman’s experience of herself in illness and her body, a neglected area in the literature on cancer care to date. The discourses of the body differ to the discourses of tragedy and numeracy in that while the young women actively resisted the constraints of the discourse of tragedy and were confused by the discourse of numeracy, with regard to the body discourse, they are active in the construction and the maintenance of its power.

This chapter is organised in the following manner; firstly, I give a brief summary of the body as it has been viewed from within medicine. Secondly, I begin the trace of the various discourses through the stories told by the young women themselves. Thirdly, I move the trace into the professional medical literature before extending it further into the collated newspapers. Finally, I discuss the effects these discourses have on the bodies and lives of the young women concerned. While I have discussed the various discourses as separate entities, it will become apparent that the discourse boundaries do blur.

### **The body in medicine**

Within medicine, the body has been of central concern for centuries. However, the body that is of concern is an *object body* - a body that is separate to the mind. The object body is a container for disorder and death and something that is acted upon by others: it is a 'target and effect of medical practice' (Armstrong 1985, p. 111). This view of the body as object has pervaded Western thought for thousands of years. In the 17<sup>th</sup> century, the philosopher Descartes extended the idea of a separate mind and body to include a separation of the mind from nature (Grosz 1994). The body could then be seen as any other object in the natural world and therefore subject to the same natural laws. As a result, medicine came to view the body as a machine - an object - something that could be experimented upon and mapped in exquisite detail. According to Lupton, the machine metaphor has often been used in discourses of the body (Lupton 2003, p. 62). The medical model is therefore mechanistic as this next quote attests:

The medical model, while it deals overtly with the body, does so in a way which is reductionist and deterministic, and it stresses relationships of cause and effect. It is a model that is fundamentally mechanistic. (Lawler 1991, p. 34)

Dualism, the legacy of Descartes (Cartesian Dualism), assumed that there were two distinct mutually exclusive categories – mind and body. Cartesian Dualism led to a devaluing of bodily intelligence, which is evident in the health care arena today (Grosz 1994).

The English language has only one word for the body, and that is 'the body'. It does not differentiate in language between the body as an object and the body as it is lived. In

order to try to capture these different realities, we use the term *embodiment* to refer to the intimacy between the body as an object and the body as it is lived. Scheper-Hughes and Locke refer to this intimacy as the ‘mindful body’ or, ‘the myriad ways in which the mind speaks through the body, and the ways in which society is inscribed on the expectant canvas of human flesh’ (1987, p. 10). This ‘canvas of the human flesh’ is the domain of medicine. However, the *mindful* or *lived body* enables us to interact with the world in a meaningful way. In contrast, *disembodiment* refers to the rift that occurs between the body we have and the body we are (Seymour 1989). This intimacy between body and mind may be disrupted by major changes to the body’s appearance or functioning state, leading to a feeling of alienation from one’s body.

Medicine has taken over the body of a young woman living with advanced breast cancer, thus separating her body from her mind. How best to treat it, how best to extend its survival, how best to contain its propensity to disintegrate, how best to maximise its prognostic indicators. In these various domains in which the body resides, various discourses can be found that ‘shape how the body can be spoken about and acted upon’ (Street & Kisanne 2001, p. 165). Therefore, from a poststructural point of view, the body is a social construction and reflects powerful forces at work within the society in which we live.

### ***Tracing the discourses***

Unlike the previous two chapters, I begin the trace of the various bodily discourses within the young women’s stories. I start in this manner to highlight that discourses travel in both directions; from the professional, lay media, and into the women’s stories and from the women’s stories back into media in all its varied forms, attesting to the reflexive nature of how discourses shape our understandings of our lives and bodies.

#### ***1. In the stories told by the young women***

Advanced breast cancer causes major changes to the body and within the body of a young woman living with this disease. Therefore, it is not surprising that a greater part of their stories centred on their bodies. It lends itself to stories. Stories are in fact ‘corporal acts’ (Young, K 1997, p. 141) and several discursive constructions of the body

are to be found in them. The main discourse however was the discourse of a declining body.

**a. The ‘volume in perpetual disintegration’<sup>25</sup>: the discourse of a body in decline**

The ‘volume in perpetual disintegration’ describes the body of a young woman living with advanced breast cancer. This discourse is similar to that of the object body however; unlike the discourse of the object body, it highlights the slippery and dangerous nature of the body as it contends with indiscriminate cancer cells.

Young women living with advanced breast cancer have to contend with an ever-changing body. Some of the changes are temporary, like hair loss or the loss of menstruation, and some are permanent, like the loss of a breast or an enlarged limb. Irrespective of whether the changes are either temporary or permanent, the body of the young woman is the focus of concern and this concern emanates from both the medical profession and the young women themselves. Surveillance activities and the desire to look normal shape the discourse of the declining body.

**1. Bodily surveillance**

The young women in this project were understandably concerned about their bodies, for cancer’s progression, while at times insidious, can be tracked and measured within a body. The women kept records of these small changes and they interpreted them as either positive or negative depending where they were on their illness trajectory. Anna, for example was considered disease-free for nearly five years after her original diagnosis and she had been having regular checkups along the way. Recently however, she noticed a lump on her chest wall and did not suspect that this feature signalled cancer’s return.

I went for my 5-year check up to the doctor and I said to him, ‘what do you think this might be?’ And I told him about this lump. He said ‘you have just pushed a bone out of its place in your chest ...we’ll send you off for a bone scan’ and he said ‘your 5 year check up, we’ll just

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<sup>25</sup> *A volume in perpetual disintegration* comes from the words of Foucault (1977 p. 148). This phrase is part of a larger quote where the body is being described as “the inscribed surface of events (traced by language and dissolved by ideas), the locus of a dissociated Self (adopting the illusion of a substantial unity), and volume in perpetual disintegration”. The body from Foucault’s perspective is not a neutral medium, but rather a surface upon which cultural and societal values are inscribed.

give you the all clear anyway, and just see if anything shows up on that'. And I think that he was probably as shocked as I was, because it actually showed that the bone had been pushed out, that there was a tumour behind it. (P. 67)

Anna went on to have a total body scan and cancer was detected in a number of her bones, areas in which she had previously felt no symptoms. Her body hid the fact that cancer had been growing indiscriminately within the bones of her spine. She felt that the body she had looked after so well and for so long had betrayed her.

It's amazing isn't it when you really believe that nutrition takes it, it plays such an important role in your life, to finish up getting cancer again, it does, it, I do question that, or I did question that, and it amazes me that it came back. (P 253)

Belinda's bodily surveillance, like most of the young women, took the form of blood tests and mammograms.

I'm having a blood test and a mammogram and he [doctor] said that particularly for the next 3 years we'll be keeping a close eye on you, clinically through blood tests and mammograms. But the last blood test they did on me, I wanted to know about my white cells, have they come back up, and she [nurse] say's they're still low but, you know, they'll [the blood count] will come up. She said, oh we're doing a new test on you to know, she said it's to test if cancer is returning, and I said, well what does 4 mean, she said, well as long as it's under 35 there's nothing to worry about, so if it goes over 35, be concerned. So she said it's 4, and I said, 'oh I suppose that's OK' and she said, 'yes there's nothing to worry about'. (Belinda, P 490)

For the next three years, Belinda will be monitoring the numbers that will most likely show a body in an inevitable decline. Belinda has an incurable illness and eventually the markers in her blood will indicate this. However, in the meantime her nurse tells her that there is nothing to worry about and that her doctor will be keeping a close eye on her (body). However, rigorous bodily surveillance will not save her.

Carol views her ongoing surveillance as an indicator of what is happening inside her body. If the numbers go up, she panics. She is having blood tests every three to four weeks. *I see it [blood tests] as, even though I know I'm not supposed to, I see it as a guide as to what's going on inside, if it goes up then I'll panic, and if it goes down then I think great.* (P. 169). In Carol's case, the numbers are nearly certainly going to

increase indicating cancer's progression and she will no doubt suffer anxiety when this happens.

Fran, like many of the women in this study, eventually reached a point where she was reluctant to go back to the doctor and participate in surveillance activities. Unfortunately, as this next extract shows, Fran believes that in order to live, she has to be compliant.

You sort of get to a point where you don't want to go to the doctors and you don't want to make another appointment. You don't want to see them again but you know that you have to because you know that they've got to keep a check on you and do all these tests for you, especially if you do want to live. You can't sort of ignore them and say no I can't, I don't want to do anything. (P 88)

Consequently, whether the women wanted to or not, they frequently participated in ongoing surveillance activities. These activities involved a great emotional investment. What difference this made to their long-term survival is unclear.

However, bodily surveillance is not always a negative activity. Blood and other biomarkers can tell doctors if a particular treatment regime is working and technology, through sophisticated imaging techniques, can detect cancer in its earliest stages. I am not placing blame on the medical profession for the instigation of such activities and the resulting need the women have to engage in them. However, I agree with Morris that we need to recognise that surveillance activities impact on how the young women experience their bodies and themselves in the context of a life limiting illness (Morris, 1998 p. 147).

## 2. Looking (ab) normal

Even though their bodies were declining in structure and function, how they looked in other people's eyes mattered. The desire to look normal is perhaps similar to Goffman's 'presentation of the self' to avoid stigma (Goffman 1963). The young women wanted to hide their bodily changes from those around them. Largely, they were successful at this, but in the privacy of their intimate relationships, this success was tested. For Jessica, it was a relief that even though she felt disfigured, her husband did not turn away from her.

I felt so disfigured, and um, I thought oh he won't like me and you know won't find me attractive and all that but he was really good, he was much stronger about that than I was and that gave me strength and he was looking at the sutures, look how they've done that, isn't that interesting? ... And I think that him being like that was a huge relief for me and just made a huge difference to how I felt about it. (P. 327)

While Jessica felt abnormal in her own eyes at least, she did not appear so to the person closest to her. She gained some reassurance knowing that her husband did not find her repulsive in how she looked. However, a number of the young women did lose a sense of being sexually attractive to their partners. Helen mourned the loss of her cleavage and said that '*my husband was robbed of that as well*' (P. 24) inferring that her husband had to contend with other losses such as the loss of a breast or an intimate relationship. Helen also complained that images of breasts were everywhere and these reinforced for her just what she had lost. In her eyes, her body had indeed changed.

Other visible markers of cancer's progression within the body also caused anguish. These markers reinforced the discourse of a *declining body*. Anna disliked how the metastases to her chest wall were visible to others and she carefully dressed to hide them. It distressed her to consider that one day she might not be able to hide the growing lumps. She also hid her arm from sight as the lymphoedema made it swollen and 'horrible'.

I don't like what they [lumps on the chest wall] look like and so therefore I just dress accordingly and I just hope it [the lump] doesn't push out further because you know, its going to be really obvious. So, like yesterday I wore a shirt and I just had a scarf, just try to detract from it. ... And I don't like my arm showing, I think its horrible, see that's really soft today but sometimes its really swollen, it's very tight actually. (Anna, P. 323)

Other research has also found that lymphoedema affects a woman's self-image (Martin & Hanson 2000). Anna appears ashamed of her body and was perhaps engaging in what Street and Kissane (2001) have previously described as the *shameful body discourse*. These authors found that, in their research into euthanasia, some people responded to the changing body and the breakdown in its integrity with feelings of humiliation and shame (2001, p. 166). While Anna was not considering euthanasia, she was responding to the cancer's visible presence with similar feelings as those described by Street and Kissane. Thomas-Maclean also found in her research that managing appearances was important for women surviving breast cancer (Thomas-MacLean 2005).

The lumps of tumour are part of Anna's body and yet she calls them 'it' or 'they'. Her oedematous arm is also an 'it'. She considers these pathologies as separate from her, something alien from her essence as a person or her identity. She is not alone in speaking of her body as an object. Jessica also talked about *the lymph nodes*' (P. 71) and not *my lymph nodes*, Gena referred to *her tumours* as *the tumours* (P.125). Emma had a lump in *the breast* (P.10) and not *my breast* and Belinda said that *I'm going to have it removed and everything will hopefully be better*, (P. 466) and not 'I am going to have *my cancer* removed'. Fran had *a brain tumour removed because the cancer decided to spread to the brain* (P. 27). She did not refer to *my brain* or *my lump*, yet for all these young women, their cancer arose from their own tissue and genetic coding. The cancer cells developed as a result of a multistep process within their own bodies. It may well be that these women, as a result of their continuing disease and bodily surveillance, move from *being* a body to *having* a body, one that was the object of their own and other people's gaze. According to Sartre (1966), it is this look of the Other that shatters our unreflective way of being in the world. These young women certainly reflected on how they looked in other people's eyes. As Toombs suggests, 'one sees one's disordered body through the eyes of the Other and thus constitutes it in a negative fashion' (1995, p. 18). However, viewing the body objectively and negatively is common in life-limiting illnesses (Fassett & Gallagher 1998).

The sense of feeling abnormal is perhaps a Western individual's obligation to herself. However, other cultures view this individual responsibility differently. For example, in Chinese culture, looking normal is a societal issue, a social obligation (Lam & Fielding 2003).

### ***Hair loss***

The loss of a breast has been the centre of much of the work on body image and breast cancer to date. As shown in the literature review, these studies have all been conducted on older women and/or women with early breast cancer, not young women with advanced disease. None of the young women in this project seemed to dwell on the loss of a breast or part of a breast, other than to mention the reaction of significant others to their scar. What appeared to be of greater concern to many of these women was the loss of their hair. For example, consider this next extract from Belinda's story. The multidisciplinary team had just been discussing the optional treatment for her stage of cancer. Belinda hoped that they would recommend the treatment option that still allowed her to go to work and not lose her hair. However, her hopes were not realised:

They have a big round table conference and then they decide your future as far as treatment goes. I was thinking well I want the least option, one that's not going to effect my life much and I can still go to work and all that and of course it was the worse one, you know, 'you are going to lose you hair'. ... In looking back, well I suppose I should have prepared myself for that [hair loss] because that was the most traumatic thing. (Belinda, P. 594)

Belinda was not alone in thinking that hair loss would be a devastating outcome. Carol also found it hard; *it was the hardest thing for me* (P. 101). One would suppose that other things would have been more difficult for a young woman with advancing disease and yet at this point in their journey, it was the hair loss that was the most distressing. There were many reasons why hair loss was so devastating and the reasons varied from woman to woman. Donna found hair loss difficult because it meant that her cancer would no longer be invisible; *others would see*. (P. 213). Similarly, Emma, found that her hair loss was something everyone could see (P. 118) and she actually found this loss more difficult than losing her breast. Most of the women in this project wore a wig or a scarf when out in public in the hope that they would not appear abnormal in the eyes of others. Yet, wigs and scarves are symbols of cancer treatment and wearing such disguises are noticeable to others and mark them as a 'cancer patient'. The hoped for privacy becomes shattered. Other research has also commented on the fact that hair loss made their diagnosis public (Harcourt & Frith 2008; Rosman 2004).

Looking normal was important to these women. Looking normal meant that they did not look like a person who had cancer. Inge just wanted, in the time she had remaining, to look normal and not different, *'it would be nice if I could sort of have some of the time*

*that I have left just without having to wear a wig and put makeup on to make myself look normal'* (P. 270). Inge died 8 months later and I doubted if she did achieve this desire to look normal in the eyes of those around her. Other young women in this project looked normal from the outside and probably fulfilled Inge's definition of normal (with their own hair and eyebrows) and yet on the inside their cells were acting very abnormally. Feeling normal was all about appearances.

In order to make their bodies appear as normal as possible, some women early in their cancer journey considered a breast reconstruction and some doctors actively encouraged it. Anna's doctor said, *'he said, you are a young lady, you should have a reconstruction, but Anna refused it saying, I never really wanted to. I was happy enough dressed.* (P. 325). Anna, as long as she appeared normal on the outside, was happy with her appearance. Emma's doctor commenced his discussion of surgery by explaining the possibilities of later breast reconstruction to her. She said *he was very concerned that it [my appearance] would be of concern for me, but I wasn't really listening at all* (P. 36). However, in contrast to both Anna and Emma, Carol who was diagnosed with breast cancer at the age of 27 had a double mastectomy and bilateral reconstructions. The body that was surgically assaulted could be made to look more normal, at least in the eyes of others. This normalisation process reinforces the mind-body dichotomy.

### **3. An embodied self- a mindful body**

Due to the many and varied changes within the body of a young woman living with advanced breast cancer, a different concept of 'the body I am' needed to be found as their previously known body had faded in the light of constant change and decline. Even though they mostly talked about their bodies as objects, some could also imagine their body as having its own memory and intelligence. The *body I have* and *the body I am* seemed to be able to coexist. In this next example, unlike earlier, Jessica could also talk about *my breasts* and not *the breasts*. The cancer is the object and not her breast.

My breasts have also been very lumpy and in fact every medical person I have seen since then has commented on that, and my left breast has always been bigger than my right and with the hormonal changes every month, you know, it was harder to pick up. (P.43)

It may be that the women in this project constantly moved between these two bodily constructions. Nonetheless, the idea of bodily intelligence came through strongly in the women's stories. Some women's bodies seemed to *know*. Donna listened to her body and knew it well.

I'm a great believer in knowing your own body and knowing when something isn't the way that it should be, whether you can actually explain what is wrong, because you feel fine, but knowing.

*Katrina: Something's not right?*

Yeah. It's very hard, yeah, extremely hard, because they [doctors] have to see something in front of them to say that it's there, they can't believe, or they are not allowed to believe, or they actually need proof, living proof that something's there. But I think you know yourself when things aren't 100%. Even though you don't know *what* is not right, you know something's not right. (P. 28)

The medical profession looked on the body as an object and needed to see markers of cancer's presence in order to diagnose. The women however often needed no such markers. Like Donna, Gena also felt something was wrong in her breast even though she could not feel a lump.

When I lay down again, I got a similar pain but this time I could identify the area more easily as to where the pain was. So I knew it wasn't heartburn or anything like that. So I just sort of felt around my left breast and I couldn't feel anything, things were just a bit tender but I knew that my period was due within the next 4-5 days so once again I thought that that's probably what it is. Then the next morning I got up and got the pain again and I thought, no this is not right. I wasn't very happy with that at all even though the pain went fairly quickly it wasn't something that endured for the rest of the day or anything like that. I thought, no this is not right. (P.6)

Her *knowing* meant that her highly aggressive cancer was most likely diagnosed earlier than it would have been otherwise. Unfortunately, her cancer returned 10 months later; a very poor prognostic sign. Previous qualitative research on survivorship has also found this bodily knowledge present in women's stories of surviving cancer (Breaden 1997).

### **b. The thin body discourse**

The thin body discourse is the second major discourse shaping the women's stories. It is another facet of bodily surveillance mentioned earlier. And it is a discourse in its own right due to its pervasiveness within the young women's stories and its ability to form the object of which it speaks – in this case the thin body. This discourse is perhaps an extension of Blood's discourse of 'body reduction' in which women's bodies are seen as being excessive and needing reduction through self improvement practices such as dieting (Blood 2005, p.84).

The young women with advanced breast cancer viewed their bodies as something to be controlled. This control took the form of bodily surveillance around weight loss and weight gain. They, like many in our society, were horrified that they might gain weight as a result of the disease process and/or treatment. Emma for example was frightened by the prospect.

I have heard that you can either, people tend to put on weight and some people lose weight but I guess I haven't. If anything, I might have lost a little bit but not much.

*Katrina: Does putting on weight frighten you?*

Yes. (P.431)

Emma was reassured that she had not gained weight and seemed pleased that, unlike other people, she had actually lost some weight. Carol was not so fortunate and found her weight gain intolerable.

With the Dexamethasone they put you on, I got all this fat and it increased my appetite no end and so I had insatiable eating. So now I've got all this weight and I hate it, absolutely detest and I turn on myself and blame myself and I hate it. (P. 105)

Carol blames herself for her weight gain and yet it was perhaps something beyond her control. Dexamethasone is a notorious cause of weight gain in many conditions, not just in the setting of cancer treatments.

Like Carol, Jessica found that it was her changing body shape that distressed her the most:

My body shape has changed and the putting on of weight is very distressing for me, as I always have prided myself on how I looked. The increase in weight means that I no longer go out; I shut myself off from the outside world ... I put the weight increase down to chemotherapy. The things that I would normally do to lose weight are no longer available - exercising or walking. If I walk too far, my arm with the lymphoedema blows up. Swimming is out because of my reduced lung capacity. I am now conscious of my tummy now sticking out. (P.27)

With the onset of her weight gain and reduced mobility, Jessica now leads a very restricted existence. She is not alone in this. Inge also finds that being unable to run and keep fit has impacted on the way she views her body and her ability to interact with the world around her.

I have probably got less muscle, like tone than I did have. I'm pretty fit, I used to run a couple of times a week and now I can't do that, I'm too tired but I walk still. I probably lost some muscle tone and maybe got a little bit of extra softness around the middle. I don't like that. I like to be fit and to look fairly fit as well. (P.148)

Inge's desire to remain fit looking was always going to be difficult given that her cancer was diagnosed in an advanced stage and its rampant spread meant that inflammatory cytokines would be contributing to her ongoing fatigue.

Fran said that she used to be a lot thinner '*I used to be a nice size 10-12 but I think my shape has changed a lot*' (P. 58) inferring that whatever size she was now, it wasn't *nice*. Sue described herself as once being 'stunning and slim':

I used to be stunning and slim, and the weight increase since my diagnosis has been very distressing ... especially when I see a photo with 'those big double chins'. I consider myself to be unemployable now as who would want such a large and tall person working for them. (P. 6)

For Sue, the impact of her weight gain has meant that she now believes that no one would employ her. This view of her body has had a detrimental financial impact on Sue and her family.

Many of the young women after their cancer diagnoses tried to eat healthily and this often involved the buying of organic produce. Generally, organic food is expensive and, therefore, the desire to eat healthily brought with it a great cost in terms of money and time. In addition, some young women hoped that by eating well, extra weight could be lost. Karen at least believed this would be so.

I mean we always ate fairly healthy anyway, we're not junk food people, we don't eat a lot of meat anyway, but we've just taken a different look at things, we've gone a lot onto the organic foods as well, eat a lot more organic food.

*Katrina: Is it more expensive?*

Yeh it is, and we started tracking down all the organic places and different sorts of shops and things like that and as I said I was doing as much research into it as possible and I still feel that once I have lost the weight I want to go back onto a lot of the vegan diet as well because I think that really did help me during that time. (P. 237)

Karen wanted to lose weight. Donna on the other hand had already lost weight before her cancer was diagnosed. She was proud of this accomplishment. In this next extract, I had just asked Donna about her changed body shape and this was her reply.

I lost 8 kilos before I got sick. I went on this diet, I've never lost any weight in my life and I was just always a little bit over weight and I hated the fact that I was just a little bit podgy ... So I went to [a weight loss company] and lost this weight and I was proud of myself and I was so disciplined for the first time in my life because I really like food. I was so disciplined about losing weight and then that was before Easter and then at Easter and we had family here and everybody said how horrible I looked because I had lost so much weight. This was before I was diagnosed. They were all saying, 'You've lost too much weight and are you sure you're alright, you're a bit sick.' I thought I looked good and felt good, I actually felt really well and energetic, healthy, everything. Bought new clothes and loved the way I looked ... and then I got this damn diagnoses afterwards, and they all thought, oh yes she's lost the weight because she was sick and they all attributed it to that and they said that I was too skinny. Skinny was never a word that you used. So anyway just because I was always just a little bit plump and you know older people think that plump is happy you know and I wasn't happy at all. So, when I got diagnosed I thought, oh damn, now they're all going to think that it's because of the cancer. So, my first concern was then well I forgot about the diet. I'd reached my goal anyway. My first concern was that I was going to get fat again and I'll hate myself for that because I'll be with cancer and fat. (P. 227)

In this moment, Donna's major concern was that she was going to get fat again and not the fact that she was potentially going to lose her life. She went through the treatment process and prided herself on the fact that, unlike others, she did not put on weight.

Concern about weight gain during and after cancer treatments is a common thread throughout the young women's stories.

Uninvited changes in body weight and shape were distressing for the young women in this project. Belinda hoped that she was going to lose weight during chemotherapy.

I said this is the worst thing that you could have told me, I said I thought I was going to lose weight. Because that is your impression when you see, know someone who has cancer they are usually quite thin, and I imagine those are the people that are just vomiting a lot through chemo, and I wasn't like that. So, you know just not eating, those people were, whereas I was eating more, I was hungry quite a lot at the beginning, it's panned out since then, because I've had no exercise what so ever. (P. 251)

Belinda, and the other women mentioned above, see the cancer body as a thin body – a desirable body. Gaining weight is an unwelcome surprise. Where is the origin of the belief that cancer will make them thinner? The *thin body* discourse is embedded in our culture, inscribed on our bodies from an early age and gains momentum as we get older. And yet, the thin body discourse also appears in other cultures. For example, the study conducted by Lam and Fielding (2003) on the experience of illness amongst Chinese women with breast cancer (n=17) found that weight gain (and hair loss) caused more distress than did the loss of a breast or treatment induced nausea and vomiting. Half the women in their sample were under the age of 45.

### **c. In summary**

The various discourses that one has access to determines what stories can be told (Belsey 2002). The similarities between the young women's accounts of their body in advancing illness meant that they were drawing from similar discourses circulating in society at this point in time and these discourses were being imprinted on their bodies (Morris 1998).

The main discourses identified in their accounts were the discourses of the declining body and the thin body discourse. The declining body discourse contained a number of aspects such as the use of bodily surveillance as a vehicle of control, the desire to look normal while contending with bodily changes and the acceptance of embodied wisdom.

## **2. In the professional medical literature (journals and textbooks)**

The professional medical literature drew heavily upon the discourse of an object body. This discourse dominated all texts. However, other discourses could also be seen at work within the accounts; the discourse of the disintegrating body and the discourse of the gendered body. For the purpose of this illustration, I have combined both the texts and the journals as the discourses in each were the same.

### **a. The discourse of the object body**

Medicine inscribes the body into a discourse of objectivity ... In the realm of medicine, the body is rendered an object. It is inspected, palpated, poked into, cut open. From being a locus of self, the body is transformed into an object of scrutiny. (Young, K 1997, p. 1)

The *object body* discourse appearing in the varied medical texts is pervasive and seductive. Treatments happen *to* a body, chemotherapy *fills* a bodily container, genetic mutations occur at the level of the cell *within* this object body. The deterioration of the body is scrutinised and plotted. Medical treatment focuses on individual women's bodies. For both doctors and the young women alike, the object body becomes the 'house of suspicion' (Breaden 1997, p. 978), something to be constantly watched over for the indicators of cancer's spread.

Within this discourse, mind and body are separate entities. Disease happens to a body and depression and other psychological disorders happen to a mind. The surveyed journal articles reinforced this separation. Only 8% (21/251) of the articles focused on areas other than the object body such as psychological issues and the effects of support on a young woman's survival. In addition, the clinical practice guidelines relating to young women contain 11 summary guidelines for best practice. Only one guideline refers to a young woman's emotional state. The remaining ten relate to diagnosis, treatment and their side effects, and to issues involving subsequent pregnancies (National Breast Cancer Centre 2004, pp. 4-5). No articles talked about embodiment<sup>26</sup>.

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<sup>26</sup> Within the general breast cancer literature, there were several articles that referred to embodiment. These articles did not focus on young women or advanced breast cancer in particular. The majority were written by the same author, Thomas-Maclean whose work was reviewed in chapter 2 (Thomas-MacLean 2004a, 2004b).

The disease of advanced cancer is firmly located within the individual women and medicine searches for causal links.

### ***1. Breast cancer causation***

The causes of breast cancer in young women and/or breast cancers that are highly aggressive are generally unknown; however, researchers have developed strong associations between several factors such as obesity and genetic malfunctions. Three percent of the articles referred to obesity as a risk factor (8/251) and a further 16% (40/251) referred the presence of the genetic mutations BRCA1 and BRCA2.

#### **a. Obesity**

Gaining weight from an oncology perspective happens to an individual object body. Being obese is undesirable in the general population as it carries with it certain risk factors for a number of diseases including breast cancer. This extract was taken from the text *Cancer: principles and practice of oncology* (2005).

Obesity is also considered an independent risk factor for breast cancer. Among premenopausal women, those who are substantially overweight or obese have 10% to 30% lower risk of breast cancer than normal weight or thinner women (those with a BMI less than 25 kg/m). Paradoxically, adult obesity and adult weight gain have both been associated with higher breast cancer risk among postmenopausal women. Most studies have reported relative risks of 1.5 to 2.0 when comparing the most obese women or those with the largest weight gain to normal weight women or those with the least weight gain. A pooled analysis of data from eight prospective studies of BMI ... indicated that risk increases 18% per 5 kg/m increase in body mass. (Henderson & Bernstein 2005, p. 240)

Being postmenopausal, overweight or obese raises the stakes in the breast cancer lottery.

#### **b. Genetic mutations**

Thus far, researchers have discovered two main genetic mutations - BRCA1 and BRCA2. Younger women who get breast cancer are more likely to have one of these genetic mutations than older women.

Cancers arising in BRCA1 mutant patients are typically high-grade invasive ductal carcinomas negative for ER and HER2/neu that resemble certain types of sporadic breast cancer. This similarity is supported also by the strong overlap of gene expression profiles in comparisons between the familial BRCA1 and sporadic subtypes. Tumors in BRCA2 mutant carriers typically show a wider spectrum of histologic features. Risk-reducing prophylactic breast surgery is indicated for female patients who have tested positive for BRCA1 or BRCA2 mutations or have strong family histories of early-onset breast cancer. (Hawley & Pandolfi 2005, p. 163)

In an attempt to pre-empt cancer developing, these authors advocate the radical treatment of a bilateral mastectomy. Some young women take up this option. However, the causes of breast cancer are multifactorial and complex and yet such responses by medical authors reduce these causes to an individual pathology within the experiencing woman. Any thought that breast cancer might be a social construction is missing from these accounts, for from within medicine, 'disease is individual, and not a social problem (Filc 2004, p. 1276).

## ***2. Treatments***

Treatments are given to an object body, one that is passive and docile. Such treatments include surgery, drugs, radiation, hormones and immunotherapy. Nearly a quarter of the articles surveyed focused on the various treatments (61/251).

Young premenopausal breast cancer patients treated with adjuvant CMF chemotherapy had higher risk of relapse and death than older premenopausal patients, especially if their tumours expressed oestrogen receptors. The endocrine effects of chemotherapy alone are insufficient for the younger age group and these patients should strongly consider additional endocrine therapies (tamoxifen or ovarian ablation) if their tumours express oestrogen receptors. (Aebi et al. 2000, p. 1869)

A whole gamut of treatments is needed for the cancer that lies hidden within the young woman's body and these treatments act on the object body.

### **b. The 'volume in perpetual disintegration': the discourse of the body in decline**

The young women's bodies involved in advanced breast cancer invariably change and disintegrate over time. From a medical perspective, the body is still an object; however, it has become a body that is decidedly unstable; an abject body.

### ***1. Prognostic pessimism***

Within the young woman's body, oncologists and others look for certain prognostic features. These features, mentioned in previous chapters, signal the body's decline and their presence means that the prognosis is poor. For example, the over-expression of c-erbB-2 and p53 together with negative oestrogen and progesterone receptors signal a very poor prognosis (Guerra et al. 2003). The reduction in cytotoxic T lymphocyte count is a marker of rapid disease progression (Blake-Mortimer et al. 2004). Sometimes, prognosis can be improved, at least temporarily and the body's decline can be halted for a period.

Overall, young women with low risk disease who did not receive adjuvant treatment had a significantly increased risk of dying; risk increased with decreasing age at diagnosis. ... However, no similar trend was seen in patients who received adjuvant cytotoxic treatment. (Kroman et al. 2000, p. 474)

However, in general there is prognostic pessimism when it comes to young women with either early or advanced disease - as this next quote attests.

The two groups were compared [women with breast cancer under 40 and those over 40] with regard to prognostic factors and mortality. In summary, young women are more likely to have negative prognostic factors. Young women were significantly more likely to have estrogen receptor-negative tumours ... and progesterone receptor-negative tumors ... These women were also more likely to have higher staining for Ki-67 [a marker of cellular proliferation]. (Hartley et al. 2006, p. 1190)

Oncologists generally consider that the smaller breast cancer is at presentation, the greater the prognostic optimism. However, in young women, this optimism is generally not warranted.

... a greater proportion of young women in this study had node-positive disease (61%), confirming the unfavourable pathology that has been generally found in women of this age [35 years and less] group, though the significant number of cases without axillary nodal information may potentially undermine this conclusion. The current mean tumour size of 2.8cm was smaller than in our previous group of women whose tumours averaged 3.1cm. In spite of this, the node rate was higher, implying that though the tumour size may be comparatively smaller in young women, they are biologically more aggressive (as indicated by the larger numbers revealing grade 3 histology) with a greater likelihood of regional metastases. (Fernandopulle, Cher-Siangang & Tan 2006, p. 221)

Prognostic pessimism occurs when bodily indicators reveal that the disintegrating process has begun.

## **2. *Weight loss***

Weight loss is common in the setting of advanced cancer. It is one of the early warning signs that cancer has spread beyond its original confines and forewarns of bodily disintegration. There are a number of mechanisms behind this phenomenon, one being the increase in circulating cytokines which results in a condition known as cachexia (Schulmeister 2001). Once cachexia is present, it is almost impossible to reverse. The body declines before our eyes.

Cachexia is derived from two Greek words meaning “bad condition,” which is exactly the situation in which advanced cancer patients find themselves. It is characterized by weakness, poor appetite, alterations in metabolism, and wasting of muscle and other tissues ... cancer cachexia is sometimes present even in people whose disease is still localized and relatively small, so it is clear that factors account for it other than a tumor’s gobbling up of its host’s resources .... Numerous studies of people with malignancies reveal various kinds of abnormalities in the utilization of carbohydrates, fats, and proteins, the causes of which are uncertain. Some tumors even seem capable of increasing a patient’s expenditure of energy, thereby contributing to inability to maintain weight. To add to the problem, certain malignancies and even some of the host’s own white blood cells (monocytes) have been shown to release a substance appropriately given the name cachectin, which decreases appetite by direct action on the brain’s feeding centre. (Newland 1993, pp. 217-8)

Weight loss associated with cancer is regarded as a poor prognostic sign, affecting the quality of that person’s life and the length of their survival. Even though weight loss does occur in advanced stages of breast cancer, it is usually associated with other cancers such as renal and lung cancer where the weight loss has been found to be a significant predictor of a shortened survival (Kim et al. 2004; Vigano et al. 2000).

Young women living with advanced breast cancer are urged to pay attention to their nutritional intake. A number of publications contain advice on how to maintain or put on weight (Davidson & Richardson 2004; Kemp 2001; Schulmeister 2001). For example:

Women with breast cancer, like those with any chronic illness, need to pay attention to their nutrition. It is most important to ensure adequate energy (calorie/kilojoule) intake. (National Health and Medical Research Council 2001a, p. 122)

In the face of the ongoing bodily disintegration of advancing disease, no amount of calories or good nutrition will halt its decline. However, many will try.

### **3. *Weight gain***

Three percent of the articles surveyed (8/251) talked about weight gain and its prognostic significance in young women with breast cancer. Many women gain weight after the diagnosis of breast cancer - irrespective of whether the disease is early or advanced (Chlebowski, Aiello & McTernan 2002). There are at least four reasons for this. Firstly, many young women suffer depression when they are told that they have a condition that is incurable and may eat more in response to these feelings of sadness and hopelessness. Secondly, many women gain weight during chemotherapy (a common treatment in the management of both early and advanced breast cancer) (Schulmeister 2001). One reason suggested for this increase is the fact that pre-menopausal women often become menopausal as a consequence of the treatments and their sequelae.

The risk of weight gain appears higher in women who become menopausal during the first year after treatment, and for those who have longer duration of chemotherapy treatment. In one small study, two-thirds of women experienced a significant weight gain three years after treatment. The precise mechanism for this weight gain is unclear; increased dietary intake does not appear to be a major contributor, although reduced physical activity or metabolic changes may contribute. (National Breast Cancer Centre 2004, p. 27)

Weight gain is common in many women after menopause, irrespective of if they have cancer or not and is often blamed on the ageing process. Hormonal factors are implicated in this increase.

Thirdly, in advanced disease where cure is not an option, increased length of survival becomes the goal. A greater number of chemotherapy cycles have been found to increase the length and quality of survival (National Health and Medical Research Council 2001a). Therefore, repeated cycles are commonly offered to young women with advancing disease. Frequent side effects of chemotherapy are nausea and vomiting. Steroids are given prior to its commencement in an attempt to minimise these distressing symptoms. They are also used to reduce cerebral oedema, a common symptom in breast cancer that has spread to the brain. A side effect of steroids, however, is that they increase a person's appetite and consequently his or her weight.

Fourthly, chemotherapy also brings with it a tremendous sense of fatigue and hence less exercise is attempted (Lopromzi et al. 1996). The reduction in physical activity may also have a part to play in the weight increase experienced by many women.

Women with breast cancer report a reduction in physical activity during the course of treatment, with an increase after active treatment has concluded. However, this post-treatment increase in exercise may not reach the level of their pre-diagnosis activity. (National Breast Cancer Centre 2004, p. 43)

However, chemotherapy cannot solely be blamed for the weight increase. Some researchers have found that women being treated for breast cancer gain weight regardless of whether they have had chemotherapy or not (Monnin et al. 1993). In addition, this increase has been observed especially amongst young women with advanced breast cancer.

Greater increase in weight were observed among women diagnoses with higher disease stage, younger age, being postmenopausal, and women who decreased their physical activity from diagnosis to up to 3 years after diagnosis. (Irwin et al. 2005)

Whatever the reason, in the setting of advanced breast cancer, weight gain is common, and as I have shown, is distressing for the young women concerned. Body image and health concerns aside, these women have a reason to be fearful of weight gain. A number of studies now have found that weight gain is strongly associated with a greater chance of recurrence and an earlier death (Abrahamson et al. 2006; Chan et al. 2000; Chlebowski, Aiello & McTernan 2002; Daling et al. 2001).

Within the professional medical literature pertaining to breast cancer, discussions of body weight contain a paradox. The paradox is this: on the one hand, weight loss is seen as undesirable in the context of serious illness and on the other, weight gain as a side effect of cancer treatments, is undesirable because of its correlation with decreased survival. The young women are caught in the paradox and the disintegrating body becomes even more unstable.

### **c. Discourse of the gendered body**

Treatments and prognostic information happen to and within a female body. Information on pregnancy-related breast cancer, infertility, preservation of fertility and premature menopause accounted for nearly 42 of the 251 articles (18%) surveyed. All the medical texts contained similar information. The clinical practice guideline relating to younger women summarised several studies that examined infertility and early menopause, distressing side effects for many young women.

Induced ovarian failure is an outcome of chemotherapy treatment for some younger women, resulting in infertility and onset of menopausal symptoms. Clinicians should openly discuss fertility before treatment, and outline the probability of menopause based on the woman's age and treatment regimen. Women who wish to consider childbearing after treatment should be offered referral to a specialist with expertise in fertility treatment *prior to the commencement of treatment*. (National Breast Cancer Centre 2004, p. 5), Emphasis in the original

Chemotherapy renders many young women infertile. For those diagnosed with advanced breast cancer and whose fertility returns after treatment, they are advised against future pregnancies. A further example of the gendered body discourse can be found in several of the journal articles relating to fertility preservation prior to treatment.

Breast cancer accounts for one third of all neoplasms seen in reproductive-age women and affects tens of thousands of women each year in that age group. The adjuvant chemotherapy regimens used for the treatment commonly affect fertility and cause premature ovarian failure. There have been recent advances in the field of fertility preservation, which can allow many of these breast cancer survivors to have children in the future. The most established option is embryo cryopreservation; oocyte cryopreservation can be considered in single women ... When and if a breast cancer patient does not have time to undergo ovarian stimulation prior to chemotherapy, ovarian cryopreservation for future autotransplantation can be offered as the last resort. (Sonmezer & Oktay 2006, p. 422)

In the context of the paragraph above, the *breast cancer patient* is clearly female. It appears as though *single women only* have the option of egg cryopreservation. Does this mean that women with partners are excluded from this consideration? Nonetheless, women are clearly the focus of this paragraph and not men.

Difficulties that sometimes arise during pregnancy happen not only to an object body, but also to one that is female.

An advanced stage at presentation and a poor prognosis have been reported in the literature and are thought to result from delays in diagnosis. Clinical evaluation of the breast in pregnant or lactating women is confounded by the normal physiologic changes associated with pregnancy. The increased firmness, nodularity and hypertrophy may cause an ominous mass to be overlooked or to be misinterpreted as benign condition common in pregnancy. (Samuels et al. 1998, p. 172)

Changes within a woman's breast during pregnancy are not to be ignored. Dire consequences can occur if these changes are overlooked. The young woman is responsible for cancer's early detection and consequently for her ultimate survival. Furthermore, breast cancer and pregnancy are prognostically a poor combination.

Early full-term pregnancy is thought to be one of the most effective means of decreasing lifetime breast cancer risk. Paradoxically, young women diagnosed with breast cancer shortly after giving birth have a higher risk of dying from their disease. These seemingly opposing effects have been largely attributed to mammary epithelial stem cell differentiation and precancerous cell proliferation, respectively, induced by pregnancy-associated hormonal changes. However, recent studies suggest that remodeling of the cellular microenvironment and extracellular matrix during pregnancy and involution may contribute to the enhanced invasive and metastatic potential of breast carcinomas and thus lead to their worse clinical outcome. (Polyak 2006, p. 151)

The poor clinical outcome referred to in the above paragraph occurs within a young woman's body. Even though a small percentage of men are diagnosed each year with breast cancer, they are rarely mentioned in the breast cancer literature. Breast cancer is a gendered disease.

#### **d. In summary**

In summary, within the professional texts three main discourses dominate the writing and thinking about young women with advanced breast cancer. The discourse of the object body speaks of the body of the young women as being a stable and knowable entity. Causal links between obesity and genetic faults are made and various treatments are aimed at a bodily container. The discourse of a declining body, while similar to the object body discourse, inscribe a body that is changeable and disintegrating in function. The body within this discourse is a dangerous beast that forever changes its form; it is

chaotic and abject. The declining body discourse also contains a paradox: health care professionals and the young women themselves expect weight loss. However, health care professionals expect weight loss as a sign of cancer's progression and the young women expect weight loss as an anticipated and desired outcome of cancer treatments. In fact, very often, the opposite happens and weight gain is observed. Within the medical literature, advice can be found on how to increase or maintain weight and the dangers of being too thin. Advice can also be found concerning weight loss strategies in the face of a chronic illness and the dangers of being overweight in relation to prognosis. Finally, the discourse of the gendered body firmly locates the disease within a young female body.

### **3. In the media**

The newspapers are powerful sites for the production of women's bodies and identities (Blood 2005, p. 66). The portrayal of the body of the young woman with either early or advanced breast cancer (the media often did not distinguish between the two) reinforced the discourse of the object body. There were just over 72% (165/230), of the articles that referred to the bodies of young women. However, other discourses were also apparent, although at times it was difficult to disentangle them from each other. One such discourse, hidden behind cultural messages of thinness and beauty was *the thin body* discourse.

#### **a. The thin body discourse**

The young women whose stories appeared in the newspapers were often those of celebrities, Belinda Emmett, Jane McGrath, Kylie Minogue and Megan Williams. By western cultural standards, these women are considered both thin and beautiful. Just over 18% (42/230) of the articles referred to these particular women in their content. In addition, the patron of the National Breast Cancer Centre is the Australian model Sarah O'Hare, another thin and beautiful woman. She appeared in a few of the articles in her attempt to raise the awareness that the disease does occur in younger women. Using such thin beautiful models to raise awareness has been criticised by some, but the practice continues.

While some critics have questioned the appropriateness of using skimpy T-shirts and pert-breasted supermodels to raise awareness of a disease that disfigures women's bodies, there is no doubt the glamorous global campaign has helped put breast cancer on the agenda. (Hutchinson 2004)

The use of thin celebrities to convey the message of breast cancer awareness is unhelpful irrespective of whether such images help 'to put breast cancer on the map'. It is unhelpful because it distorts public perception of who gets breast cancer, its risk factors and the best early detection methods for younger women. A recent study on Australian television found that while there was an overrepresentation of reports on breast cancer, celebrities were pivotal in cancer reporting (MacKenzie et al. 2008). Therefore, the practice is likely to continue.

While celebrities were common, newspapers also featured ordinary Australians. The stories of these women often appeared immediately after a celebrity disclosure of breast cancer. Just over a quarter (62/230) of the articles contained stories on such women. Nevertheless, stories of the thin and beautiful celebrities seemed to overshadow those of ordinary women.

The thin body discourse, as it was in the young women's stories, was evident in the newspaper articles. The stories resonated strongly with those of the young women previously mentioned. Julie Phelan's story is similar to that of Donna's. Julie also lost weight prior to her breast cancer diagnosis:

Julie Phelan thought it was fabulous when she inexplicably went from size 12 to size 8 in months. In truth, at the age of just 27, her weight loss was an early sign of breast cancer taking hold. (Gora 2001)

Julie was pleased with her weight loss - at least until it was explained to her that it was an early sign of cancer. Journalists did not chronicle the future outcome of either Julie's weight loss or gain in the months and years that followed. However, there were other stories that revealed the anguish many young women had over the shape of their bodies. Ruth Picardie, the author of *Before I Say Goodbye*, (1998) published part of her story in a newspaper. She was only 32 when diagnosed with breast cancer.

And that lump in your left breast, the one you noticed after you stopped breastfeeding last summer? ... the hospital would smile and tell you not to worry, it was the harmless fibroadenoma they'd found in 1994. But this time ... your lump. I'm sorry to say, is actually cancer. Or should we say lumps, because, oops, it's spread to the lymph nodes under your arm and in your neck which means it's stage-three cancer and you've a 50:50 chance of living five years ... Everybody think cancer makes you thin. In fact, I'm getting fatter and fatter. I know this because people keep coming up to me and saying "You look so well". Actually, I don't look particularly well – I'm pale and my hair is falling out behind my ears, - so what they really mean is, "You look so fat". ... I can now only wear clever layered clothes with elasticised waists ... I'm half way through my chemotherapy and I was hoping for a little payback: something – a couple of cheekbones, say – in return for the aching veins, the puking, the headaches, the disastrously thinning eyebrows ... Why am I so fat? (Picardie 1998)

Ruth, like other young women, was hoping that chemotherapy would bring about visible weight loss, 'a couple of cheekbones' at the very least. She was distressed at her weight gain. Sarah West was diagnosed with multiple breast cancers at the age of 20 and because of chemotherapy's side effects, gained weight around her waist. Three years of hormone therapy also put her in 'temporary' menopause, producing long-term changes in her body. 'My bust is smaller, but my waist is thicker,' she [Sarah] explains (Hall 2004). Jane Howard was 35 when her breast cancer was diagnosed' "I had rather hoped to look like Audrey Hepburn but ended up like Rosanne Barr on high-dose steroids. To help me cope with the drugs I packed the weight on' (Howard 2004). Jane, in this last extract, echoed many of the voices of young women with advanced breast cancer. She was hoping for cancer and its treatments to produce thinness and consequently, beauty.

**b. The 'volume in perpetual disintegration': the discourse of the body in decline**

Nearly 23% (52/230) of the articles surveyed referred to a body in decline or advanced breast cancer. It may be the luxury of hindsight, but indications of a body in decline can be traced back over the years of breast cancer reporting. For example, Belinda Emmett who died during the course of writing this thesis (1999-2008) was initially cleared of cancer's spread.

**I'm alive: Belinda cleared of breast cancer**

Home and Away star Belinda Emmett was celebrating yesterday after learning she is clear of breast cancer. Belinda revealed surgeons had found no trace the cancer has spread, after an operation at the weekend to remove a cancerous lump in her breast. The 24-year-old actress now faces six weeks of radiation therapy to ensure any possible traces of cancer are removed ... 'I've got the pathologist's results back and it's all clear, which basically means that

cancer hasn't spread'... 'I've had a lumpectomy so I've had the lump and some tissue removed and I'll have some treatment, which will be radiation therapy, to make sure that they've got any remaining cancers left in the breast. It looks like I've got out of chemotherapy, ha ha! (Sweetman 1998)

The object body discourse is evident in this article with reference made to *the lump* and *the breast*. The body is a stable and knowable entity, even down to the level of the cell in which pathologists vainly search for minute cancer deposits. However, micro-metastases must have been present in Belinda's body at diagnosis. The chemotherapy that might have killed these dangerous cells before they could do damage was not recommended for early-stage disease back in 1998. It is a different picture today; oncologists routinely offer young women chemotherapy. If we now turn the clock forward by three years, the discourse of the declining body becomes evident. What was early breast cancer has now become advanced breast cancer and the disintegrating process has begun.

**Belinda's agony: The cancer she conquered once has struck again**

Television star Belinda Emmett has been diagnosed with cancer again. The actor was having a routine medical check-up recently when the new cancer was detected. In 1998, the then 24-year-old discovered a malignant lump in her left breast ... The relapse is a major setback for Emmett, but she remains 'strong and positive', and has decided to take time off to devote her time to fighting the cancer. (Keogh 2001)

In 2001, Belinda's cancer returned in her bones. Now, if we move forward to 2005, we see that the already thin body has now become 'beautiful and tragically thin'. Her 'look' in the various photographs at that time was of a young woman in the grips of cancer cachexia. Her body was continuing its decline towards death.

... enormous sympathy and, of course admiration for her guts, the many photographs of the beautiful and tragically thin Belinda Emmett taken at the Logies recently struck fear into many of our hearts. (Singer 2005)

As I read this description and saw the photographs back in 2005, I do remember thinking that Belinda was not long for this world, bringing to the fore my palliative care bias of doom and gloom. Eighteen months later, she died.

A similar trace of bodily decline can be found in the story of Jane McGrath who was diagnosed in 1997. Her initial treatments were gruelling.

Jane Steele [McGrath] was in a relationship with Australian Test cricketer Glenn McGrath for less than two years when, at 31, she was diagnosed with breast cancer ... Jane had a mastectomy and then underwent gruelling chemo and radiotherapy... Jane writes in the book of difficulties she had. "My hair thinned and came out in handfuls ... during the final months of chemotherapy, the side-effects began to take their toll. I felt as though my body was falling apart". (Anonymous 2000)

Jane felt as though *her body was falling apart*. The decline of her body started at treatment and continued over the years into recurrence.

Brave Jane McGrath's seven-year health battle has suffered a new setback after tests revealed more cancer ... Diagnosed with cancer in 1997; Jane had a mastectomy and was in remission. The cancer returned last year, but recent tests reveal it has stabilised ... Despite warnings that she might never be able to conceive after cancer treatments, Jane gave birth to 2 healthy children. (Hockley 2004)

Jane McGrath died in June 2008, just outside the data collection period. Her bodily decline continued until death. Other young women also died during this period. The discourse of a bodily decline can be seen in several other the newspaper articles. For example, the decline of Jane Kite's body was accompanied by a great deal of pain and despair.

For the past 3 weeks, she [Jayne Kite] has been taking morphine daily to help overcome the pain from cancer that has spread to her hips, leg bones and a lung. But yesterday, she was tired and dispirited. On September 20, she has to decide whether she will begin her fourth round of chemotherapy or let nature take its course and enjoy a "better quality of life" in her remaining days. "I've got nothing against chemotherapy – its been marvellous at prolonging my life – but my arteries have collapsed and I'll have to have a shunt to take the drugs ... (Hailstone 2000)

Danielle in this next extract had experimental chemotherapy in the hope of cure. In the process, her body became infertile and declined in function to such an extent that she could no longer walk unaided.

Danielle<sup>27</sup> was determined to beat the cancer and was prepared to offer herself as a guinea pig to win the battle. Mrs Molloy says her daughter's courage during the four different chemotherapy campaigns was a testament to that fact. The ongoing radiation therapy was also having a devastating effect on her body but Danielle was determined to take every chance offered ... Danielle's treatment had also stripped her of the ability to have children, adding to her daughter's disappointment ... By Easter this year, those blonde locks were gone and Danielle, racked by cancer and chemotherapy, had little hair and walked with the aid of a cane. (Steene 2000)

The discourse of a declining body shaped Danielle's experience of her body towards the end of her life.

### **c. The discourse of an object body**

The discourse of an object body was strongly evident in the reporting in newspapers. The young woman's body was the subject of 72% (165/230) of these articles. The body seen from within this discourse was one that was often a receptacle for increasing amounts of chemotherapy.

A world-first breast cancer treatment that gives 50-100 times the normal dose of chemotherapy is being trialled in Melbourne. It centres on a unique development enabling tiny magnetic beads to find good cells in a patient's blood sample. A magnet then draws the good cells, which are re-infused after chemotherapy minus the magnetic beads, and the cancerous ones are discarded. He [Director of Peter MacCallum's blood and bone transplant service] said that traditionally, as the chemotherapy dose increased so did damage to other cells in the bone marrow, including stem cells –immature bone-marrow cells ... This damage could increase the toxicity of the chemotherapy and leave patients open to infection. (Carter 1997)

News about new drug therapies that showed promise in clinical trials appeared in the media from time to time. The discourse of an object body was reinforced in this reporting as the trials happened to a fixed and passive body. The mind was not visible. Such reporting is embedded in the scientific paradigm. An example of this discourse is taken from the reporting of Herceptin, a relatively new drug in the field of cancer treatment.

Herceptin used to be only available to a small proportion of young women with advanced disease. Early trials were showing that this drug had a far wider application

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<sup>27</sup> Danielle was diagnosed with breast cancer before 25 years of age and has since died of the disease

and would benefit those women with early-stage breast cancer. If other women wanted the drug, they had to pay for it (\$7,000). Due to public pressure, Herceptin is now available on the Pharmaceutical Benefits Scheme for women with both early and advanced breast cancer. However, it took a number of years of further testing, public campaigning and political intervention before the drug became widely available. The reporting of Herceptin began in the Australian press in 1998.

WASHINGTON: The US Government has approved a breakthrough treatment for advanced breast cancer. A bioengineered drug called Herceptin marks the first big payoff in 20 years of research to attack the genes that cause cancer. Herceptin does not help all breast cancer patients, just the 30 per cent of cases fuelled by the bad gene HER2. The Food and Drug Administration approved Herceptin's use by advanced breast cancer patients whose HER2-positive tumours have spread to other organs ... About 30 per cent of breast cancer patients have too many copies of HER2. A healthy version of this gene produces a protein that signals cells to group and multiply normally, but in women who have too much HER2, the breast cells reproduce out of control and spread through the body. (Anonymous 1998)

Seven years later, results of further drug trials with Herceptin were published.

The study, published this week in the New England Journal of Medicine, involved 5000 women from 39 countries including Australia. Experts describe the results as 'revolutionary, stunning' and 'jawbreaking'. (Riley 2005a)

The object body, under the influence of such groundbreaking treatment, has become a useful container. However, the object body discourse was not confined to the reporting of innovative treatments. It was also present in many of the articles that focused on celebrities with breast cancer. This next extract is talking about Kylie Minogue's possible treatment.

Invasive breast cancer, typically the worst type, may involve further chemotherapy or hormone therapy to prevent it spreading. In extreme cases, doctors can perform a mastectomy, where the breast is surgically removed. ...The advantage of early breast cancer is that good local control through surgery and radiotherapy, with additional therapies can potentially contain the cancer. (Jones 2005)

Kylie's breast was referred to as 'the breast' and the 'good local control through surgery and radiotherapy' were occurring in a lived body, not an object. The body in these

newspaper extracts is passive and docile; others act upon it. The mind is absent, so too is a mindful body. Such reporting reinforces the mind-body separation.

#### **d. The discourse of the gendered body**

The gendered body discourse weaves its way strongly through the professional medical literature and can be seen in the newspaper articles. All the articles (100%) in this data set were about young women with or without breasts, a much gendered body part. Breast reconstructions were not uncommon.

In a Collingwood restaurant the other night, a woman in her 30s lifted up her shirt and triumphantly displayed her nipples to fellow diners. The other guests weren't shocked, but they were impressed. The woman was displaying nipples, which had been created out of skin grafted from other parts of her body, and stitched onto her reconstructed breasts ... Five years ago, at 35, Tanya was diagnosed with breast cancer. She underwent a mastectomy, six months of chemotherapy and a breast reconstruction. (Kearney 2002)

This young woman mentioned above probably looked normal with her clothes on. She had nipples after all! She looked like a young woman should, at least from the perspective of the culture and society in which she lived. Carmen in the next extract, while fearful that cancer might come back, was also concerned about her appearance. She chose to have bilateral breast reconstructions at the time of her initial surgery.

When Carmen Davidson's mother was diagnosed with breast cancer, she opted for a lumpectomy – having part of her breast removed. A decade later, the cancer returned and within 18 months, she was dead. So when Ms Davidson, 33 of Vacluse, discovered a lump she took no chances ... She chose to have both breasts removed and reconstructed ... 'I needed to live my life knowing I don't have a cancer playground on my chest'. (Anonymous 2004)

Carmen talked of not wanting 'a cancer playground in her chest'. Her fear of cancer's return led her to the drastic step of having both breasts removed. However, given that minute cancer cells may have already spread beyond her breast and be 'playing' in other parts of her body, she may well be too late.

In May 2005, Kylie Minogue was diagnosed with breast cancer. Her diagnosis encouraged a sort of hysteria amongst young women and cancer clinics were inundated

with young women wanting reassurance and mammograms. The reporter in this next extract reinforces the discourse of the gendered body.

Kylie has breast cancer. The news has quickly reverberated as we absorb the notion of our Kylie, so young and so healthy, getting breast cancer. Her famous sweet, strutting little breasts are now suffering the insult of this disease ... Mum has had a mastectomy and is still having drug treatment, my aunty has had the double whammy of two mastectomies decades apart ... Breast cancer seems to be everywhere ... (Singer 2005)

Using words like 'sweet, strutting little breasts' is highly evocative. The reporting reinforces the sexualized image of breasts widespread in our society and some would argue that it contributes towards the oppression of women (Bordo 2003; Greer, G 1999).

Another fact of the discourse of the gendered body involves young women's pregnant bodies. In the newspapers, there were several stories of young pregnant women with breast cancer.

Breast cancer is often missed in pregnant women because heaviness and lumpiness in breasts are considered normal ... Dr Hugh Carmalt said breast cancer was occurring more often in pregnant women and doctors should investigate every suspicious lump. "the majority will, of course, turn out to be benign, but too often they are missed because in pregnancy the breast enlarge, they have fluid retention and can become quite nodular" he said. (Rouse 2001)

A young woman's body in pregnancy can skilfully hide the presence of cancer growing in her breast. The normal physiology involved in preparing her body and breasts for the birth of a child can hide the early signs of cancer's growth. Growth and chaos sit side by side.

Anna was diagnosed with breast cancer three years ago. She was pregnant with her daughter when she discovered a lump in her breast ... After months of aggressive treatment, Anna was in remission until six weeks ago when another tumour was discovered in her liver. (Coffey 1998b)

In the above paragraph, the discourses of the gendered body and tragedy merge. Pregnancy, a time for hope and joy is marred by the presence of destructive cancer cells. For Anna, with the discovery of cancer in her liver, her death becomes inevitable. She

has a daughter that sadly she is going to leave behind. Heather's story below is somewhat similar to that of Anna's. Heather discovered her cancer while breastfeeding

Like many sufferers, Heather was a healthy, fit young woman who didn't think breast cancer could happen to her... Heather discovered a lump while breastfeeding...Having always been fit, Heather was shocked to discover that the one thing she'd taken for granted – her health – was very much under threat. “The diagnosis was grade 4, level 1. That's bad.” (Taylor, D 2004)

I agree with this reporter that Heather's life was indeed under threat. Grade 4 is a highly aggressive cancer and her long-term outlook is uncertain.

### **e. In summary**

There are several discourses shaping media reporting over the last decade and the discourse boundaries often merged. The most dominant of the discourses was that of the gendered body which was implicated in the reporting of breast surgery, celebrities and cancer-related pregnancies. The discourses of the gendered body and tragedy wrapped around each other, making it difficult at times to distinguish between the two. The thin body discourse showed that young women with both early and advanced disease desired thinness and were distressed at weight gain. These young women were caught up in cultural projections of female body weight and shape. The object body discourse was everywhere reinforcing the prevailing view of a separate mind and body. The declining body discourse traced a body in the process of disintegration.

### **4. Discussion**

The women's stories of their bodies in illness are embedded within the wider social and cultural networks in which they live. The bodily discourses that they draw upon to make sense of their illness relate to a body that is both an object – a container for aberrant cells, a subject – an embodied experience, and an in between abject. The young women's bodies are also inscribed by cultural messages of thinness and gender. While the female body in illness has already been the subject of a vast amount of research and theorising, the female body in advancing disease has been neglected in these writings to date. And, while these discourses of the body occurred with differing emphasis across

the three data sets, there does appear to be a major consensus concerning these discourses.

The young women in this research drew upon an array of bodily discourses to make sense of their experience of living with a life limiting illness. The effects of such discourses upon their understandings and experiences are several. I have identified four:

1. The urge to be thin;
2. Looking (ab)normal: A disturbance of body image;
3. The gendered body;
4. The body as the site of abjection.

### **Effect 1: The urge to be thin**

A woman's desire to be thinner can be seen as a reflection of a widespread struggle around female identity currently being promoted by the Western cultural standard of body weight shape which places great emphasis on an external image. These dominant cultural standards are conveyed to a large extent by the media. The thin image sells newspapers and magazines, enlarging and perpetuating values and beliefs already widespread throughout our society (Gordon, R 2000). However, the images portrayed represent only a small part of any population. Even in the face of advancing disease, the women in this project sought after body image that was one of thinness. Why do these young women participate in what is clearly an unproductive quest? One answer to this question lies in the writings of Foucault on the topic of the docile body.

The human body was entering a machinery of power that explores it, breaks it down, and rearranges it. A 'political anatomy', which was also a 'mechanics of power', was being born; it defined how one may have a hold over others' bodies, not only so that they may do what one wishes, but so that they may operate as one wishes, with the techniques, the speed and the efficiency that one determines. Thus, discipline produces subjected and practised bodies, 'docile' bodies. (Foucault 1995, p. 138)

Over the last 20 years or so, the body has been seen as less of a machine and more of a site of contestation; a surface upon which our cultural and social values are inscribed. This process of inscription has led to docile bodies; bodies that can be moulded and shaped according to the disciplinary practices engaged in.

Technologies of the self are a collection of techniques that can be used by individuals to control their bodies, thoughts and practices and thus attain some level of perfection and happiness in life (Danaher, Schirato & Webb 2000, p. 129). As Foucault states, technologies of the self are practices which;

... permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thought, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality. (Foucault 1988b, p. 18)

In what technologies of the self do young women with advanced breast cancer participate, in order to attain some sense of happiness and wisdom? Like many others, they diet and they exercise. They position themselves within the *thin body* discourse. They seem not to resist it.

In an attempt to gain social and personal acceptance, many women strive for the ideal body. The thin image perpetuated by the media evokes a strong emotional response in many women. They frequently feel dissatisfied with their own bodies and strive to attain what they consider to be the ideal figure (Dolan & Gitzinger 1995). However, the media alone cannot be blamed for the entire shaping of perceptions of fat and thinness in our culture. As I have indicated, the institution of medicine also supports an ideal body shape and weight according to the body's position on a particular disease trajectory.

The desire to be thin is not unlike a religious decree, 'thou shalt not indulge in gluttony or slothfulness' or in other words 'eat right, watch your weight and exercise'. Those suffering with anorexia nervosa are not alone in their adherence to this creed. All society's members are affected to some extent (Seid 1994). Dieting is one of the techniques;

of subjectification through which human beings are urged and incited to become ethical beings, to define and regulate themselves according to a moral code, to establish precepts for conducting or judging their lives, to reject or accept moral goals. (Rose 1996, p. 156)

Being thin therefore is an ethical and moral requirement of living in a particular society. The young women are seduced by these requirements.

The media is an ideal vehicle for public health messages. However, these messages can be contradictory as found in the reporting of cholesterol and diet (Lupton & Chapman 1995). In relation to weight and health, the public health message is to 'lose weight and gain life'. This promotion currently appears in a number of popular Australian women's magazines. The extremes of being either underweight (a body mass index under 20) or being obese (a body mass index over 30) are considered to be bad for your health. Being extremely overweight does carry with it some health risks such as diabetes and heart disease, but for most of us, carrying around a few extra kilos does not constitute a health risk. One can be overweight and healthy (Cooke 1994). The paradox is that for young women living with advanced breast cancer, losing weight is often an ominous sign that the cancer is progressing and perhaps not a feature to desire at all. Recall the picture of Belinda Emmett discussed during this chapter and the one on Tragedy where the journalist described her as being 'beautiful and tragically thin'. For experienced palliative and cancer care clinicians, such an image brings to the fore a suspicion that all is not well.

The concept of an 'ideal weight' emerged as a post World War II phenomenon. This questionable concept decreed that every one of the same height and bone structure should weigh the same - with no accounting for individual differences or genetics. The assumption underlying the concept was that weight and fat were a direct result of what a person ate and the amount he or she exercised, and if you were fat, then it was your fault as all you had to do was exercise will power (Seid 1994). The young women in this study endeavoured to shape their bodies and lives from the cultural material available. The cultural messages proclaim repeatedly that the responsibility for thinness (or fatness) rests with the individual woman.

Diet is linked to the introduction of a science of nutrition, and thus administrative power in Foucault's sense; but it also places responsibility for the development and appearance squarely in the hands of its possessor. What an individual eats, even among the more materially deprived, becomes a reflexively infused question of dietary selection. Everyone today ... is on a diet. (Giddens 1992, pp. 31-2)

To be fat is considered a disgrace, a stain on one's character, a moral flaw. Perhaps it is time to ditch the concept all together, as this next quote suggests:

More and more evidence is emerging that discredits this whole ideology and shows that its premises are empirically flawed. The thinner are not necessarily healthier, nor are they more fit. Our fundamental beliefs – that people of the same height should have the same weight and that people can exercise absolute control over their body weights – are also flawed. Numerous studies demonstrate that the majority of the 'fat' cannot slim down permanently. The problem is not their lack of will power, but the unreasonable expectation placed on them to weigh a certain amount. (Seid 1994, p. 7)

Disciplinary practices, such as the push for a population's ideal weight discussed above, attempt to shape the lives and bodies of individuals in order for them to fit into institutional structures and norms. The operations of the discourse of numeracy can also be seen at work here in the collection of biostatistics used to determine the ideal weight. The ideal weight concept and the desire to be thinner is also an aspect of *governmentality* (Foucault 1982b), a mechanism for regulating and controlling populations, ensuring that they remain healthy and efficient so that they continue to be productive and reliable citizens. These are vital qualities required by all capitalist societies (Turner, B 1992). An important aspect of governmentality is its ability to focus on self-government (dieting). This self-governing is an ongoing process in which we constantly assess and reassess new information in the light of what we know about ourselves (Nettleton 1997, p. 218). We are all required to participate in these self-governing activities. No one tells us to comply, yet we participate with and without thought or critique.

There is nothing wrong with these disciplinary practices on the whole, but it is important to recognise their impact on how we understand and experience our own bodies and the bodies of those around us (Morris 1998). According to Foucault, individuals do not hold power but rather power comes into being through the actions of individuals as they participate in disciplinary practices (such as in the production of the 'ideal' body) that are in accordance with the normative views of society. Such self-surveillance activities 'assures the automatic functioning of power' (Foucault 1973, p. 201).

Young women both promote and consume an unhelpful and contradictory message in their pursuit of thinness. These young women must negotiate their cancer containing bodies through the cultural maze that has, as its holy grail, the perfect body. The social consequences of this failure to attain perfection are feelings of guilt, shame and failure, as illustrated in the extracts from this study, and I believe that those who do not attain this ideal are stigmatised and excluded. The young women in this study are not the only ones to have fallen under the cultural spell of the 'body beautiful'. Many of us have succumbed to this obsession. I am not saying that young women living with advanced breast cancer should not be concerned about their weight or health or how they feel about themselves. After all, weight gain after breast cancer treatment has been shown to be related to poorer disease outcomes, possibly due to the effect of weight increase on fat tissue and changes in steroid hormone metabolism (Herbert, Hurley & Ma 1998; Zang et al. 1995). However, young women living with advanced breast cancer are living with a poor prognosis anyway, and have many other concerns apart from their fear of weight and fat.

Perhaps it is too difficult to reject the self-surveillance messages. The discourse of the thin body shapes how individuals act and behave and limits other ways of being in the world. In this research, these other ways of being were not evident. The power of this discourse lies not only in its ability to render the bodies of the young women passive and docile, as Foucault's earlier writings suggest. Its power also lies in the ability to engage the women in the business of actively shaping their own lives (Blood 2005, p. 52). While resistance to such messages is possible, the women in this research positioned themselves firmly within the thin body discourse. To resist actively the powerful cultural message of thinness requires conscious energy – energy that many young women with advanced disease seldom have.

There is nothing new in a woman's urge to be thin, and we might expect it in young women in the grip of anorexia nervosa. However, the desire for thinness in the face of a chronic life-limiting disease is an unexpected finding. The urge to be thin is one attempt to look normal even though 'normal' (thin) is a statistical rarity. Looking normal provides a powerful motivation for all sorts of actions.

## **Effect 2: Looking (ab)normal– a disturbance of body image**

There has been a considerable amount written on body image and women's acceptance of their bodies and I will not repeat the arguments here. Suffice to say that a young woman's body image involves the colonisation of any number of objects, if they remain attached to the body for long enough. The absence or presence of clothing for example can alter her posture (Grosz 1994). A body part such as a breast has been accommodated within a body since puberty and therefore, even when removed, remains a part of a woman's body image for a very long time. Body image takes time to change; it is 'temporally out of step' with the current image held (Grosz 1994, p. 84)

The women in this research wanted to look normal, both in their own eyes and in the eyes of others. This looking normal involved their perception of what their bodies looked like from the perspective of their conscious minds (Blood 2005, p. 25). Seeing body image in this way reinforces the subject/object division and the body becomes a fixed knowable object. However, body image is never stable; it waxes and wanes depending on the social and cultural climate. In addition, the body is more than an object of one's perception; it is also a construction, for perceptions are shaped by the social and cultural context in which we find ourselves. Body image:

... characterizes the perceptions a consumer has of his/her body, and these perceptions are conditioned by a field of social relationships, cultural ideals, normative prescriptions, and moralistic meanings regarding self-control and discipline. The social world in which each consumer is embedded operates to enforce and reinforce this system of bodily meanings and practices. The result is a form of socialization that inspires a deeply internalized duty to discipline and normalize one's body. (Thompson & Hirschman 1995, p. 150)

The desire to look normal demanded certain strategies that involved concealment (covering up tumours and the effects of treatments), surgery (breast reconstructions) and self-discipline (dieting and exercise). The desire by these women to look normal implies a rational self which leaves no room for contradictions or inconsistencies (Blood 2005, p. 31). However, the image we have of ourselves is often distorted or inaccurate. It is as though we were looking at ourselves through a distorted mirror not unlike the mirror of Jacques Lacan's theory of human development in which he suggests that we do not become a fully human subject unless or until we form an image of ourselves as discrete beings (Lacan 1977).

As previously mentioned, the urge to be thin requires continual self-surveillance and self-correction. The desire to look normal also requires self-surveillance and self-correction activities. Looking normal requires that the young women living with advanced breast cancer continually bring up an ideal image of themselves against which they judge and compare themselves.

The idea of the norm is at the heart of surveillance, establishing what is 'normal' and classifying people in relation to this norm. Norms serve as models against which the self continually judges, measures, disciplines and corrects itself (Blood 2005 p.53).

The young women gain a sense of control over their bodies by participating in the various surveillance mechanisms. Women take up the position within the varied discourses of the body as willing subjects, at least initially. However, over time, their bodies can become sites of resistance, and women are able to contest the forms of power that make them subjects, although in my research I did not find this so. The young women who participated in this project were firmly entrenched in current notions of thinness and normality. However, they did perhaps occupy contradictory subject positions at times, caught in between self-acceptance (body image literature) and the desire for bodily improvement. As I did not visit the women again after the initial interviews, they may have been able to find another subject position from which to speak. Susan Bordo (1999) speaking of Foucault's work says that power relations do not have rigid borders, but are 'always spawning new forms of culture and subjectivity, new openings for potential resistance to emerge' (Bordo 1999, p. 254). Therefore, the young women may have in fact been engaged in resistance while appearing to be participating in the management of a docile body. By trying to conform to the norm of thinness and appearing normal, they may have felt more in control of their bodies in decline – their abject bodies.

### **Effect 3: The gendered body**

A woman's breasts are the most obvious sign of her sexuality and her gender and are important aspects of her identity. Yet, a woman cannot be simply reduced to her anatomy, because anatomy, like the body, is socially constructed. Breast cancer is almost exclusively a female disease and the female body in which the cancer grows and resides has been the topic of feminist debate for decades. From a feminist perspective,

women's experiences of their bodies have been shaped by representations of the female body within the social and cultural networks of our society (Blood 2005). Tensions exist between the cultural appropriations of the female body and the body as it is experienced and lived by women everywhere (Conboy, Medina & Stanbury 1997, p. 1). The urge to be thin could be seen as one example of this appropriation. However, the gendered body encompasses more than just the concern to be thin; it also involves a fertile, reproductive body.

Within the medical literature and newspaper articles, many of the studies highlighted the body of a young woman with advanced breast cancer as a previously fertile body that, because of treatments, becomes infertile. Even if fertility remains, these young women are advised against subsequent pregnancies because of the incurable nature of the disease and the possibility that future pregnancies may accelerate cancer's progression. Her body contains a dangerous potential to conceive and hence shorten her life. Her body and its fertility must therefore be controlled, and the medical profession (read male) promotes this control. Her body becomes a problem to be managed.

If a young woman with advanced breast cancer purposely becomes pregnant, some might consider her a monster. How could she give birth to a child that she was going to leave prematurely? How could she become pregnant and have treatment that may leave her child deformed? These questions invite censure on the young woman and her body if she goes against such advice. This censure is perhaps beyond gender. Two women in this study decided on having children, even though they were living with an uncertain prognosis. One was Helen, one of the women interviewed, and the other Jane McGrath who was reported on in the media. These women were perhaps creating a new site of resistance from where they could challenge traditional and gendered notions of motherhood.

Of course, these young women living with advanced breast cancer are not monsters. They hope that they are not going to die before their time and will live to see healthy children born and grow up. However, life is never that certain. If she is optimistic about her long-term outcome, she may immerse herself in the technology of fertility preservation and these technologies are implicated in the networking of disciplinary power (Sawicki 1991, p. 83). However, a diagnosis of advanced breast cancer renders

her unlikely to be offered such technologies. Therefore, because of treatment and technologies, new individuals are created whose bodies are either infertile or unfit for pregnancy. As Sawiki states, 'as these medical disciplines isolate specific types of abnormality or deviancy, they construct new norms of healthy and responsible motherhood' (1991, p. 84).

The young women involved in this project admitted to having difficulties in how they viewed their bodies. Our interviews could be seen as a form of a confessional, which according to Foucault is meant to be a freeing practice. However, confessing one's sins, so to speak, is connected to the practices in which people are made subjects and are hence part of the wider network of power relations.

The confession is a ritual of discourse in which the speaking subject is also the subject of the statement; it is also a ritual that unfolds within a power relationship, for one does not confess without the presence (or virtual presence) of a partner who is not simply the interlocutor but the authority who requires the confession, prescribes and appreciates it, and intervenes in order to judge, punish, forgive, console and reconcile. (Foucault 1978, pp. 61-2)

The women spoke of their male partners, who were virtually present during our interviews as the arbiters of their bodies. Recall Jessica's words earlier where she described her relief when her husband appeared to accept her body with its mastectomy scars. Society casts men in a position of authority and as judges of the women's bodies before them. Men take up the gaze that subdues and controls the bodies of countless women (Blood 2005, p. 88). Men do not have to be present to effect control, for the 'gazer can see without being seen, and as Foucault has pointed out, this possibility is a major source of modern disciplinary powers' (Young, IM 1990, p. 193). Yet, while the male gaze constructs breasts as objects, this process of objectification is not the sole province of women, men too suffer from being the object of a 'female gaze'.

In summary, the effect of a gendered body construction on the lives of the young women is far-reaching. Their bodies are the objects of a gendered gaze. In addition, the young women often occupy new subject positions of unfit mothers and infertile beings. However, these new subject positions also offer new sites of resistance.

#### **Effect 4: The body as a site of abjection**

*Abject* refers to the ‘utterly humiliating or despicable’ (Macquarie Encyclopedic Dictionary 1990) and *abjection* is the condition of being ‘utterly humiliating or despicable’. The last effect that the discourses of the body have upon the young women lives and subjectivities is that of abjection, a term first used by Julia Kristeva to refer to the sick, unbounded and polluted body in illness (Kristeva 1982). The young women’s bodies, as they decline and disintegrate towards death, take on a mantle of shame and humiliation. Bodies and body parts are covered up. Looking normal is the salve to looking and feeling abnormal. Abjection is always present – merely covered up by our civilising processes. In death, the ability of containment becomes less effective.

The abject body in advancing disease aligns itself with neither the subject nor the object. It takes up residence in the spaces between these two modes of being.

The place of the abject is where meaning collapses, the place where I am not. The abject threatens life, it must be radically excluded from the place of the living subject, propelled away from the body and deposited on the other side of an imaginary border which separates the self from that which threatens the self. (Creed 1993, p. 65)

For the young women concerned, to be in a place ‘where I am not’ must be a place of alienation and loneliness - a state of abjection.

As breast cancer cells rampage throughout the body, pain disrupts a feeling of embodiment, of being at home with one’s body (Waskul & van der Riet 2002). Bone cells are invaded and they implode, lung cells become overwhelmed and as they haemorrhage, they suffocate; liver cells, under the weight of the invading hordes, no longer function. Pain accompanies each event and foreshadows a body’s decline. What was once inside, body fluids for example, begin to seep out as the inside and outside merge. This ‘volume in perpetual disintegration’ as it slides towards death, is accompanied by horror; horror of the unknown, horror of the shamefulness of an unbounded body and horror at its devastation and final humiliation. Kristeva (1982) writes that on death we are at the border of the territory of the living. Once death has occurred, our bodies move beyond this border ‘until from loss to loss, nothing remains in me and my entire body falls beyond the limit – *cadere*, cadaver’ (Kristeva 1982, p. 3).

### **5. Conclusion**

From a poststructural perspective, the discourses of the body that were evident in the professional and lay media and used by the young women, acted as bodily inscribers. In our consumer society, consumption is a mechanism of control used to shape the outside and the inside of bodies. The women wanted to look normal and yet the image being put forward by the media was far from normal, it was decidedly abnormal. It was a tragically thin body. It was a female body. It was an object body and finally it was a disintegrating body. It seemed almost impossible for these young women to step outside these prevailing discourses of the body (Hardin 2003c, p. 15).

## CHAPTER 8: CONCLUSION

Deconstruction of the texts created by researcher and researched by interrupting and disrupting them can also serve to clarify these discourses and to challenge the constructed text, opening it to a range of interpretations, all of which are transitional and none of which can be finite. No conclusions are possible. (Grbich 2004, p. 123)

In this research, I have deconstructed several texts in order to identify and challenge the discourses at work in the area of young women living with advanced breast cancer. I agree with the above quote that the interpretations I have made in this thesis can never provide the final word on this subject; all interpretations are in a constant process of flux and change. Conclusions to such an endeavour are therefore difficult and yet in this final chapter I must attempt to comply with academic convention and draw the various threads of the thesis into a cohesive whole. This task is indeed a challenge. In this study, I set out to answer two questions.

1. What discourses in the professional and popular literature are currently being drawn upon to represent advanced breast cancer in younger women; and
2. How do these discourses shape and regulate the experiences and meanings of young women diagnosed with advanced breast cancer, that is to what effect?

I will now provide a summary of the results in order to answer these questions.

### **1. Summary of results**

#### **Question 1**

What discourses in the professional and popular literature are currently being produced and drawn upon to represent advanced breast cancer in younger women?

The professional medical texts and the newspaper reports were read, with and against, the conversational texts of young women living with advanced breast cancer in order to identify the dominant discourses at work. These discourses were; the discourse of numeracy, the discourse of tragedy and several discourses of the body; the thin body, the declining body, the object body and the gendered body. While the emphasis of each of these discourses varied across the three data sets, they were all present in each to some degree, reflecting broader cultural stories within which the individual stories are located (Hardin 2003b). For example, the discourse of numeracy strongly shaped the

professional medical texts. Medicine used numbers to establish authority and the semblance of control over a disease that resisted control. The newspapers also used the discourse of numeracy, repeating statistics and numbers that originally appeared in research articles. The institutions of medicine and the media appeared to support each other through the overt use of this discourse and through this mutual support, they were able to exclude alternative understandings such as those offered by the complementary and alternative therapy movement. The young women, with varying degrees of success, also drew upon the discourse of numeracy in an attempt to understand their treatment options, disease staging and prognoses.

The discourse of tragedy was most dominant in the newspaper articles where young women with breast cancer were commonly portrayed as being tragic heroes. However, within the professional medical texts, there existed only faint traces of this discourse. It was still shaping them, but was doing so in a way that was covert and silent. The discourse of tragedy also appeared to be shaping the young women's stories, especially in the way that they described the loss of an imagined future that featured their children. Furthermore, while the discourses of the body were evident across all three data sets, they appeared in different combinations depending on the data set in question. In the young women's stories, the discourses of the thin body and the declining body dominated. Within the professional medical texts, the discourses of the object body, the declining body and the gendered body were evident. And in the newspaper articles, all of the above mentioned discourses could be seen shaping the reporting and representation of advanced breast cancer in young women.

### **Question 2**

How do these discourses shape and regulate the experiences and understandings of young women diagnosed with advanced breast cancer, that is to what effect?

The effects of these discourses on the lives of the young women concerned were profound and far-reaching. In chapter 5, I showed how the discourse of numeracy was used to manipulate the young women diagnosed with advanced breast cancer through the deliberate use of statistical calculations on risk and prognoses. The discourse was also used to add weight to the moral imperative to survive at all costs, recruiting the young women into an elusive quest for certainty and survival. This quest also led them into

complementary and alternative therapies. Furthermore, via the calculation of normal distributions to classify the young women as curable or incurable, the discourse alienated them from others living with breast cancer. Finally, the effect of such a manipulation on the lives of the young women concerned was one of confusion and despair. These young women, through the effects of this discourse, were transformed into objects and were categorised as being incurable and therefore non-survivors. They became part of the apparatus of biopower and the practices that controlled them at both an individual and a population level.

In chapter 6, I identified three effects of the discourse of tragedy. First, the discourse reinforced the stereotype of the tragic hero. The newspapers were especially active in this construction. The deliberate use of the tragic genre meant that young women living with advanced breast cancer were stripped of their individuality. They became an homogenous group that were subject to living out society's preformed ideas of what it is like to be young and living with a life-limiting illness. The young women concurrently occupied the subject positions of both heroes and victims within the newspaper articles and yet in their own lives they rejected both. Second, through its use of the tragic hero stereotype, the discourse prescribed the type and intensity of emotions that could be experienced in the situation of a life-limiting illness. Sadness and despair were emotions to be managed and at times the 'feeling rules' caused an emotional dissonance to occur. Third, the discourse of tragedy reinforced values and beliefs around the right timing of things and the cultural norms of motherhood. Newspapers were a key site where such norms were given voice, thus highlighting their ideological dimension.

In chapter 7, there were four discourse effects; however, the most outstanding effect identified was the shaping of the young women's desire for thinness in the face of advancing disease. The media promoted and perpetuated this cultural standard and yet, being thin meant a different thing to the medical profession where losing weight was an unwanted state of affairs. Medicine however did support the ideal body shape and weight in early disease, only abandoning it as death became apparent. To control ones weight and shape is part of the drive for self-responsibility for ones health and the women in this project submitted their bodies to several self-governing activities, even though they had a life-limiting illness thereby illustrating powerful force of the discourse of the thin body to 'form the object of which it speaks' (Foucault 1972, p. 49).

The desire to be thin was not the only effect of the various bodily discourses, the desire to look normal was also a strong motivator for the young women concerned. This second desire and effect was evident in the need for concealment and the involvement by the young women in self-surveillance activities. Advanced breast cancer caused more than a disturbance in body image, it also affected the relationship these women had with the world around them. The third effect that the discourses of the body had on the lives and subjectivities of the young women concerned was in the formation of the gendered body and in the creation of new individuals such as unfit mothers and infertile beings; their bodies became the sites of struggles over identity. They struggled against being tied to a self-identity that relegated them to the category of terminally ill and incurable. It may be that identity construction for these young women continued to be developed through their investment in those left behind. The fourth effect was that of abjection. Abjection awaited as the young women's bodily order became threatened (Mansfield 2000, p. 53).

Lupton (2003, p. 71) suggests that the dominant discourse around cancer is the discourse of hope. The dominant discourse around young women living with advanced breast cancer is not predominantly that of hope but of numeracy, tragedy and discourses involving the body.

## ***2. Discussion of the theoretical significance of the study***

As the individual chapters indicate, this thesis has drawn together the various insights from previous studies concerning young women diagnosed with advanced breast cancer and has added to it, thereby building upon our current stock of knowledge in this area. I have adopted a poststructural approach to explore discourses that are currently shaping the values and beliefs about what it is to be young and be living with a life-limiting condition in our society today. This approach has highlighted that these young women lived in multiple discursive worlds that were frequently constraining. No single discourse appeared to empower or free the young women concerned. The positions that these young women took up and identified with within the various discourses constructed their identities as innumerate, often tragic beings involved in futile self-surveillance practices. The poststructural approach has also assisted in relocating the disease of advanced breast cancer from within the individual young women to within

the broader practices of the society and culture in which they live (Hardin 2003c). This relocation has meant that they cannot be either blamed or praised for their non-survival or survival in the face of advanced breast cancer.

The writings of Foucault were helpful in interpreting the results, especially his understanding of the operation of power. This analysis of power and its effects takes the findings of this research beyond the descriptive and into a critical dimension. As I have shown, individuals in this research did not hold power; rather it was built around and filtered through institutions such as medicine and the media. The institution of medicine divided the young women into categories, separating them out from others diagnosed with the disease. They were separated out from those women for whom cure was possible and were placed into the category of 'incurable'; they were categorised according to their difference and these differences were mediated by numbers. Medicine justified such divisions based on population studies and biological attributes and the appearance of the cancer cell. These dividing practices contributed to the young women's identity. They felt isolated from other women with breast cancer and out of step with their peers. These feelings only added to their sense of personal tragedy. However, I believe, like Seale (1998a), that these dividing practices helped to organise the chaos that uncertainty of a life-limiting illness engenders. The media, instead of categorising young women into either early or advanced breast cancer, incurable or curable, stereotypically placed them all into one tragic homogenous group. These young women were neither entirely free nor autonomous individuals; they were the focus and product of larger forces at work (Mansfield 2000, p. 58). Foucault's writings on governmentality were also useful. Governmentality, carried out at all levels of society, showed how these young women governed themselves in line with societal norms. They did not need any external control. They willingly positioned themselves within several prominent discourses of the body.

The varied discourses illuminated in this research can be seen as operating within current societal values and beliefs, so much so that they become internalised over time and appear as common sense or self-evident. Yet at times, there is resistance to these controlling discourses and refusal to participate in their definitional work.

### **3. Limitations of the study**

There were several limitations involved in this research. Firstly, I could have canvassed broader publications involving young women with breast cancer. Yet, it was impossible to study the entire world of breast cancer due to the enormous amount of literature that this subject generates, both in the professional and popular press, and there are many issues and concerns that confront all women diagnosed with advanced disease irrespective of their age. I have therefore focused on one area that has not been specifically examined before. This area included the representation of advanced breast cancer in the professional and lay domain and the relationship these representations had with the lives of actual women living with advanced breast cancer. As such, the research could be classified as a 'reception study' according to Seale's media studies' classifications (Seale 2003).

Secondly, the results of this project are not generalisable to other contexts. However, the identified discourses are important both inside and outside the world of advanced breast cancer and therefore warrant consideration when weighing up the integrity of the conclusions derived from the discussions. The significance of this study is not confined to the narrow focus of young women living with advanced breast cancer. The discourses identified are evident in many areas of health and illness. In addition, the sample size for the interviews was small. However, again because the purpose of the research was not to produce results that could be generalised, the number of participants for the research project was not crucial. Small sample sizes are a feature of qualitative research. I balanced the smaller number of interviews against the larger collection of research and newspaper articles that spanned over a decade.

Thirdly, this study did not produce cost benefits as such. By this, I mean that the results of the discourse analysis are not going to save money on health care or make the therapeutic interventions more cost efficient. However, the ability to influence practice must never be underestimated. In the practice of cancer and palliative care it is never too late to reflect upon what we do, why we do it, and the invisible and seductive forces shaping all our lives.

Fourthly, as evidence of the frequency of certain discourses within the newspapers and medical texts, I used percentages. By doing so, I was also promoting and perpetuating the discourse of numeracy rather than challenging its power. I was trying to convince the reader of the integrity of my findings; however, here I was operating within positivist assumptions about the validity and truth of numbers. The only way I thought I could be certain of my findings was to cling to what I could count and measure (Parker & Burman 1993, p. 160). While I was aiming for a degree of certainty, I do acknowledge that certainty is an elusive ideal and not to be found within a poststructural approach to research.

Fifthly, discourses and experiences change over time. I have provided just one snapshot of the world of young women living with advanced breast cancer. In years to come, these discourses will most likely change as different societal conditions give rise to different discourses. In addition, I have provided only one 'truth' amongst many other possible truths. This thesis is not the last word on the topic of discourses shaping knowledge in the area of cancer care. I am also a producer of discourses, as are others who read and write in this area. I have merely constructed a discourse about discourses. As Foucault states, 'we are doomed historically to history, to the patient construction of discourses about discourses, and to the task of hearing what has already been said' (1973, p. xiv). Nevertheless, I have also offered to the reader views that have not already been said in the domain of young women and advanced breast cancer.

Finally, different types of texts work in different ways (Parker & Burman 1993, p. 158) and yet in this research, I have treated all the texts as the same and asked similar questions of all three data sets. For example, the professional medical texts are not accessible to all readers and the stories told by the young women disappear after some time. Yet, I was conscious that the texts were different and needed differing considerations. Nevertheless, in the end, I decided to treat the data sets in a similar fashion, as they were all written texts and not a mixture of pictures or film images.

#### **4. Areas for further research**

The areas for further research can be drawn from the limitations mentioned previously. The first area for further research concerns the scope of the literature used for data

analysis and the types of texts used. Examining broader publications such as magazines, film and other images may assist in seeing what discourses are being promoted and perpetuated in different types of texts. There is also the potential to interview editors and journalists of newspapers, medical texts and other publications to understand further why and how breast cancer in young women is currently being portrayed. Furthermore, focus groups of young women with all stages of breast cancer could be held to explore the discourses found in this research with the aim of raising awareness of how discourses constrain what can be said and by whom. This awareness raising is the first step in challenging the constraining nature of discourses. Through such an activity, there is the potential for the generation of new understandings of the experience of living with a life-limiting illness.

This research focused on a small but significant proportion of people who get breast cancer. Further discourse analytic research could be conducted on other marginalised groups within the breast cancer population such as single women, women without children, women in same-sex relationships, indigenous women, partners of young women, parents of young women, and men. There is also the potential for further research to explore other common cancers in young women such as cancer of the cervix and ovarian cancer. Comparisons could be made between different discourses being drawn upon by these groups of young women with the purpose of providing tailored information for each specific group. Finally, this research focused on discourses at one point in time. Further research could be conducted longitudinally to examine how discourses change over time and what conditions make these changes possible.

### ***5. Implications for practice***

Health care professionals in the area of cancer care come across young women diagnosed with advanced breast cancer from time to time. This research has shown that many of these young women will be concerned and confused about the meaning of probabilities and percentages that inform their prognoses. They will also be concerned with popular representations of the tragic hero and the need to reframe current understandings of this tragic genre. Finally, they will be concerned with looking normal and this includes body weight and shape. It is particularly difficult for young women to resist the lure of thinness and beauty, leading in many cases to the loss of self-image and subsequent depression. Cancer nurses and doctors in particular can be alert for these

concerns and assist in the process of refuting the various myths and misconceptions that cancer generates. We can reassure these women that they are not to blame for their poor prognoses, their incurable disease, their weight gain or their declining body. However, the cultural obsession of thinness, beauty, longevity and normality is so widespread that convincing each health care professional on their own will effect little difference at a societal level, unless we too have understood and resisted the claims made upon us by our consumer society. And while it is difficult to stand outside the various discourses shaping our lives, we can question them and if not serving us well, we can resist them. We can resist society's push for a utopian body and accept that imperfections are a sign of our shared humanity (Morris 1998, p. 163). We can also challenge the assumptions underlying these discourses and thereby challenge their claims of 'truth' (Burman & Parker 1993). The institutions of the media and medicine can be the site of these interventions and challenges. These challenges can offer up new possibilities for rethinking survivorship, tragedy and the body.

Health care professionals also need to view advanced breast cancer in young women in a more positive (and less tragic) light. Rather than viewing her body as declining, full of abjection and horror, we can come to realise that her body is more than its pathology and see it as a living body rather than a dying one (Dell & Papagiannidou 1999, p. 402). We can also take note of the discourses shaping the lives of those we care for and open up a space for conversations about sadness and despair, a space where alternative understandings of health and illness can be aired and previously silenced voices heard. We can promote alternative discourses, ones that offer different subject positions to those of self-responsibility and victimhood.

Finally, as health care professionals, we can provide patient information and clinical practice guidelines that incorporate the findings from this research, information that moves beyond simple solutions to common problems to one that raises awareness of the forces shaping and controlling our lives and the part that individuals play in this process.

### **6. Reflections on the research process**

In this research, I have been an active participant. My values and beliefs, shaped by my previous experiences concerning young women living with advancing disease were present as I selected, collated and analysed the texts. They were present in the interviews and can be seen in the sort of questions I asked of the data. I have also been actively involved in the writing up process and in the interpretations made. This participation did not make the research less rigorous, but it did mean that I have had to question the assumptions underpinning this research and for whom I was producing the knowledge:

We need to recognize our ambiguity, to be open about the dilemmas we face and the choices we make, and to think through the implications of these choices for the knowledge we produce. (Ribbens & Edwards 1998, p. 205)

One of the dilemmas I faced was the way that I controlled the analysis of the data. The young women did not want the transcripts back after the interview. Therefore, I took this control from the participants and perhaps disempowered them in the process. This was never my intention. It is a privileged place in which to be, to 'name and represent other people's realities' (Mauthner & Doucet 1998, p. 139). However, it is also a powerful one. I am not suggesting that I needed to have approached the data analysis differently; but I do need to acknowledge that in spite of not wanting it so, power differentials between the researcher and the researched existed in this project.

In addition, although I constantly struggled for it not to be so, I do acknowledge that the language used in this thesis will most likely exclude those young women outside academia who might want to access the findings of this research project. It was not my intention to alienate them, however as a beginning researcher enrolled in a PhD programme, I am bound by certain academic conventions relating to style and language. I have other audiences to consider. I also acknowledge, in a similar way to Kay Standing (1998), that the writing of this thesis will be unlikely to make any real difference to the lives of the young women I interviewed. No matter what I did or did not do, these women were still going to die before their time. This saddens me as I did not want to profit from their lives in anyway, yet accept that power differentials do exist even when the research is conducted by (me) a woman, on and for women. Yet, perhaps

I did create a space in which the young women could safely voice their current feelings of sadness and despair. A number of the young women did say that I was the only person thus far who they could speak to of these things. Outside of the private homes in which I conducted my interviews, it was perhaps difficult to fully hear their voices due to society's uncomfortableness with the juxtaposition of the notions of youth and death and matter out of place. Maybe, through retelling their stories, I can make this very private knowledge public and thereby reduce the mystery around such enterprises. This is indeed my hope.

### **7. Final thoughts**

Breast cancer in young women has come to the forefront at this point in time because these items, when coupled together, are newsworthy and appeal to many people in our community. Even if we never come across young women living with advanced breast cancer, it is inevitable that we will be affected in some way for we are part of a never-ending web of human connections.

No man is an island entire of itself; everyman is a piece of a continent, a part of the main. If a clod is washed away by the sea, Europe is the less, as well as if a promontory were, as well as if a manor of thy friend's or thine own were. Any man's death diminishes me, because I am involved in mankind. And therefore never send to know for whom the bell tolls: it tolls for thee. John Donne 1624, *Devotions Upon Emergent Occasions, Meditation XVII*. (Alford 1839)

As this well-known poem suggests, each young woman's life and death affects us. Their passing leaves all of us diminished in some way.

How can I bring what I have written here to a point of closure? To ask a question is to only bring up more questions, the deconstructing of one text only brings to light another. Rather than a closure, this way of viewing advanced breast cancer in young women offers up possibilities, a way of thinking beyond the surface, a way of looking beyond the obvious.

## **Epilogue**

A great deal of time has transpired since the commencement of this thesis. The professional medical literature continues to feature young women with breast cancer in all its stages. Newspapers continue to represent young women as tragic heroes involved in games of chance. The young women have either lived or died, yet they have all survived in one form or another - physically, psychically or spiritually - within the hearts and minds of those closest to them.

It does seem a lifetime ago since I wrote the prologue outlining why I chose this particular topic for further research. Sadly, my work as a nurse has had to cease due to injuries sustained in an accident some years ago. My professional identity has had to undergo a remodelling process yet I am grateful that I am not living with a life-limiting condition.

Even though much water has passed under the bridge, the stories that the women relayed to me and the content of the hundreds of journal and newspaper articles read stay with me to this day. Each time I hear or read of another young woman diagnosed with breast cancer, the voices of the young women I interviewed come back to haunt me. I wonder if I will ever forget. I hope not.



## APPENDICES

**Appendix 1: Chronological list of medical journals, content areas and titles**

Year	Title	Journal	Content
1997	Family history suggestive of an inherited susceptibility to breast cancer and treatment outcome in young women after breast-conserving therapy	International Journal of Radiation Oncology Biology Physics	Treatment and survival
1997	Influence of pregnancy on the outcome of breast cancer: A case-control study	International Journal of Cancer	Prognostic factors and survival
1997	Does pregnancy influence breast cancer outcome in young women?	International Journal of Radiation Oncology Biology Physics	Prognostic factors and survival
1997	Bisphosphonate risedronate prevents bone loss in women with artificial menopause due to chemotherapy of breast cancer: A double-blind, placebo-controlled study	Journal of Clinical Oncology	Treatment and related side effects
1997	Breast cancer in young women	ANZ journal of surgery	Prognostic factors
1997	Angiogenesis and estrogen receptor (ER) in young women with breast cancer	International Journal of Radiation Oncology Biology Physics	Prognostic factors
1997	Differential contributions of BRCA1 and BRCA2 to early-onset breast cancer	New England Journal of Medicine	Germ line mutations
1997	Is breast cancer in young women (<36 years) a more biologically aggressive tumour?	Pathology	Prognostic factors
1997	Pharmacokinetics of high-dose doxorubicin administered as a 6-h intravenous infusion in breast cancer patients	Bulletin du Cancer	Treatment
1997	Does breast conservation therapy in young women with breast cancer adversely affect local disease control and survival rate?	Breast	Treatment and survival
1997	The treatment decision-making process: age differences in a sample of women recently diagnosed with nonrecurrent early-stage breast cancer	Gerontologist	Treatment decision making differences
1997	Pregnancy decision making among women previously treated for breast cancer	Journal of Psychosocial Oncology	Pregnancy and breast cancer
1998	Long-term outcome in women less than 30 years of age with breast cancer	Journal of Surgical Oncology	Prognostic factors
1998	BRCA-associated breast cancer in young women	Journal of Clinical Oncology	Prognostic factors & germ line mutations
1998	C-erbB-2, p53, and nm23 gene product expression in breast cancer in young women: immunohistochemical analysis and clinicopathologic correlation	Human Pathology	Prognostic factors
1998	Intrusiveness of illness and quality of life in young women with breast cancer	Psycho-Oncology	Quality of Life & psychosocial factors
1998	Sources of support and the physical and mental well-being of young women with breast cancer	Psycho-Oncology	Support and quality of life
1998	Family history and treatment outcome in young women after breast-conserving surgery and radiation therapy for early-stage breast cancer	Journal of Clinical Oncology	Family history, treatment and survival
1998	Does prior pregnancy influence breast cancer outcome in young women?	European Journal of Cancer	Prognostic factors and pregnancy
1998	Long-term outcome in women less than 30 years of age with breast cancer	Journal of Surgical Oncology	Prognostic factors and survival
1998	A close or positive margin after mastectomy is not an indication for chest wall irradiation except in women aged fifty or younger	International Journal of Radiation Oncology Biology Physics	Treatment and recurrence

Year	Title	Journal	Content
1998	Marker panel predictive of lymph node metastasis in young patients with breast carcinoma	International Journal of Surgical Pathology	Prognostic factors
1998	Women 35 years of age or younger have higher locoregional relapse rates after undergoing breast conservation therapy	Journal of the American College of Surgeons	Treatment and recurrence
1998	Relation of time since last birth and parity to survival of young women with breast cancer	Epidemiology	Prognostic factors and survival
1998	Pregnancy after breast cancer. The relationship of pregnancy to breast cancer development and progression	Critical Reviews in Oncology Hematology	Prognostic factors
1998	Age as a prognostic factor in breast cancer	Anticancer Research	Prognostic factors
1999	Survival in hereditary breast cancer associated with germline mutations of BRCA2	Journal of Clinical Oncology	Survival/ prognosis in hereditary breast cancer
1999	Mutation-specific survival of inherited breast cancer	Disease Markers	Survival/ prognosis in hereditary breast cancer
1999	Breast cancer in pregnancy	Surgical Clinics of North America	Pregnancy associated breast cancer
1999	The influence of familial and hereditary factors on the prognosis of breast cancer	Annals of Oncology	Survival/ prognosis in hereditary breast cancer
1999	p53 and survival in early onset breast cancer: Analysis of gene mutations, loss of heterozygosity and protein accumulation	European Journal of Cancer	Prognostic factors in hereditary breast cancer
1999	Breast cancer in young women: clinicopathologic correlation	Seminars in Diagnostic Pathology	Prognostic factors
1999	The influence of familial and hereditary factors on the prognosis of breast cancer	Annals of Oncology	Prognostic factors in hereditary breast cancer
1999	Genetic alterations in early-onset invasive breast cancers: Correlation of c-erbB-2 amplification detected by fluorescence in situ hybridization with p53 accumulation and tumor phenotype	International Journal of Cancer	Tumour markers and prognosis
1999	Breast cancer and pregnancy	Surgical Clinics of North America	Pregnancy associated breast cancer
1999	Frequent allelic losses at 11q24.1-q25 in young women with breast cancer: association with poor survival	British Journal of Cancer	Genetic alterations and prognosis
1999	p53 and survival in early onset breast cancer: Analysis of gene mutations, loss of heterozygosity and protein accumulation	European Journal of Cancer	Genetic alterations and prognosis
1999	Aetiology-specific effect of premature ovarian failure on bone mass - is residual ovarian function important?	Clinical Endocrinology	Treatment related side effects
1999	Mutation-specific survival of inherited breast cancer	Disease Markers	Prognostic factors in hereditary breast cancer
1999	Age-related distress among young women with breast cancer	Journal of Psychosocial Oncology	Psychosocial factors
1999	Survival in hereditary breast cancer associated with germline mutations of BRCA2	Journal of Clinical Oncology	Germ line mutations and survival
1999	Major concerns and needs of breast cancer patients	Cancer Nursing	Psychosocial concerns
1999	Offering a choice between two adjuvant chemotherapy regimes: a pilot study to develop a decision aid for women with breast cancer	Patient Education and Counseling	Educational intervention and treatment choices
2000	Prognostic significance of germline BRCA2 mutations in hereditary breast cancer	Journal of Clinical Oncology	Survival/ prognosis in hereditary breast cancer
2000	BRCA1 mutations and clinicopathological features in a sample of Italian women with early onset breast cancer	European Journal of Cancer	Survival/ prognosis in hereditary breast cancer

Year	Title	Journal	Content
2000	Life expectancy gains from cancer prevention strategies for women with breast cancer & BRCA1 or BRCA2 mutations	JAMA	Prevention of secondary cancers/ BRCA1 & BRCA2
2000	Optimum treatment for young women with breast cancer needs to be determined	British Medical Journal	Treatment
2000	BRCA1, C-erbB-2, and H-ras gene expressions in young women with breast cancer - An immunohistochemical study	Applied Immunohistochemistry & Molecular Morphology	Prognostic factors
2000	Serum levels of C-erbB-2 in young women bearing breast cancer	Annals of Oncology	Prognostic factors
2000	Frequency of BRCA1/BRCA2 mutations in a population-based sample of young breast carcinoma cases	Cancer	Breast cancer and germ line mutations
2000	Factors influencing the effect of age on prognosis in breast cancer: population based study	British Medical Journal	Prognostic factors
2000	Breast cancer in young women: Prevalence of LOH at p53, BRCA1 and BRCA2	Journal of Pathology	Prognostic factors
2000	Loss of heterozygosity in bilateral breast cancer	Breast Cancer Research and Treatment	Breast cancer and germ line mutations
2000	Family history in breast cancer is not a prognostic factor	Breast	Prognostic factors
2000	Stage 0 to stage III breast cancer in young women	Journal of the American College of Surgeons	Clinical features and prognosis
2000	Relationships between age, mammographic features and pathological tumour characteristics in non-palpable breast cancer	British Journal of Radiology	Prognostic factors
2000	Management of the contralateral breast in patients with hereditary breast cancer	Breast	Treatment
2000	Young women's experience of breast cancer: Defining young and identifying concerns	Psycho-Oncology	Experience of disease
2000	Breast cancer in women <= 35 years: Review of 1002 cases from a single institution	Annals of Oncology	Clinical features and prognosis
2000	Surveillance, survival and palliative care: a discourse analysis of advanced breast cancer and young women	Psycho-Oncology	Experience of disease
2000	Breast cancer in women <= 35 years: Review of 1002 cases from a single institution	Breast Cancer Research and Treatment	Prognostic factors
2000	Is chemotherapy alone adequate for young women with oestrogen-receptor-positive breast cancer?	Lancet	Treatment
2000	Quality of life, survivorship, and psychosocial adjustment of young women with breast cancer after breast-conserving surgery and radiation therapy	Oncology Nursing Forum	Quality of life and psychosocial issues
2001	Ovarian failure after adjuvant chemotherapy is associated with rapid bone loss in w. with early-stage	Journal of Clinical Oncology	Treatment and long term side .effects
2001	The management of menopausal sequelae in patients with breast cancer	Clinical Oncology	Treatment and premature menopause
2001	Biophenotypes and survival of BRCA1 and TP53 deleted breast cancer in young women	Breast Cancer Research and Treatment	Prognostic factors and hereditary
2001	Tumor markers of prognosis in 934 young women with breast cancer	Breast Cancer Research and Treatment	Prognostic factors
2001	Sex of first child and breast cancer survival in young women	Journal of Women's Health & Gender-based Medicine	Prognostic factors
2001	The impact of age on local control in women with pT1 breast cancer treated with conservative surgery and radiation therapy	European Journal of Cancer	Prognostic factors
2001	Deletion mapping of chromosome segment 11q24-q25, exhibiting extensive allelic loss in early onset breast cancer	International Journal of Cancer	Breast cancer and germ line mutations
2001	Sources of support and the physical and mental well-being of young women with breast cancer	Social Science & Medicine	Psychosocial factors/ support
2001	Is breast cancer in young Latinas a different disease?	American Journal of Surgery	Prognostic factors

Year	Title	Journal	Content
2001	Frequency of loss of heterozygosity (LOH) of metastasis-related tumor suppressor genes in y. women w breast cancer	Laboratory Investigation	Breast cancer and germ line mutations
2001	Relation of body mass index to tumor markers and survival among young women with invasive ductal breast carcinoma	Cancer	Prognostic factors
2002	Genetic and histologic features of breast cancer in young women	European Journal of Cancer	Breast cancer and germ line mutations
2002	Presumed benefit: lessons from the American experience with marrow transplantation for breast cancer	British Medical Journal	Treatment
2002	Immunohistochemical features of early br. C. in young women; a translational research project using high-throughput tissue microarray technology	European Journal of Cancer	Technology
2002	Incidence and prognosis in early onset breast cancer	Breast	Prognostic factors
2002	Does family history influence survival of breast cancer patients?	International Journal of Cancer	Survival/ prognosis in hereditary breast cancer
2002	Long-term prognosis of teenagers with breast cancer	International Journal of Surgical Pathology	Prognostic factors
2002	Cancer and pregnancy: the obstetrician's standpoint	Bulletin Du Cancer	Pregnancy associated breast cancer
2002	Heritable breast cancer in twins	British Journal of Cancer	Breast cancer and germ line mutations
2002	Frequent loss of BRCA1 nuclear expression in young women with breast cancer.: an immunohistochemical study from an area of low incidence but early onset	Applied Immunohistochemistry & Molecular Morphology	Breast cancer and germ line mutations
2002	Breast cancer management 11. Breast cancer in young women	International Journal of Clinical Practice	Treatment and prognostic factors
2002	Breast cancer in young women: Prevalence of LOH at p53, BRCA1 and BRCA2	International Journal of Cancer	Breast cancer and germ line mutations
2002	Breast cancer racial differences before age 40 - Implications for screening	Journal of the National Medical Association	Racial differences and breast cancer
2002	The relation of reproductive factors to mortality from breast cancer	Cancer Epidemiology Biomarkers & Prevention	Prognostic factors
2002	Very young women (< 35 years) with operable breast cancer: features of disease at presentation	Annals of Oncology	Clinical features and prognosis
2002	The value of adjuvant treatment in young women with breast cancer	Drugs	Treatment and long term side effects/ infertility
2002	Preservation of fertility and ovarian function and minimalization of chemotherapy associated gonadotoxicity and premature ovarian failure: the role of inhibin-A and -B as markers	Molecular & Cellular Endocrinology	Treatment and long term side effects/ infertility
2002	Is reduction of high local recurrence rate in young women possible?	European Journal of Cancer	Prognostic factors
2002	Management of premenopausal women with early stage breast cancer: is there a role for ovarian suppression?	Clinical Breast Cancer	Treatment
2002	Young age as an adverse prognostic factor in premenopausal women with operable breast cancer	Clinical Breast Cancer	Prognostic factors
2002	I used to be stunning and slim: advanced breast cancer in young women	Australian Journal of Cancer Nursing	body weight
2003	Breast cancer in young women (<= 35 years): Genomic aberrations detected by comparative genomic hybridization	International Journal of Cancer	Breast cancer and germ line mutations
2003	An evaluation of support groups for young women with early breast cancer	Psycho-Oncology	Psychosocial factors/ support
2003	Breast cancer in young women: clinicopathological features and biological specificity	Breast	Clinical features and prognosis
2003	Racial/ethnic variation in clinical presentation, treatment, and survival among breast cancer patients under age 35	Cancer	Racial differences and breast cancer

Year	Title	Journal	Content
2003	Breast cancer in adolescents and young women	European Journal of Cancer	Prognostic factors and treatment
2003	Breast cancer in women younger than 40 years	International Journal of Fertility and Women's Medicine	Prognostic & Psychosocial factors/ support/ information of an action group
2003	The prognostic impact of hormone receptors & c-erbB-2 in pregnancy-associated breast cancer and their correlation with BRCA1 & cell cycle modulators	International Journal of Surgical Pathology	Prognostic factors and pregnancy related breast cancer
2003	New data on chemotherapy in the adjuvant setting	Breast	Prognostic factors and treatment
2003	A web-based survey of fertility issues in young women with breast cancer	Breast cancer research and treatment	Treatment and long term side effects/ infertility/ information needs
2003	Longevity after early surgical menopause-the long-term effect of a permanent cessation of reproductive function & female sex hormone loss	European J. of Obstetrics, Gynaecology, & Reproductive Biology	Treatment and premature menopause & Survival
2003	Prognostic factors affecting survival and disease-free survival in lymph node-negative breast carcinomas	Journal of Surgical Oncology	Prognostic factors
2003	Prognostic influence of pregnancy before, around, and after diagnosis of breast cancer	Breast	Prognostic factors & pregnancy related breast cancer
2003	The value of a positive margin for invasive carcinoma in breast-conservative treatment in relation to local recurrence is limited to young women only	International J. of Radiation Oncology, Biology, Physics	Treatment and survival/prognosis
2003	Nothing Fit Me: cross-Canada consultations of the information and support needs of young women with breast cancer	Psycho-Oncology	Psychosocial factors/ support/information of support group
2003	Counting the costs of treatment: the reproductive and gynaecological consequences of adjuvant therapy in young women with breast cancer	Internal Medicine Journal	Treatment and side effects/ infertility & premature menopause
2003	Fenretinide breast cancer prevention trial: Drug and retinol plasma levels in relation to age and disease outcome	Cancer Epidemiology Biomarkers & Prevention	Prevention of secondary breast cancers
2003	Breast cancer in young women: problems and questions	Pathologie Biologie	Prognostic factors and treatment
2003	Prevalence of BRCA1 and BRCA2 germ line mutations in young breast cancer patients: a population-based study	International Journal of Cancer	Breast cancer and germ line mutations
2004	Reproductive history and mortality after breast cancer diagnosis	Obstetrics and Gynecology	Prognostic factors & recent pregnancy
2004	BC mortality patterns and time trends in 10 new EU member states: mortality declining in young women, but still increasing in the elderly	International Journal of Cancer	Incidence and mortality rates
2004	Laparoscopic fertility preservation	Obstetrics and Gynecology Clinics of North America	Preserving fertility
2004	Ipsilateral breast tumour recurrence in hereditary breast cancer following breast-conserving therapy	European Journal of Cancer	Prognostic factors and hereditary & Treatment
2004	Childbirth and breast cancer prognosis	International Journal of Cancer	Prognostic factors & pregnancy
2004	What is the role of ovarian ablation in the management of primary and metastatic breast cancer today?	Oncologist	Treatment and prognosis

Year	Title	Journal	Content
2004	Prognosis of premenopausal breast cancer and childbirth prior to diagnosis	Journal of Clinical Oncology	Prognostic factors and pregnancy
2004	Web-based survey of fertility issues in young women with breast cancer	Journal of Clinical Oncology	Treatment and long term side effects/infertility/information needs
2004	Psychosocial functioning in women who have undergone bilateral prophylactic mastectomy	Psycho-Oncology	Psychosocial factors and treatment
2004	Allelic variation of BAT-25 and BAT-26 mononucleotide repeat loci in tumours from a group of young women with breast cancer	International Journal of Oncology	Breast cancer and germ line mutations
2004	Functional impact of breast cancer by age at diagnosis	Journal of Clinical Oncology	Psychosocial factors and quality of life
2004	Young age: an independent risk factor for disease-free survival in women with operable breast cancer	BMC Cancer	Prognostic factors
2004	Breast cancer in young women: what's different and what should we do about it?	Breast Cancer Research and Treatment	Prognostic factors and treatment
2004	Protein intake and breast cancer survival among young women	Cancer Epidemiology Biomarkers & Prevention	Survival
2004	Frequency of CHEK2 mutations in a population based, case-control study of breast cancer in young women	Breast Cancer Research	Breast cancer & germ line mut.
2004	The diagnosis of breast cancer on women younger than 40	Breast	Prognostic factors and diagnosis
2004	Breast cancer in young women aged 35 or less	Journal of Clinical Oncology	Prognostic factors
2004	Body mass index as a prognostic feature in operable breast cancer: the International Breast Cancer Study Group	Annals of Oncology	Prognostic factors & treatment
2004	Age-specific detriments to quality of life among breast cancer patients one year after diagnosis	European Journal of Cancer	Psychosocial factors and quality of life
2004	Trends in breast cancer presentation and care according to age in a single institution	American Journal of Surgery	Prognostic factors and treatment
2004	Obesity and breast cancer survival among young women	American Journal of Epidemiology	Prognostic factors and survival
2004	Patterns of weight and body composition change in premenopausal women with early stage breast cancer	Cancer Nursing	Side effects
2004	Adjuvant therapy for very young women with breast cancer: response according to biologic and endocrine features	Clinical Breast Cancer	Treatment
2005	Factors affecting outcome for young women with early stage invasive breast cancer treated with breast-conserving therapy (BCT)	International J of Radiation Oncology Biology Physics	Treatment and survival/prognosis
2005	Depression experienced by young women newly diagnosed with breast cancer	Psycho-Oncology	Psychosocial factors
2005	The role of ovarian ablation in the management of breast cancer	Breast Journal	Treatment/ovarian ablation and early menopause
2005	The fertility - and menopause-related information needs of young women with a diagnosis of early-stage breast cancer	Journal of Clinical Oncology	Treatment & long term side effects/infertility/information needs/early men
2005	Multiple births and breast cancer prognosis: A population based study	European Journal of Epidemiology	Breast cancer/birth/survival/prognostic factors
2005	Subsequent surgery after initial breast conserving surgery: a population based study	ANZ Journal of Surgery	Treatment outcomes
2005	Disparities in surgical treatment of breast cancer in young women	Annals of Surgical Oncology	Treatment outcomes

Year	Title	Journal	Content
2005	Fertility in female cancer survivors: pathophysiology, preservation and the role of ovarian reserve testing	Human Reproductive Update	Treatment and preservation of fertility
2005	Fertility preservation options for female patients with malignancies	Current Opinion in Obstetrics & Gynecology	Nature Clinical Practice Oncology
2005	LH-RH analogues, tailored adjuvant chemo & total estrogenic block in patients with (ER+) tumors, preserve ovarian function & improve the clinical outcomes of young women with early breast cancer	Breast Cancer Research and Treatment	Treatment outcomes
2005	Survival of young and older breast cancer patients in Geneva from 1990 to 2001	European Journal of Cancer	Prognostic factors
2005	Breast cancer in young women age < 36 years: a retrospective analysis of prognostic factors in 908 patients in 8 French institutions. GETNA Group	Breast Cancer Research and Treatment	Prognostic factors
2005	Fertility after breast cancer: Questions abound	Journal of Clinical Oncology	Treatment & long term side effects/infertility/information needs
2005	Young women's preferences about adjuvant endocrine therapy for breast cancer	Lancet Oncology	Treatment
2005	Molecular profile and clinical variables in BRCA1-positive breast cancers. A population-based study	Tumori	Breast cancer and germ line mutations
2005	HER-2/neu and p53 overexpression as biomarkers of breast carcinoma in women age 30 years and younger	Cancer	Prognostic factors
2005	Understanding delay in breast cancer diagnosis in diverse young women	Oncology Nursing Forum	Prognostic factors
2005	Obesity and outcomes in premenopausal and postmenopausal breast cancer (Australian study)	Cancer Epidemiology Biomarkers & Prevention	Prognostic factors
2005	Effect of reproductive factors on stage, grade and hormone receptor status in early-onset breast cancer	Breast Cancer Research	Prognostic factors & pregnancy
2005	Weight, weight gain, and survival after breast cancer diagnosis	Journal of Clinical Oncology	Prognostic factors and survival
2005	Follow-up and sexual counseling for young women after breast cancer treatment	International Journal of Fertility & Women's Medicine	Treatment & long term side effects/infertility/information needs
2005	Influence of exercise activity on quality of life in long-term breast cancer survivors	Quality of Life Research	Psychosocial factors and quality of life
2005	Breast cancer characteristics and 10 year survival in young women	Breast Cancer Research and Treatment	Clinical features and prognosis
2005	Is age at diagnosis an independent prognostic factor for survival following breast cancer?	ANZ Journal of Surgery	Prognostic factors
2005	Long term effects of hysterectomy on mortality: nested cohort study	British Medical Journal	Prognostic factors
2005	Hormone receptors do not predict the HER2/neu status in all age groups of women with an operable breast cancer	Annals of Oncology	Prognostic factors
2005	Breast cancer in young women age < 36 years: A retrospective analysis of prognostic factors in 926 patients in 8 French institutions. GETNA group	Journal of Clinical Oncology	Prognostic factors
2005	Breast cancer in young Asian women: Study on survival	ANZ Journal of Surgery	Prognostic factors and survival
2005	Discussions regarding reproductive health for young women with breast cancer undergoing chemotherapy	Journal of Clinical Oncology	Treatment & long term side effects/infertility/information needs/early menopause
2005	Early stage breast cancer in young women: does selection of surgical treatment impact overall survival?	Breast Cancer Research and Treatment	Treatment and survival

Year	Title	Journal	Content
2005	Impact of news of celebrity illness on breast cancer screening: Kylie Minogue's breast cancer diagnosis	Medical Journal of Australia	Breast cancer and the media
2005	Contribution of BRCA1 and BRCA2 germ-line mutations to incidence of breast cancer in young women: Results from prospective population-based study in France	Gene Chromosomes & Cancer	Breast cancer and germ line mutations
2005	Neoadjuvant vs. adjuvant chemotherapy: young women's experiences, attitudes and information needs after diagnosis	Breast Cancer Research and Treatment	Treatment, experiences, attitudes and information needs
2005	Depression in young women with early stage of breast cancer study from Eastern India	European Journal of Cancer Supplements	Psychosocial factors
2005	Special issues related to the adjuvant therapy in very young women	Breast	Prognostic factors and treatment and survival
2005	Chemoendocrine therapy for premenopausal women with axillary lymph node-positive, steroid hormone receptor-positive breast cancer: results from INT 0101 (E5188)	Journal of Clinical Oncology	Treatment
2005	Sexual dysfunction related to the treatment of young women with breast cancer	Clinical Journal of Oncology Nursing	Treatment side effects
2005	Breast cancer in young women... eighth article	Australian Family Physician	Psychosocial and physical challenges
2006	Breast cancer diagnosis in women <= 40 versus 50 to 60 years: Increasing size and stage disparity compared with older women over time	Annals of Surgical Oncology	Prognostic factors
2006	Fifteen-year results of a randomized phase III trial of fenretinide to prevent second breast cancer	Annals of Surgical Oncology	Prevention of secondary cancers
2006	The preferred treatment for young women with breast cancer - mastectomy versus breast conservation	Breast	Treatment
2006	Anticancer treatment and fertility effects. Literature review	Journal of Experimental & Clinical Cancer Research	Treatment and infertility
2006	Cyclin E overexpression and breast cancer among young women	Cancer Epidemiology Biomarkers & Prevention	Prognostic factors
2006	Developing an integral model for a cancer support programme	Psycho-Oncology	Psychosocial factors
2006	Fertility preservation in young women undergoing breast cancer therapy	Oncologist	Treatment and fertility preservation
2006	Coexpression of her-2/neu and p53 in breast cancer identifies a subset with an aggressive biopathological profile	Tumori	Prognostic factors
2006	Correlation of HER-2/neu overexpression with mammography and age distribution in primary breast carcinomas	Academic Radiology	Prognostic factors
2006	Pregnancy and breast cancer: the other side of the coin	Cancer Cell	Prognostic factors & pregnancy
2006	Can ovarian function be protected in young women receiving chemotherapy?	Nature Clinical Practice Oncology	Fertility preservation
2006	Outcomes in young women with breast cancer of triple-negative (TN) phenotype: The prognostic significance of CK19 expression	International Journal of Radiation Oncology Biology Physics	Prognostic factors
2006	Is anthracycline-based chemotherapy alone adequate for young women with estrogen receptor-positive breast cancer?	Breast	Treatment and survival
2006	Infiltrating breast cancer in women younger than 25 years: 73 cases	Presse Medicale	Prognostic factors
2006	Role of endocrine responsiveness and adjuvant therapy in very young women (< 35 years) with operable breast cancer and node negative disease	Journal of Clinical Oncology	Treatment

Year	Title	Journal	Content
2006	Analysis of incidence and prognostic factors for ipsilateral breast tumour recurrence and its impact on disease-specific survival of women with node-negative breast cancer: a prospective cohort study	Breast Cancer Research	Prognostic factors and survival
2006	Reproduction beyond cancer: A message of hope for young women	Gynecologic Oncology	Treatment and infertility
2006	BRCA1-positive breast cancers in young women from Poland	Breast Cancer Research and Treatment	Breast cancer and germ line mutations
2006	Menopausal-type symptoms in young breast cancer survivors	Annals of Oncology	Treatment and menopause/information needs
2006	Differential expression of prognostic factors and effect on survival in young (< or =40) breast cancer patients: a case-control study	American Surgeon	Prognostic factors
2006	Breast cancer treatment - later pregnancy and survival	European Journal of Gynaecological Oncology	Treatment, pregnancy and survival
2006	Racial diffs in incidence of BRCA1 and BRCA2 mutations in a cohort of early onset breast cancer patients: African American compared to white women	Journal of Medical Genetics	Germ line mutations and racial differences
2006	'Nothing fit me': nationwide consultations with young women with breast cancer	Health Expectations	Psychosocial factors & support/information needs
2006	Tumour characteristics and adjuvant treatment in very young women (< 35 years) with early breast cancer (EBC). A multicenter retrospective study	Annals of Oncology	Treatment and prognostic factors
2006	Body image and sexual problems in young women with breast cancer	Psycho-Oncology	Treatment, body image and sexual difficulties
2006	Breast carcinoma in women 35 years and younger: a pathological study	Pathology	Prognostic features
2006	Infertility and pregnancy after breast cancer: current knowledge and future perspectives	Cancer Treatment Reviews	Treatment and fertility preservation
2006	Issues and concerns of young Australian women with breast cancer	Supportive Care in Cancer	Support/information needs
2006	Role of endocrine responsiveness and adjuvant therapy in very young women (< 35 years) with operable breast cancer and node negative disease	Annals of Oncology	Treatment factors and prognosis
2006	Familiar and personal characteristics of very young women (< 35) with early breast cancer (BC). Result of a retrospective, multicenter study	Annals of Oncology	Prognostic factors
2006	Obesity and prognosis of breast cancer	Obesity Reviews	Prognostic factors
2006	Symptoms and treatment in cancer therapy-induced early menopause	Oncologist	Treatment and menopause
2006	Adjuvant hormonal therapy for premenopausal women with breast cancer	Seminars in Oncology	Treatment
2006	General and abdominal obesity and survival among young women with breast cancer	Cancer Epidemiology Biomarkers & Prevention	Prognostic factors
2006	Tamoxifen after adjuvant chemotherapy for premenopausal women with lymph node-positive breast cancer: International Breast Cancer Study Group Trial 13-93	Journal of Clinical Oncology	Treatment
2006	Preliminary results on safety and activity of a randomized, double-blind, 2 x 2 trial of low-dose Tamoxifen & Fenretinide for breast cancer prevention in premenopausal women	Journal of Clinical Oncology	Treatment
2006	A qualitative analysis of reproductive issues raised by young Australian women with breast cancer	Health Care for Women International	Treatment and infertility
2007	Large genomic alterations in BRCA1 in young women with breast cancer participating in the breast cancer family registry	Breast Cancer Research and Treatment	Germ line mutations

Year	Title	Journal	Content
2007	Locoregional recurrence rates in young women with breast cancer by treatment approach	International Journal of Radiation Oncology Biology Physics	Metastatic disease
2007	Intratymoral IGF-I protein expression is selectively upregulated in breast cancer patients with BRCA1/2 mutations	Endocrine-Related Cancer	Germ line mutations/ endocrine related
2007	Ovarian function and childbearing issues in breast cancer survivors	Gynecological Endocrinology	Treatment and pregnancy
2007	A comparative study of Korean with Caucasian breast cancer reveals frequency of methylation in multiple genes correlates with breast cancer in y, ER, PR-negative breast cancer in Korean women	Cancer Biology & Therapy	Prognostic factors and racial differences
2007	Intervention study investigating the benefits of young women (20-45 years) with breast cancer participating in a residential, psycho-educational program of support	Psycho-Oncology	Psychosocial factors and support
2007	Breast cancer and fertility: making hard choices easier - The development and evaluation of fertility-related decision aid for young women with early breast cancer	Psycho-Oncology	Australian study, Fertility and information needs
2007	Factors affecting outcome for young women with early stage invasive breast cancer treated with breast-conserving therapy	Breast Cancer Research and Treatment	Treatment and survival
2007	Factors associated with anxiety and depression in young women recently diagnosed with breast cancer	Psycho-Oncology	Psychosocial factors
2007	Large genomic alterations in BRCA1 in young women with breast cancer participating in the breast cancer family registry	Breast Cancer Research and Treatment	Germ line mutations
2007	Predictors of ovarian reserve in young women with breast cancer	British Journal of Cancer	Infertility and ovarian reserve & treatment
2007	Young women with breast cancer: A meta-analysis of age differences across quality of life domains	Psycho-Oncology	Quality of life
2007	Age of menopause among w. who remain premenopausal following treatment for early bcr: Long-term results from International Breast Cancer Study Group Trials V and VI	European Journal of Cancer	Treatment and early menopause
2007	Absence of conclusive evidence for safety and efficacy of gonadotropin-releasing hormone analogue treatment in protecting against chemotherapy-induced gonadal injury	Oncologist	Fertility preservation
2007	I'm pregnant and I have breast cancer	BMC Cancer	Breast cancer and pregnancy
2007	Egg retrieval with cryopreservation does not delay breast cancer treatment	American Journal of Surgery	Fertility and egg retrieval
2007	Adjuvant endocrine treatment of early breast cancer	Hematology - Oncology Clinics of North America	Treatment
2007	Multifocal breast cancer in women <= 35 years old	Cancer	Prognostic factors
2007	Differences in outcome for positive margins in a large cohort of breast cancer patients treated with breast-conserving therapy	Acta Oncologica	Treatment and survival
2007	Chemotherapy-induced female infertility and protective action of gonadotropin-releasing hormone analogues	Journal of Obstetrics and Gynaecology	Treatment and fertility preservation
2007	Breast cancer and climacteric complaints: Weighing up risks of hormone therapy against quality of life	European J. of Obstetrics Gynecology & Reproductive Biology	Menopause treatment
2007	Young women's experiences with breast cancer: An imperative for tailored services	Oncology Nursing Forum	Experience of breast cancer & information and support needs

Year	Title	Journal	Content
2007	Prospective study of outcomes in sporadic versus hereditary breast cancer (POSH): study protocol	BMC Cancer	Germ line mutations
2007	CDKN2A-positive breast cancers in young women from Poland	Breast Cancer Research and Treatment	genetics
2007	Providing psychosocial group support for young women with breast cancer: findings from a wellness-based community collaboration	Journal of Psychosocial Oncology	Psychosocial factors and support and quality of life
2007	Is mastectomy superior to breast-conserving treatment for young women?	International Journal of Radiation Oncology, Biology, Physics	Treatment and survival
2007	Insights on adjuvant endocrine therapy for premenopausal and postmenopausal breast cancer	Expert Review of Anticancer Therapy	Treatment
2007	Prognosis of early-onset breast cancer based on BRCA1/2 mutation status in a French population-based cohort and review	Breast Cancer Research and Treatment	Prognostic factors and germ line mutations
2007	How to preserve fertility in young women exposed to chemo? The role of GnRH agonist cotreatment in addition to cryopreservation of embryo, oocytes, or ovaries	Oncologist	Fertility preservation
2007	A web-based expressive writing intervention for young women with newly diagnosed breast cancer	Oncology Nursing Forum	Psychosocial factors and support
2007	Spectrum of breast cancer in Asian women	World Journal of Surgery	Incidence rates and prognostic factors in Asia
2007	Treatment of premenopausal women with early breast cancer - old challenges and new opportunities	Drugs	Treatment
2007	Horner's syndrome as an initial sign of metastatic breast cancer: case report	Cancer Detection and Prevention	Metastatic disease
2007	Effects of Fulvestrant 250 mg in premenopausal women with oestrogen receptor-positive primary breast cancer	European Journal of Cancer	Treatment
2007	Zoledronic Acid prevents cancer treatment-induced bone loss in premenopausal women receiving adjuvant endocrine therapy for hormone-responsive breast cancer	Journal of Clinical Oncology	Treatment
2007	Breast cancer survival and tumor characteristics in premenopausal women carrying the CHEK2*1100delC germline mutation	Journal of Clinical Oncology	Germ line mutation and prognosis
2008	Treatment of breast cancer with trastuzumab during pregnancy	Journal of Clinical Oncology	Treatment and pregnancy
2008	A pilot study of predictive markers of chemotherapy-related amenorrhea among premenopausal women with early stage breast cancer	Cancer Investigation	Treatment side effects
2008	Fertility and menopausal outcomes in young breast cancer survivors	Clinical Breast Cancer	Fertility and menopause
2008	Survival after adjuvant oophorectomy and tamoxifen in operable breast cancer in premenopausal women	Journal of Clinical Oncology	Treatment and survival
2008	Endocrine effects of adjuvant Letrozole + Triptorelin compared with Tamoxifen + Triptorelin in premenopausal patients with early breast cancer	Journal of Clinical Oncology	Treatment

## **Appendix 2: List of Newspapers and coding schema**

Coding procedures for the analysis of content adapted from (Shiel 1999)

### **Part 1: General information concerning articles selected**

1. Identification number
2. Publication (Readership figures 2007- [000's])<sup>28</sup> (number of articles)<sup>29</sup>
  - a. The Australian/Weekend Australian [1723], (31)
  - b. The Australian Magazine [included in the above figures]
  - c. Daily Telegraph (NSW) [1158], (48)
  - d. Sunday Telegraph (NSW) [1785], (11)
  - e. Sunday Telegraph Magazine (NSW) [included in the figure above], (1)
  - f. The Sun VIC old – not included, outside date range
  - g. The Herald Sun (VIC) [1467], (27)
  - h. Sunday Herald (VIC) old – not included, outside date range
  - i. Sunday Herald Sun Magazine [1532], (1)
  - j. Sunday Herald Sun (VIC) [included in the above figure], (20)
  - k. (The Weekly Times (VIC) omitted, local paper
  - l. The Advertiser (SA) [542], (22)
  - m. The Sunday Mail (QLD) [1473], (11)
  - n. The Courier Mail (QLD) [614], (24)
  - o. The Sunday Mail (SA) [739], (8)
  - p. Q Weekend (QLD) [this figure included in 'n' above], (2)
  - q. The Mercury (TAS) [281], (8)
  - r. Sunday Tasmanian (TAS) [142], (2)
  - s. Northern Territory News/ Sunday Territorian (NT) [NA], (8)
  - t. The Centralian Advocate (NT) [NA], (1)
  - u. Homes Magazine (WA) [NA], (0)
  - v. Sunday Magazine (WA) [NA], (0)
  - w. Sunday Times (WA) [840], (5)

**Total number of articles = 230**

3. Date
4. Page Number
5. Photo
  - a. Featuring a particular young woman (women) or woman (women) with breast cancer
  - b. Other photo
  - c. None
6. Headline (Actual Words)
7. Headline Tone
  - a. Neutral or Ambiguous: Can't tell from the headline what the article is about
  - b. Optimistic- hopeful for good. An uplifting statement or a positive outcome

<sup>28</sup> Readership figures are larger than circulation figures because usually a paper is read by more than one person. (Herman 2007). I have used readership figures rather than circulation figures here.

<sup>29</sup> The number in brackets ( ) after the readership figures is the number of articles from each particular newspaper.

- c. Negative, critical or discreditory of something or someone
- d. Sensational- aimed at grabbing attention, a warning or caution.
- e. Poignant – sad
- f. Directive- urging a course of action strongly

## ***Part 2 Referring to the content of the article***

1. Breast cancer statistics
  - a. Incidence
  - b. Mortality
  - c. Probabilities or percentages
  - d. None
  
2. Source of information in 1
  - a. Government agency or cancer registry or politician
  - b. Medical Expert(s)
  - c. Research
  - d. Not mentioned
  - e. Individual
  
3. Risk factors for breast cancer
  - a. Weight gain – especially after menopause
  - b. Pill usage or Hormone replacement therapy
  - c. Abortion
  - d. Smoking/drinking
  - e. Lack of exercise
  - f. Family history involving genetic factors such as BRCA1 or BRCA2
  - g. Increasing age/gender
  - h. Country of birth i.e. Women living in Japan have a decreased risk
  - i. Hormonal factors - age of menarche, menopause, first pregnancy/HRT
  - j. Diet
  - k. Psychosocial factors - negative thinking
  - l. Affluence
  - m. Decreasing risk such as using phyto-oestrogens
  - n. Not mentioned
  - o. Environmental exposure factors - radiation, cosmetics, hair products
  - p. Previous cancer diagnosis
  
4. Legal case(s) cited or inferred
  - a. Missed lump, misdiagnosis or some other form of medical negligence (not following up a positive pathology report
  - b. Doctors fearing litigation
  - c. Guideline use and fear of litigation
  
5. Early Detection
  - a. Breast self-examination
  - b. Screening mammography for women with no symptoms aimed at women >50
  - c. Infers/mentions early detection increases survival
  - d. Women over 50 should attend screening programme every two years- free
  - e. Women over 40 can attend on request
  - f. Breast Screen Australia mentioned

- g. Number of BSA
  - h. Undiagnosed lump that progressed to advanced breast cancer
  - i. Difficulty of detecting lumps in young women's breasts ie dense breast tissue
  - j. Critical of screening program or mentions that it should be available to younger women
  - k. Need for early detection
  - l. Recommends regular check-up or breast examination
  - m. Warning signs such as dimpling of the breast or discharge from the nipple/don't ignore lump
  - n. Other – hair test/breath test
6. Diagnosis
- a. Mammogram
  - b. Ultrasound
  - c. Fine needle aspiration
  - d. Biopsy
  - e. Unnecessary tests in writer's opinion, or the cost prohibitive
  - f. False negatives/positives and the effects psychologically that it can have
  - g. Lump missed or misdiagnosed, or delays in diagnosis
  - h. Lump caught early
  - i. Difficulty in diagnosing breast cancer in young women
  - j. Clinical examination
7. Personal Story
- a. Young woman (or women) with advanced breast cancer or a young woman who has died of breast cancer
  - b. A young woman (or women) who is surviving breast cancer
  - c. Partner's story
  - d. Story about a celebrity or a celebrity mentioned
  - e. Positive experience mentioned
  - f. Negative experience mentioned
  - g. Other
8. Age of woman or women discussed in article
- a. Women 40 and under or young women or premenopausal women
  - b. All women targeted
  - c. Women over 40 or older women
  - d. Not mentioned
  - e. Age range
9. Aboriginal/Rural or other cultural groups of women mentioned
10. Treatment
- a. Mastectomy
  - b. Lumpectomy
  - c. Radiotherapy
  - d. Chemotherapy
  - e. Hormonal treatment – tamoxifen/endocrine therapy
  - f. Palliative care
  - g. Alternative or Complementary treatments such as diet to prevent recurrence
  - h. New drug or new use for an old drug, new treatments or vaccines

- i. Treatment that went wrong
  - j. Negative sequelae of treatment either physical or psychological (e.g. pain, decreasing sexual functioning or body image disturbances, lack of support, fatigue, hair loss, infertility, early menopause)
  - k. Positive aspects of treatment mentioned
  - l. A second opinion mentioned
  - m. Positive thinking/psychological therapies
  - n. Difficulty in obtaining a treatment drug
  - o. Prophylactic mastectomy, reconstructive surgery
11. Support
- a. Information on Support groups/mentions support group(s)
  - b. Need for support for young woman and/or family
  - c. Financial/practical support
  - d. Encourages support/has support
  - e. Other
12. Services for women/family living with breast cancer
- a. Phone number of a support or treatment service
  - b. Cancer information support service mentioned or some other treatment service
  - c. Other
13. Mentions or infers
- a. Breast cancer in younger women is rare
  - b. NBCC (NBCAOC from 2008), state based cancer organizations or breast cancer action groups
  - c. Guidelines/ reports or the need for them
  - d. Breast cancer in younger women is more likely to be fatal or more aggressive
  - e. Advanced breast cancer or implies it
  - f. Victim
  - g. Partner's experience
  - h. Palliative care
14. Useful quotes
- Yes
  - No
15. Main content area of article
- 1-13 from above categories
  - 14-Guidelines
  - 15- Correcting perceived misinformation
  - 17-Prevention of breast cancer
  - 18-Survival
  - 19- Grief
16. Inconsistencies/ Inaccuracies
- Yes. Either in the information presented or by omission.
  - No

17. Overall tone of article

- a. Positive - In that, the article raises awareness of breast cancer in all age groups or encourages young women to perform BSE or seek help for a breast symptom early or to reduce certain risk factors.
- b. Negative or critical of someone or something
- c. Neutral or ambiguous
- d. Disturbing, unsettling or sad
- e. Reassuring
- f. Cautiously optimistic
- g. Information giving

18. Discourse informing text

- a. Legal
- b. Tragedy
- c. Risky young women or Risk in general
- d. Scientific/Medical
- e. Psychological
- f. Responsibility to be vigilant or reduce risk factors
- g. Political
- h. Faulty inheritance -genetic
- i. Altruism i.e. a celebrity giving time to help raise money or awareness
- j. Female, youth or body
- k. Chance or luck
- l. heroism
- m. sexuality/fertility

**Appendix 3: Chronological headings of newspaper articles**

1996	Date	Title	Content Area
1	14/10/96	Breast cancer risk factors: killer taking younger victims	Increase incidence breast cancer in young women
2	31/10/96	Mum's plea on breast cancer	Pregnant mother's plight
3	13/12/96	Ignoring a husbands plea	Partner
4	18/12/96	Too young, cancer victim was told	Kathryn Curtin
5	21/12/96	Breast cancer can strike very early- letter 1	Personal story
6	21/12/96	Breast cancer can strike very early- letter 2	Critical letter
7	21/12/96	Breast cancer's human cost tragically exposed	Shifting blame
8	21/12/96	Doctors urge balance	Defensive stance
9	24/12/96	Ca concerns of women must be respected	Critical letter
10	27/12/96	Breast cancer in younger women not on the rise	Epidemiology
1997	Date	Title	Content Area
11	3/6/97	Breast cancer victim sues GP	Bonnie Tran
12	11/7/97	GP admits wrong option over lump	Bonnie Tran
13	21/6/97	<i>Damages for Mum dying of breast cancer</i>	Bonnie Tran
14	21/8/97	Breast cancer discovery breaks down family links	Genes
15	21/12/97	Fantatising our way to a better reality	fighting spirit
16	23/12/97	Lobbyist lit a candle of hope	Marcia O'Keefe
1998	Date	Title	Content Area
17	7/2/98	Surviving with the enemy	Critical of psychological support
18	28/4/98	A timely warning	Belinda Emmett
19	28/4/98	Cancer hits young the hardest	Youth/B Emmett
20	29/4/98	A self-exam saved my life, says brave survivor	Linda Bojarski
21	1/5/98	The breast cancer battle; women slow to seek advice.1:5 detect symptom	Irresponsible
22	1/5/98	Breast cancer horrible at any age	Critical letter
23	1/5/98	Lump a cyst, to the relief of Jo-Anne	Responsible
24	1/5/98	Doctors divided on breast care	Breast self-exam debate begins
25	3/5/98	Beating cancer	Advice on early detection
26	3/5/98	<i>Agony of young cancer victims</i>	Side effects & youth
27	3/5/98	Baby Rosie is Anna's lifeline	battle, war,
28	3/5/98	Cathy's plea for test	Young women & mammograms
29	3/5/98	Women face ca crisis/awareness campaign neglect young	Risks
30	3/5/98	Flaw costing lives	Critical of campaign
31	4/5/98	Male GP's shy from breast tests	Legal fear breast exam
32	4/5/98	Pill and cancer go hand in hand	Risk factor and oestrogen
33	10/5/98	On top and in control	Youth
34	15/5/98	Breast cancer: more good news	Tamoxifen
35	18/5/98	Scope: Hormone link to breast cancer	Risk
36	21/5/98	I'm alive: Belinda cleared of breast cancer	B. Emmett's survival
37	22/5/98	Star safeguards fertility before surgery	Fertility B Emmett

38	6/6/98	I want 1.7m;Cancer victims compensation claim revealed	Jane Kite
39	9/8/98	Deadly family ties	Genes
40	13/8/98	Older women survive breast cancer best	Survival analysis
41	11/10/98	Row on breast ad	Debate over add
42	16/10/98	Young breast cancer patients have an ally	Jane Poynts
43	16/10/98	Bid to treat more than the cancer	Psychological support
44	24/10/98	Untitled story: Kris Olsen talks to young women living with breast cancer	Survival stories
45	25/10/98	The book that changed Geri's life	Ruth Picardie
46	26/10/98	The scourge of women-Help on hand for younger sufferers	support for young women
47	1/11/98	Dedicated doctor offers cancer hope	New vaccine
48	1/11/98	Survival guide	Risk in 40's
<b>1999</b>	<b>Date</b>	<b>Title</b>	<b>Content Area</b>
49	10/1/99	Doctors beware	Jane Kite
50	10/1/99	Lethal beliefs	Screeners/non screeners
51	17/1/99	Cancer war hurt by power of pc	Abortion risk factor
52	10/3/99	A battle lost but Kate's bravery lives on	K Curtin died
53	13/3/99	Focus change for advanced breast cancer	Real risk of law suits
54	27/3/99	Writing well	1 woman's story early breast cancer
55	12/9/99	Diet claimed to cut breast cancer	Diet
56	18/10/99	Field of women' tribute	Early detection
57	25/10/99	Cancer network helps mum get off thin ice	Support
58	30/10/99	Clinical approach detects cancer	Early diagnosis
59	25/11/99	Don't let them die like she did	Early detection, Linda Mc.
60	13/12/99	Breast cancer	Early detection
<b>2000</b>	<b>Date</b>	<b>Title</b>	<b>Content Area</b>
61	20/1/00	Lump removal risks relapse	Lump vs. mastectomy
62	20/2/00	Is this the way to publicise breast cancer?	Image of mastectomy scar offends
63	12/3/00	Before I say goodbye	Ruth Picardie
64	31/3/00	Young women taking the risk	Risk factors
65	6/4/00	Chemotherapy age link	Young women advised to have chemo after surgery
66	19/4/00	Megan loses swift battle with cancer	Megan Williams, actor died 44
67	10/6/00	Largest killer	More aggressive in young women
68	10/6/00	Beaten by the odds	Advancing disease
69	11/6/00	A woman of substance	Story of survival
70	17/6/00	Spirit not enough	Psychological issues
71	2/7/00	Cancer: One woman's story of hope	Jane Plant, how she survived
72	10/8/00	Up front with a serious message	Fundraiser
73	16/8/00	Breast cancer awareness in fashion	Fashion, Belinda Emmett
74	12/9/00	One woman's battle inspiration to others	Story of courage
75	21/9/00	Be strict or front the law, GP's told	Legal issues

76	8/10/00	Showing off in a good cause	Fund raiser
77	19/10/00	U 40's want free b tests- cancer more aggressive in young	Statistics, urge for mammogram
78	22/10/00	Last word	Fundraiser
79	22/10/00	Special day to wear a ribbon	Fundraiser information
80	22/10/00	I used to wake up every morning and think 'Oh god' ...	Lyn Swinburne 40, bodily betrayal
81	22/10/00	Out of every 40 women in Aus, 4 will contact BC, 1 die	Fund raiser- Sarah O'Hare
82	23/10/00	Jane's battle fought and won	Jane McGrath 31
83	23/10/00	Young women cancer shock	Need for early detection in young women
84	24/10/00	In to bat for cancer	McGrath Foundation- fund raising
85	24/10/00	Breakfasting in a good cause	Fund raiser B. Emmett, Jane.Steele (McGrath)
86	26/10/00	Gene link to breast cancer	Gene link in young women
87	27/10/00	Diets role in fighting cancer	No Dairy
88	28/10/00	McGrath-Steele partnership survives the toughest test	Jane Steele (McGrath)
89	28/10/00	Young breast cancer attack plans	Debate over lowering free mammogram age
90	7/11/00	Deeper wounds of breast surgery	Sexuality +mastectomy
<b>2001</b>	<b>Date</b>	<b>Title</b>	<b>Content Area</b>
91	28/4/01	Advice on living with advanced breast cancer	Launch of guidelines
92	8/5/01	Pregnant women run breast cancer risk	Pregnancy & risk
93	21/5/01	Helping those most at risk	Prophylactic mastectomy - aggressive disease
94	21/5/01	Women at risk of cancer choose to lose breasts	Prophylactic mastectomy
95	22/5/01	Living without regrets- Letter	Prophylactic mastectomy
96	26/8/01	Advance screenings	Mammograms & BSE
97	1/9/01	If you thought only women over 40 got bc, think again	BSE & young w. Natalie Downer-Knell 29
98	4/10/01	No heading	Belinda Emmett
99	4/10/01	Belinda's agony: the cancer she conquered once has struck again (repeat)	B Emmett's relapse (war on terror caption under picture)
100	4/10/01	Alert on disease in young women	Poorer survival, need to add chemo
101	4/10/01	Cancer likely to return- Under 35's finding	BC action group, R. Martinello
102	5/10/01	Confronting a killer at a younger age	BC worse in young women
103	11/10/01	Cancer battle for Saint's wife Annie	Annie Loewe 33
104	15/10/01	Helping women beat breast cancer	R Martinello BCAG forum info
105	15/10/01	Why these women walk through life	Breast cancer a gift
106	17/10/01	Don't wait for lump	Early detection
107	18/10/01	Vicki's cancer fight for all young women	Early detection

108	19/10/01	Up to 900 women gain help in high-cost battle with tumours	Herceptin available for advanced breast cancer, especially for young women
109	21/10/01	Stand by me	3 young women's stories/ body image
110	21/10/01	Battle for survival	Young breast cancer action group
111	22/10/01	Fertility hope for younger women	Fertility preservation
112	22/10/01	Young hit hardest by breast cancer	Early detection
113	22/10/01	Lovers of life do live longer	Relapse risk without right attitude, young woman 37
114	22/10/01	Early detection key to breast cancer fight	Early detection
115	23/10/01	Aussie launce of breast cancer guide	Launch of guidelines - metastatic breast cancer
116	24/10/01	The signs	Early detection
<b>2002</b>	<b>Date</b>	<b>Title</b>	<b>Content Area</b>
117	10/4/02	Getting on with life is the only way to go, say these wonder women	Sue Murray 40, Karen Drost, 24
118	11/5/02	Tests of courage	Meredith Campbell, 33 & difficulties young women face
119	5/8/02	What happens when a jest turns 1 young couple's lives into a battle for hope & survival	Belinda Griffin 26 & partner
120	14/9/02	Doctors hail future hopes for new breast cancer pill	Tamoxifen
121	4/10/02	Attack on the young	Silvana, 27
122	7/10/02	Ten thousand reasons	Early detection & other facts
123	26/10/02	Women fighting for their lives	Tanya Wilson 35
124	27/10/02	My challenge of a lifetime	Deborah Martin 32, Dragons Abreast
125	15/11/02	Helping other survive- finding a cure (altruistic)	Nelune Rajapakse 36, raising money
<b>2003</b>	<b>Date</b>	<b>Title</b>	<b>Content Area</b>
126	5/4/03	Mum's the word for fighting breast cancer	Increase incidence & prevention
127	24/4/03	Experts find breast check age needs to be younger	Screening mammograms for 45+
128	21/8/03	Breast cancer and babies	Pregnancy & survival
129	11/9/03	Breast cancer not linked to pregnancy	Pregnancy & survival
130	6/10/03	Absolute joy - Motherhood after breast cancer	Fertility & treatment
131	20/10/03	Joyful young Melanie a full-time mum again	Melany Bussey 24, 2 y kids
132	21/10/03	Youth no defence against diagnosis	Difficult in diagnosing breast cancer in young women
134	25/10/03	Battle for life inspires hope, humour and courage. Women share the pains & gains of cancer survival	Christine Wilkinson 33/survival
135	27/10/03	Choice is children or survival	B Thewes research/infertility Early menopause
136	27/11/03	Young suffer most when cancer strikes	Gail Scapens 32, research report young women

<b>2004</b>	<b>Date</b>	<b>Title</b>	<b>Content Area</b>
137	22/2/04	Younger women told little about breast cancer	Breast detection glove
138	3/3/04	Survivor, industry prejudice, ca: how Anastacia beat them all	Anastacia singer celebrity
139	17/3/04	Cancer tests hit a hard problem	Troublesome breasts/dense/diff detect
140	21/3/04	You don't have to be alone	M. Macheras-Magias 38, online support
141	25/4/04	Breast cancer stalks young	Early detection and risk factors
142	2/5/04	Beating breast cancer	Heather Weyer 34/facts breast cancer, raise money
143	5/5/04	Survivor took no chances in fight for life	Genetic testing & treatment
145	9/5/04	The big screen	Raise awareness early detection breast self exam
146	24/5/04	Another cancer scare for Jane	Jane Steele/McGrath
147	24/5/04	Brave Jane's new battle	Jane Steele/McGrath
148	30/5/04	Every day great for Jane	Jane Steele/McGrath
149	14/7/04	Breast test age rethink urged	Lower age of screening mammograms
150	20/7/04	Living after cancer	Aftermath of breast cancer
151	17/10/04	Fashion fights back. Designers targeting breast cancer - breast wishes	Money raising, research young women & early detection
152	25/10/04	Cancer survivors warn younger women	3 young women Tasmania early detection/survival
<b>2005</b>	<b>Date</b>	<b>Title</b>	<b>Content Area</b>
153	16/1/05	Don't ignore those early warning signs	Young women, Jane Kite, raise awareness
154	2/3/05	Cancer survivors ride for worthy cause	Raising money M. Campbell
155	6/4/05	ABC newsroom tested as cancer strikes 12 women	3 young women of the Toowong cancer cluster
156	8/4/05	Reason to believe. Beating the odds on and off the field	Belinda O'Neil wife of Mark footballer
157	11/5/05	Positive course prescribed for cancer patients - Budget 2005	Money allocated to breast cancer research
158	8/8/05	Kylie's cancer crusade. Tests soar after star's brave fight	Increase in screening
159	18/5/05	Why she's so unlucky	Kylie & fundraising for new care centre
160	19/5/05	Sick celebs: help or hindrance	'Kylie effect' & other celebrities raise awareness
161	19/5/05	Its time for answers	Kylie & Belinda and risk factors
162	19/5/05	Kylie's message (Editorial)	Urge for early detection - Kylie
163	19/5/05	Don't give in	Gail 33, urges breast SE & bodily knowledge
164	19/5/05	Treatment may take up to a year	treatment choices and Kylie

165	19/5/05	Survivor chooses life	Lisa Malley 34 and fertility
166	21/5/05	Doctor lived to tell the tale	Chemotherapy side effects
167	21/5/05	Every woman's lifetime risk of dev breast cancer is 1:11	Kim Tonnet 34/ infertility & statistics
168	22/5/05	No idol matter	Catherine Kelly 24/Kylie & inc breast screen
169	22/5/05	BC can strike any woman of any age, as Kyle found out this week	Breast self-examination saves lives. K Minogue
170	22/5/05	Living proof that miracles can happen	Jane Howard 2 children, letter to Kylie
171	22/5/05	Breast cancer: the facts	Facts only, no emotion
172	22/5/05	Clinics flooded with enquiries	Kylie effect and early detection
173	23/5/05	Kylie's battle in a war we can win	Raising money Sarah O'Hare
174	23/5/05	Kylie resting after operation	Kylie's operation & future treatment
175	23/5/05	Decision time in Kyle's recovery	Treatment choices
176	25/5/05	5 simple steps to save your life: what every woman needs to know about breast cancer	Kylie & breast self exam information
177	26/8/05	Childbirth threat: cancer survivors have a lot on plate	Fertility information
178	30/9/05	No check-up, no excuse	BC awareness month, fundraising
179	9/10/05	Think pink - coping with breast cancer at any age -I'm a survivor	4 young women's experience/treatment
180	15/10/05	The hardest news	Toowong young women with breast cancer(7)
181	23/10/05	Cancer drug farce	Herceptin
182	23/10/05	Cancer mum's plea as she takes on Canberra. 'I need your help'	Young mother wants Herceptin for all
183	6/11/06	Time to act on cancer drug. A message to the Federal Government	Herceptin urge
184	13/11/05	Abbott's stand on drug 'is heartless'	Call for Herceptin be available to young women
185	26/12/05	Kylie stuns the celebrity world	Kylie received special treatment
<b>2006</b>	<b>Date</b>	<b>Title</b>	<b>Content Area</b>
186	7/2/06	A plague among women	Urging Herceptin listed on PBS & stories of young w.
187	25/25/06	Justice quest ends in tears	D Carney's legal battle over missed lump
188	3/5/06	Breast cancer strikes younger women	Statistics
189	30/5/06	Help by one who knows	One woman's story of good works
190	12/7/06	Kylie's long climb back	Kylie's recovery
191	17/7/06	Online help for sufferers	Online support for young women
192	26/8/20	P53 keeps cancer at bay (a deadly inheritance)	Discovery of p53 suppressor gene
193	16/9/06	Backing a vital cause	Raising money, young women's stories

194	16/10/06	More breast cancer, but the odds are better (report from NBCC & AIHW)	Increase incidence, 1:12 in 1983 to 1:8 2006
195	16/10/06	Determined not to be a statistic	1:8 women
196	21/10/06	Against the odds: lonely road back to life for a grandfather and new mum	Young woman's story followed by facts on breast cancer
197	22/10/06	Think pink	Risk factors and new treatments
198	25/10/06	Breast cancer fuddle	Correcting misinformation of 'Kylie effect'
199	25/10/06	Kylie adds to cancer confusion	'Kylie effect' & correcting misinformation
200	5/11/06	Lucky Star	Kylie's survival story
201	12/11/06	Disease feared by women world-wide	Urge for early detection
202	12/11/06	Call to look out for early signs	Early detection/ donations wanted
203	12/11/07	Age no barrier to breast cancer	Urge for early detection
204	13/11/06	Mourning Belinda -Heartbroken Rove takes time out of the limelight	B. Emmett's death
205	13/11/06	A challenge that changes your life - Belinda Emmett 1974-2006	Stories of several young women, one with advanced breast cancer
206	13/11/06	Young women given a lead	Emmet's death & urge for early detection
207	14/11/06	Life and death struggles	B Emmett/Kylie Minogue comparison
208	14/11/06	Belinda Emmett 1974-2006 Rove never left her side.	Tragedy of B Emmett's death
209	19/11/06	Help young watch for cancer risk	Research early detect in young women needed
210	19/11/06	Shared grief	Tributes to Belinda Emmet and Rove
211	26/11/06	Cancer screening plea	Cost of mammography for young women
212	9/12/06	Lip service	'Kylie effect'
213	22/12/06	ABC cancer revelation shocks staff	Toowong cancer cluster
<b>2007</b>	<b>Date</b>	<b>Title</b>	<b>Content Area</b>
214	9/3/07	New cancer weapon -Hi-tech breast screening to save younger women	New breast imaging machine
215	15/3/07	Younger women hit harder by cancer	Research report-emotional/bodily effect
216	11/5/07	Survivor has cancer charities covered	Raising money
217	19/5/07	Chemo-free cancer hope (research report)	Zoladex and fertility preservation
218	7/8/07	Pink warrior's war on cancer	2 sisters, one cured and one advanced breast cancer
219	16/9/07	Tracey's a rock for best pal Jane (McGrath)	Foundation to raise money breast care in India
220	3/10/07	Breast cancer survival linked to age (report AIHW) repeated in other papers	Disparity in survival rates acc age
221	13/10/07	Ordinary people	Leonie Young, work, chemo & survival
222	15/10/07	Age no barrier to hurt	Kerry Tisdall/Karen Henderson

223	30/10/07	Time to think of yourself	Need for early detection, Kylie factor
224	9/12/07	Be alert and seek treatment for breast cancer	Mixed messages, early detection push
225	27/12/07	Cancer beaten, now for Tasman	Survival story & Emma Pontin
<b>2008</b>	<b>Date</b>	<b>Title</b>	<b>Content Area</b>
226	3/2/08	Women who make bravest decision. Radical surgery to curb cancer	Terry Friebe BRCA1 gene
227	22/2/08	Soil toxin tests at c cluster site - claims about banned poison spark ABC inquiry	Cancer cluster and poisons
228	9/4/08	Doctors got it wrong on my breast cancer	Kyle misdiagnosed (Tykerb)
229	9/4/08	Drug offers better quality of life for sufferers of cancer	Herceptin for Her-2 positive breast cancer (Tykerb)
230	24/4/08	McGraths to offer breast cancer hand to India. Quick: they need help	India's growing incidence of breast cancer

#### **Appendix 4: Interview guide**

The following questions will serve as a guide for the focussed conversations between the researcher and the volunteers.

1. Please tell me your perspective of living with advanced breast cancer.
2. In what ways is your life now different to how it was before?
3. What has been the most difficult aspect of living with advanced disease?
4. Can you describe for me what it has been like for you since you have known of your diagnosis?
5. How has your diagnosis affected your relationships?
6. How has the diagnosis of advanced disease affected your day-to-day life and physical activities?
7. Can you describe for me what it has been like for you since you have completed your treatment?
8. What treatment(s) if any are you still having?
9. What visits to health care professionals do you now have? Can you describe them for me?

These three questions represented above will serve as the foundation for the focussed conversations. However, clarifying and probing questions will also be asked depending on the content of preliminary conversations with the participants. For example, some additional questions that may be asked are; can you tell me more about ...? or what exactly was it about ... that affected you so deeply? I wish to stress that I would be following the participant's lead in the conversations. Should the participant not wish to follow a particular line of questioning, I will not pursue the topic.

**Appendix 5: Participant information**

<b>Participant code name</b>	<b>Children</b>	<b>Age at advanced diagnosis</b>	<b>Initial treatment &amp; age of initial diagnosis</b>	<b>Partner</b>	<b>Present Treatment</b>
Anna	3 under 15	44	39 in 1995 Mastectomy, No tamoxifen suggested, not offered radiotherapy, refused chemotherapy	Yes	Wants no further treatment
Belinda	3 under 15	38	38. Partial mastectomy, chemotherapy and radiotherapy	Yes	Is on a clinical trial
Carol	2 children	38	27, partial mastectomy, radiotherapy and Chemotherapy	Yes	None
Donna	2 teenagers	39	32. Partial mastectomy. No other treatment	Yes	None
Emma	2 under 16	38	38. Chemotherapy and then surgery and then more chemotherapy	Yes	Tamoxifen
Fran	1 age 8	40	36. While breast-feeding. Lumpectomy and removal of nodes, radiotherapy and oophorectomy	Single	Tamoxifen-like treatment
Gena	3 under 15	44	43. Lumpectomy, chemotherapy and radiotherapy. Tamoxifen	Yes	Herceptin and Pamidronate

Helen	2 under 4	29	33. Mastectomy & chemotherapy & radiotherapy	Yes	None
Inge	2 children under 6	36	Doxerubicin and cyclophosphamide. Did not have surgery	Yes	Doxitaxel Is Her2 positive
Jessica	2 under 10	40	40. Lumpectomy followed by mastectomy. Had chemotherapy in between 2 courses of radiotherapy	Yes	None
Karen	Teenager and a 10 year old	36	Lumpectomy followed by radiotherapy	Yes	None
(Louise) Sue	No children	43	43 Surgery and radiotherapy Refused chemotherapy once cancer returned.	Single	Tamoxifen-like drug plus pamidronate

## **Appendix 6: Process of sorting and coding**

Defining and naming themes and subthemes

### **Theme 1: Control of uncertainty**

Definition: many aspects of living with advancing illness are uncontrollable.

Uncertainty concerning prognosis and ultimate survival causes anguish. Chaos can be managed. Chance can be tamed.

#### **Subtheme**

- a. Prognosis calculations – attempts at certainty and containment
- b. Survival/non-survival – uncertainty in relation to prognosis separates survivors from non-survivors. Divisionary practice excludes
- c. Death hidden – uncertainty means that death can be hidden, at least in the professional literature.

### **Theme 2: Women responsible for their survival**

Definition: self-responsibility for health and illness means desperate searches for cure.

Not to survive is to fail in this aspect of self-management. All women living with advanced breast cancer are perceived as failures.

#### **Subtheme**

- a. Alternative/complementary therapies - Perhaps this therapy/product will deliver cure. Heavy burden to survive
- b. Thinking right – Eat right, think right. Women with advanced breast cancer have not tried hard enough and are therefore responsible for their own demise.

### **Theme 3: Time's effect**

Definition: Dying young means that the young women are outside life's trajectory. To increase clock-time, women take on tasks/strategies and self-responsibility.

Burdensome for many.

#### **Subtheme**

- a. The imperative to increase time – prognosis and time are connected. Lived time diminishes
- b. Out of step with time – women outside the time set by others.
- c. Loss of future time – dreams of an imagined future diminish. Children a big part of this loss of an imagined future

### **Theme 4: A tragic loss**

Definition: The loss of a young life is a tragedy. Even more so when children are brought into the picture. What future for these children? Loss of feeling whole. Loss of identity

#### **Subtheme**

- a. Young women are victims and heroes. Battle is part of this, but it is a battle that they cannot hope to win
- b. Motherless children – not to be borne. Anguish
- c. Loss of a future – children main part of this loss

**Theme 5: A body affected**

Definition: Advanced breast cancer happens within a lived body. The body bears the tracers of social and cultural conditioning. An abject body

**Subtheme**

- a. A thin body – Cancer makes you thin and this is desirable
- b. An object body – Cancer and its treatments happen to a bodily container
- c. A disintegrating body – A body in decline happens to a lived body. The body is lost between subject and object; the state of abjection
- d. A female body – Cancer is inscribed within a gendered body. Mothers and cancer.

## **Appendix 7: Information Sheet**

FLINDERS MEDICAL CENTRE



Bedford Park  
South Australia 5042

Telephone  
Facsimile  
E-mail:

### **Title: Young women living with advanced breast cancer: a socio-cultural analysis.**

You are invited to participate in a study, which aims to discover how advanced breast cancer affects young women, in particular their outlook on life, their interests, attitudes, and the effect of it on family and work. As younger women tend not to be the majority of those who get breast cancer, their unique needs are often overlooked. My research intends to explore some of your needs in relation to living with stage III or IV breast cancer

I am a nurse of over 23 years experience and have worked in a variety of health care contexts, both in Australia and overseas. At present, my work as a nurse involves cancer care and the support of those living with life-limiting illnesses. I am particularly interested in your story, it will illuminate some of the concerns younger women, and their families face as they go through this difficult journey.

If you agree, you will be asked to meet with me, Katrina Breden (PhD student) to share your views in an audiotaped interview. Participation will involve at least one (1) interview of approximately 30-60 minutes duration. I will also contact you the day following the interview to answer any queries or concerns you may have about the process. There will also be an opportunity for you to listen and edit the tape if you so choose.

Any information you choose to share will be treated with respect and confidentiality and I will not pursue any topic that you may feel uncomfortable with. A pseudonym will be

used instead of your real name when the tapes are later transcribed. The times and places for the interviews will be arranged at your convenience.

Your involvement in this study is entirely voluntary, and your non-participation will not affect your treatment at (.....) in any way. Should you decide to withdraw from the study you may do this freely and without prejudice to any future treatment at (.....). All records containing personal information will remain confidential and no information, which could lead to your identification, will be released.

After the interviews your story will be analysed and the study will be written as part of a thesis which, when completed, will be available in the Library at the Flinders University, Adelaide. The study may also be published in professional journals and presented at relevant conferences.

If you wish to participate in the study, please contact Ms Katrina Breaden on 8275 1995 or 8275 1757 at your earliest convenience. Should you require further details about the study, either before, during or after the study, please contact either Katrina Breaden on the above numbers, or Professor Ian Maddocks on 0411 517465.

Flinders Medical Research Ethics Committee has reviewed this study. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or should you wish to make a confidential complaint, you may contact the Administrative Officer - Research, Ms. Carol Hakof (8204 4507).

## Appendix 8: Consent Form

FLINDERS MEDICAL CENTRE



Bedford Park  
South Australia 5042

### CONSENT TO PARTICIPATION IN RESEARCH

*Women diagnosed with Advanced Breast  
Cancer*

Telephone  
Facsimile  
Email:

I, \_\_\_\_\_ request and give  
(first or given names) (surname) consent to  
my involvement in the research project **Advanced breast cancer and young women**

(short title of research project)

I acknowledge that the nature, purpose and contemplated effects of the research project, especially

as far as they affect me \_\_\_\_\_ have been fully explained to  
my satisfaction by Katrina Breaden and my consent is given  
voluntarily

I acknowledge that the detail(s) of the following procedure(s)

- Interviews

have been explained to me, including indications of risks; any discomfort involved; anticipation of  
length of time and the frequency with which the procedure(s) will be performed.

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project and/or the procedure(s) may not be of any  
direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the  
responsibilities of the researchers in any respect.

I declare that I am over the age of 18 years.

Signature of research subject:

Date:

Signature of Witness:

Printed Name of Witness:

I, Katrina Margaret Breaden have described to  
the research project and the nature and effects of the procedure(s) involved. In my opinion  
he/she understands the explanation and has freely given his/her consent.

Signature

Date

Status in project:

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