

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

Katrina Margaret Breaden, RN, B AppSc, MN

A thesis submitted in total fulfilment of the requirements
for the degree of Doctor of Philosophy

Department of Palliative and Supportive Services
School of Medicine
Faculty of Health Sciences
Flinders University, Adelaide

2008

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 long horizontal flourish extending to the right.

Katrina Breaden

Date: 19th October 2009

ACKNOWLEDGEMENTS

Any endeavour spanning several years requires a degree of persistence and determination; families often endure most of this burden. Therefore, I would first like to thank my family - Chris, Nick and Emily for enduring with me and believing that I could, and would finish. Second, I would like to thank my parents, John and Joan, and my wider family, Margaret, Ivor and Anne, Pookie, Naomi and Clive. The support of family members can never be underestimated. It made all the difference.

My thanks go to my initial supervisors Professor Trudy Rudge and Emeritus Professor Ian Maddocks who supported me for nearly a decade. I am sure that when I initially approached them for this task, they never thought a thesis could take so long. I also thank Professor Carol Grbich who supervised me during my last year and provided valuable guidance that assisted me in completing the task. Others who supported me along the way were:

My colleagues and friends within the department; Kim Devery, Meg Hegarty, Meredith Legg, Judy Turner and Michael Cox

My PhD cohort; Bev, Luisa, Amanda, Ali and David

Deb Parker who knew what it was like to continue in the face of several setbacks, Ali Huntir, who always kept my spirits up and my other friends who provided a sanctuary in times of distress

The members of the Southern Adelaide Palliative Service and Flinders University's Staff Development and Training Unit

My thanks also go to the young women who generously agreed to be interviewed about the process of living with an advancing and incurable illness. Talking about the possibility of dying requires some courage and a willingness to be vulnerable. Sadly, most of these women have since died. The memory of the interviews and the stories they left behind urged me to finish, for I was determined that this gift should not go unheard.

My one regret is that my mother, who died in June 2006, did not get to see me finish. Like the other members of my family, she too believed in me, in my ability to complete the task, and deserves my heartfelt thanks.

TABLE OF CONTENTS

DECLARATION.....	III
ACKNOWLEDGEMENTS.....	V
TABLE OF CONTENTS.....	VII
SUMMARY	XI
PROLOGUE.....	XIII
DEFINITION OF TERMS.....	XV
CHAPTER ONE: AN INTRODUCTION.....	ERROR! BOOKMARK NOT DEFINED.
1. INTRODUCTION	ERROR! BOOKMARK NOT DEFINED.
2. AIMS OF THE THESIS	ERROR! BOOKMARK NOT DEFINED.
3. OUTLINE OF THE CHAPTERS THAT FOLLOW:	ERROR! BOOKMARK NOT DEFINED.
CHAPTER 2: YOUNG WOMEN AND (ADVANCED) BREAST CANCER: A REVIEW OF THE LITERATURE	ERROR! BOOKMARK NOT DEFINED.
1. THE SCOPE OF THE LITERATURE REVIEW	ERROR! BOOKMARK NOT DEFINED.
2. THE PHYSICAL NATURE OF ADVANCED BREAST CANCER IN YOUNG WOMEN.....	ERROR! BOOKMARK NOT DEFINED.
<i>a. Prognostic indicators for a highly lethal disease</i>	<i>Error! Bookmark not defined.</i>
<i>b. Prognosis.....</i>	<i>Error! Bookmark not defined.</i>
<i>c. Accuracy of staging breast cancer: a determinant of survival ..</i>	<i>Error! Bookmark not defined.</i>
<i>d. Survival.....</i>	<i>Error! Bookmark not defined.</i>
<i>e. Treatments</i>	<i>Error! Bookmark not defined.</i>
<i>d. What predicts long-term survival?</i>	<i>Error! Bookmark not defined.</i>
<i>e. Fertility, Pregnancy and Sexuality.....</i>	<i>Error! Bookmark not defined.</i>
<i>f. The problem lies in the genes</i>	<i>Error! Bookmark not defined.</i>
<i>g. Palliative care's involvement in the care of young women diagnosed with (advanced) breast cancer.</i>	<i>Error! Bookmark not defined.</i>
3. SUMMARY OF THE PHYSICAL NATURE OF ADVANCED BREAST CANCER IN YOUNG WOMEN..	ERROR!
BOOKMARK NOT DEFINED.	
<i>a. Limitations.....</i>	<i>Error! Bookmark not defined.</i>
<i>b. Expert knowledge</i>	<i>Error! Bookmark not defined.</i>
4. PSYCHOLOGICAL AND INDIVIDUAL ASPECTS OF ADVANCED BREAST CANCER IN YOUNG WOMEN.	ERROR!
.....	BOOKMARK NOT DEFINED.
<i>a. Depression.....</i>	<i>Error! Bookmark not defined.</i>
<i>b. Psychological morbidity.....</i>	<i>Error! Bookmark not defined.</i>
<i>c. Body image</i>	<i>Error! Bookmark not defined.</i>
<i>d. The experience of young women living with advanced breast cancer.....</i>	<i>Error! Bookmark not defined.</i>
5. SUMMARY AND LIMITATIONS OF PSYCHOLOGICAL AND INDIVIDUAL ASPECTS	ERROR!
NOT DEFINED.	
<i>a. Body and mind.....</i>	<i>Error! Bookmark not defined.</i>
<i>b. Scales and surveys.....</i>	<i>Error! Bookmark not defined.</i>
<i>c. Interpretation.....</i>	<i>Error! Bookmark not defined.</i>
6. RESEARCH STUDIES CONDUCTED ON THE MEDIA	ERROR! BOOKMARK NOT DEFINED.
<i>a. Three broad areas of research.....</i>	<i>Error! Bookmark not defined.</i>
<i>b. Breast cancer and the media</i>	<i>Error! Bookmark not defined.</i>
7. SUMMARY AND LIMITATIONS OF BREAST CANCER IN THE MEDIA	ERROR!
8. A DISCOURSE ANALYTIC PERSPECTIVE	ERROR! BOOKMARK NOT DEFINED.
9. IMPLICATIONS OF THIS CHAPTER	ERROR! BOOKMARK NOT DEFINED.
CHAPTER 3: THEORETICAL PERSPECTIVES	ERROR! BOOKMARK NOT DEFINED.
INTRODUCTION.....	ERROR! BOOKMARK NOT DEFINED.
1. STRUCTURALISM	ERROR! BOOKMARK NOT DEFINED.
2. POSTMODERNISM OR POSTSTRUCTURALISM?	ERROR! BOOKMARK NOT DEFINED.
3. POSTSTRUCTURALISM	ERROR! BOOKMARK NOT DEFINED.
<i>a. Language.....</i>	<i>Error! Bookmark not defined.</i>

<i>b. Language and meaning</i>	<i>Error! Bookmark not defined.</i>
<i>c. Language and subjectivity</i>	<i>Error! Bookmark not defined.</i>
<i>d. Subjectivity and positioning</i>	<i>Error! Bookmark not defined.</i>
4. LANGUAGE AND DISCOURSE.....	ERROR! BOOKMARK NOT DEFINED.
5. FEATURES OF FOUCAULT’S CONCEPT OF POWER	ERROR! BOOKMARK NOT DEFINED.
6. THE SHAPING OF HUMAN BEINGS	ERROR! BOOKMARK NOT DEFINED.
7. BIOWEAPON AND GOVERNMENTALITY	ERROR! BOOKMARK NOT DEFINED.
8. THE INSCRIBED BODY: THE TARGET, OBJECT AND INSTRUMENT OF POWER.....	ERROR! BOOKMARK NOT DEFINED.
9. THE UNCONSCIOUS AND EMOTIONS	ERROR! BOOKMARK NOT DEFINED.
10. IMPLICATIONS OF A THEORETICAL POSITION	ERROR! BOOKMARK NOT DEFINED.
<i>a. Humanism: a critique</i>	<i>Error! Bookmark not defined.</i>
<i>b. Foucault: a critique</i>	<i>Error! Bookmark not defined.</i>
<i>c. A feminist contribution</i>	<i>Error! Bookmark not defined.</i>
11. IMPLICATIONS OF THIS CHAPTER AND CONCLUSION	ERROR! BOOKMARK NOT DEFINED.
CHAPTER 4: METHODOLOGY AND RESEARCH CONTEXT.....	
DEFINED.	
INTRODUCTION.....	ERROR! BOOKMARK NOT DEFINED.
1. APPROACHES TO DISCOURSE ANALYSIS.....	ERROR! BOOKMARK NOT DEFINED.
2. INSIGHTS ON DISCOURSE ANALYSIS	ERROR! BOOKMARK NOT DEFINED.
3. STEPS FOR IDENTIFYING DISCOURSES	ERROR! BOOKMARK NOT DEFINED.
<i>a. Look for discourses in the text</i>	<i>Error! Bookmark not defined.</i>
<i>b. Next step: sorting and coding</i>	<i>Error! Bookmark not defined.</i>
<i>c. Final step: analyse the material discursively</i>	<i>Error! Bookmark not defined.</i>
4. THE ISSUE OF RIGOUR	ERROR! BOOKMARK NOT DEFINED.
<i>a. Reflexivity</i>	<i>Error! Bookmark not defined.</i>
<i>b. Credibility</i>	<i>Error! Bookmark not defined.</i>
<i>c. Generalisability and representativeness</i>	<i>Error! Bookmark not defined.</i>
5. AN ETHICAL COMPORIMENT	ERROR! BOOKMARK NOT DEFINED.
6. DESCRIPTION OF THE PARTICIPANTS	ERROR! BOOKMARK NOT DEFINED.
7. SUMMARY AND CONCLUSION.....	ERROR! BOOKMARK NOT DEFINED.
RESULTS AND DISCUSSION.....	ERROR! BOOKMARK NOT DEFINED.
CHAPTER 5: THE DISCOURSE OF NUMERACY	
DEFINED.	
INTRODUCTION.....	ERROR! BOOKMARK NOT DEFINED.
<i>A brief history of numbers – from the outside looking in</i>	<i>Error! Bookmark not defined.</i>
1. IN THE PROFESSIONAL LITERATURE	ERROR! BOOKMARK NOT DEFINED.
<i>a. Medical texts (n=5)</i>	<i>Error! Bookmark not defined.</i>
<i>b. Professional medical journals (n=251)</i>	<i>Error! Bookmark not defined.</i>
<i>c. Clinical practice guidelines (n=2)</i>	<i>Error! Bookmark not defined.</i>
2. THE NEWSPAPERS	ERROR! BOOKMARK NOT DEFINED.
<i>a. Staging and prognosis</i>	<i>Error! Bookmark not defined.</i>
<i>b. A game of chance</i>	<i>Error! Bookmark not defined.</i>
3. IN THE YOUNG WOMEN’S STORIES	ERROR! BOOKMARK NOT DEFINED.
<i>a. Treatment factors</i>	<i>Error! Bookmark not defined.</i>
<i>b. Staging and prognosis</i>	<i>Error! Bookmark not defined.</i>
<i>c. The search for survival: non-conventional therapies</i>	<i>Error! Bookmark not defined.</i>
4. DISCUSSION: THE PROBLEM WITH NUMBERS	ERROR! BOOKMARK NOT DEFINED.
<i>a. Probabilities refer to groups of people, not individuals</i>	<i>Error! Bookmark not defined.</i>
<i>b. The discourse of numeracy can be used to manipulate people..</i> <i>Error! Bookmark not defined.</i>	
<i>c. The discourse of numeracy fuels the responsibility to survive... Error! Bookmark not defined.</i>	
<i>d. The discourse of numeracy forms its object: non-survivor..... Error! Bookmark not defined.</i>	
<i>e. The discourse of numeracy and the calculated management of life and death</i> <i>Error! Bookmark not defined.</i>	
5. CONCLUSION	ERROR! BOOKMARK NOT DEFINED.
CHAPTER 6: THE DISCOURSE OF TRAGEDY	
DEFINED.	
INTRODUCTION.....	ERROR! BOOKMARK NOT DEFINED.
<i>Tragedy – a play in four acts</i>	<i>Error! Bookmark not defined.</i>

TRACING THE DISCOURSE.....	ERROR! BOOKMARK NOT DEFINED.
1. TRAGEDY IN THE NEWSPAPERS.....	ERROR! BOOKMARK NOT DEFINED.
2. TRAGEDY IN THE PROFESSIONAL MEDICAL LITERATURE.....	ERROR! BOOKMARK NOT DEFINED.
3. TRAGEDY IN THE WOMEN’S STORIES	ERROR! BOOKMARK NOT DEFINED.
4. DISCUSSION.....	ERROR! BOOKMARK NOT DEFINED.
<i>a. The use of the tragic genre</i>	<i>Error! Bookmark not defined.</i>
<i>b. Effects of the tragic genre.....</i>	<i>Error! Bookmark not defined.</i>
5. CONCLUSION.....	ERROR! BOOKMARK NOT DEFINED.
CHAPTER 7: DISCOURSES OF THE BODY	ERROR! BOOKMARK NOT DEFINED.
INTRODUCTION.....	ERROR! BOOKMARK NOT DEFINED.
<i>The body in medicine.....</i>	<i>Error! Bookmark not defined.</i>
TRACING THE DISCOURSES	ERROR! BOOKMARK NOT DEFINED.
1. IN THE STORIES TOLD BY THE YOUNG WOMEN	ERROR! BOOKMARK NOT DEFINED.
<i>a. The ‘volume in perpetual disintegration’: the discourse of a body in decline</i>	<i>Error! Bookmark not defined.</i>
<i>not defined.</i>	
<i>b. The thin body discourse.....</i>	<i>Error! Bookmark not defined.</i>
<i>c. In summary</i>	<i>Error! Bookmark not defined.</i>
2. IN THE PROFESSIONAL MEDICAL LITERATURE (JOURNALS AND TEXTBOOKS)	ERROR! BOOKMARK NOT DEFINED.
DEFINED.	
3. IN THE MEDIA	ERROR! BOOKMARK NOT DEFINED.
4. DISCUSSION.....	ERROR! BOOKMARK NOT DEFINED.
<i>Effect 1: The urge to be thin</i>	<i>Error! Bookmark not defined.</i>
<i>Effect 2: Looking (ab)normal– a disturbance of body image</i>	<i>Error! Bookmark not defined.</i>
<i>Effect 3: The gendered body.....</i>	<i>Error! Bookmark not defined.</i>
<i>Effect 4: The body as a site of abjection.....</i>	<i>Error! Bookmark not defined.</i>
5. CONCLUSION.....	ERROR! BOOKMARK NOT DEFINED.
CHAPTER 8: CONCLUSION.....	ERROR! BOOKMARK NOT DEFINED.
1. SUMMARY OF RESULTS.....	ERROR! BOOKMARK NOT DEFINED.
2. DISCUSSION OF THE THEORETICAL SIGNIFICANCE OF THE STUDY	ERROR! BOOKMARK NOT DEFINED.
3. LIMITATIONS OF THE STUDY	ERROR! BOOKMARK NOT DEFINED.
4. AREAS FOR FURTHER RESEARCH	ERROR! BOOKMARK NOT DEFINED.
5. IMPLICATIONS FOR PRACTICE	ERROR! BOOKMARK NOT DEFINED.
6. REFLECTIONS ON THE RESEARCH PROCESS	ERROR! BOOKMARK NOT DEFINED.
7. FINAL THOUGHTS	ERROR! BOOKMARK NOT DEFINED.
EPILOGUE.....	ERROR! BOOKMARK NOT DEFINED.
APPENDICES	ERROR! BOOKMARK NOT DEFINED.
APPENDIX 1: CHRONOLOGICAL LIST OF MEDICAL JOURNALS, CONTENT AREAS AND TITLES ...	ERROR!
BOOKMARK NOT DEFINED.	
APPENDIX 2: LIST OF NEWSPAPERS AND CODING SCHEMA	ERROR! BOOKMARK NOT DEFINED.
APPENDIX 3: CHRONOLOGICAL HEADINGS OF NEWSPAPER ARTICLES	ERROR! BOOKMARK NOT DEFINED.
DEFINED.	
APPENDIX 4: INTERVIEW GUIDE	ERROR! BOOKMARK NOT DEFINED.
APPENDIX 5: PARTICIPANT INFORMATION.....	ERROR! BOOKMARK NOT DEFINED.
APPENDIX 6: PROCESS OF SORTING AND CODING	ERROR! BOOKMARK NOT DEFINED.
APPENDIX 7: INFORMATION SHEET	ERROR! BOOKMARK NOT DEFINED.
APPENDIX 8: CONSENT FORM	ERROR! BOOKMARK NOT DEFINED.
REFERENCES.....	ERROR! BOOKMARK NOT DEFINED.

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).