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**BREAST CANCER:  
PATIENT NARRATIVES  
AND  
TREATMENT METHODS**

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## SUMMARY

Narrative-based medicine incorporates evidence-based medicine with a humanistic dimension. In the clinical encounter it encourages a better understanding between doctor and patient therefore setting a patient-centred agenda. This links directly with the NHS plan published in 2000 which was designed to create a health service with a stronger patient focus.

This thesis concentrates on the treatment of women with breast cancer in the 19<sup>th</sup> and 20<sup>th</sup> century. It analyses written published patient narratives linking them with clinical developments. Medical history holds a rich source of information providing the view of the clinician. This includes case reports and case series from one surgeon or one hospital for the earlier period of the study and has progressed to the double blind randomised controlled trial that dominates comparative research today.

There is an imbalance in the material available for the analysis of patients' perceptions of their treatment. The patient view is not represented well in the history of medicine. This thesis attempts to provide a more complete assessment of the developments in breast cancer treatment by including the patient's view.

Three narratives provide an insight into the perception of women who were treated with breast cancer prior to the introduction of anaesthesia and infection control. The novelist, Fanny Burney (1752-1840), underwent a mastectomy in 1811. In a letter to her sister she wrote about her experience providing details of her diagnosis and treatment. In comparison, Emily Gosse (1806-1857) refused a mastectomy for her breast cancer and sought alternative treatment with caustics. Her husband, Phillip

Gosse and friend, Anna Shipton, wrote narratives about Emily's suffering. A third narrative provides the view of a woman with breast cancer who received no treatment and died of metastatic breast cancer; Zelig Martin died in 1877.

These narratives were linked to a case report by Lorenz Heister (1683-1758). Heister described the procedure for amputation of the breast in detail. His method prevailed until new scientific developments in surgery such as anaesthesia and infection control improved the short-term survival of patients and enabled surgeons to operate sooner with a greater attention to detail. At a similar time, Henry T Butlin provided clinical evidence for treatment of breast cancer with caustics.

Long-term survival of patients with breast cancer was improved by the development of cellular pathology and radiotherapy. Three surgeons were chosen to highlight major changes in the treatment of breast cancer. Theodor Billroth (1829-1894) and his pupil, William Stewart Halsted (1852-1922), and Geoffrey Keynes (1887-1982). At the turn of the century Halsted had established a standard operation for breast cancer with his description of radical mastectomy. Anaesthesia and infection control enabled surgeons to operate at an earlier stage of the disease and with greater attention to detail. Halsted's operation remained standard treatment for breast cancer until the second half of the 20<sup>th</sup> century.

The development of x-rays and radiotherapy encouraged a debate amongst clinicians as to the necessity of radical operations. Keynes was one of the first to address this problem with an initial trial conducted at St Bartholomew's hospital. He began to argue for less radical surgery.

The doctor-patient relationship changed during this time. Scientific advances ensured that doctors were less reliant on patients as their only source of information. Increasingly the patient disappeared from the medical arena. A void was created which was filled by newly developed charity organisations such as Cancer Relief Macmillan Fund. These aimed to focus on the patient's needs including practical and emotional support.

The feminist revolution of the 1970s encouraged women to seek medical attention sooner and to view their treatment more critically. Until then many women were not even aware that there was a clinical debate between radical surgery and lumpectomy and radiotherapy for certain breast cancers. The development of adjuvant therapy opened up treatment options and eventually women played a more active role in their choice of treatment.

As women began to make their voices heard, they started to write about their breast cancer experience. Narratives in this thesis can only be regarded as highlighted examples in the increasing number of publications. They were chosen to cover the period from 1970-1990 with published written narratives from the United States (Audre Lorde, Rose Kushner, Barbara Rosenblum/Sandra Butler and Joyce Wadler), Great Britain (Elisa Segrave), former East Germany (Maxie Wander) and West Germany (Angelika Mechtel). The narratives offer an insight into the diagnosis and treatment of breast cancer. In some cases the woman suffered a recurrence and wrote about palliative care and dying from breast cancer.

This thesis aims to highlight the tension between the clinician and the patient. It examines narratives from the 19<sup>th</sup> century and compares them to narratives from the

20<sup>th</sup> century, while linking them to clinical practice. It argues that the doctor-patient relationship has come full circle. Patients were the main providers of information for the clinician in the first half of the 19<sup>th</sup> century. Increasingly their voice disappeared as scientific advances enabled the clinician to make a diagnosis without the need to gain information from the patient. Recently there is a strong move to develop patient focused care. It is evident in the development of narrative medicine and the new NHS plan.

## ABBREVIATIONS

ASCC	American Society for the Control of Cancer
CAM	Complementary/alternative medicine
CHI	Commission for Health Improvement
CMF	Cyclophosphamide, Methotrexate, Fluorouracil
CRMF	Cancer Relief Macmillan Fund
GDR	German Democratic Republic
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NIH	National Institutes of Health
NSABP	National Surgical Adjuvant Breast Project
MRC	Medical Research Council
SIP	Sickness Impact Profile
POMS	Profile of Mood States
WFA	Women's Field Army

## INTRODUCTION

The purpose of the new NHS plan published in 2000 was to reform the health service and re-design it around the needs of patients. Although the NHS had delivered major improvements in health, it had not met the standards patients expected and staff wanted to provide.

NHS frontline staff were to be given more autonomy from the Department of Health, while national standards were to be ensured by regular inspections by the Commission for Health Improvement (CHI) and the National Institute for Clinical Excellence (NICE). Patients were to be given a real say in the NHS, as well as new powers and more influence within it.

In practical terms, this meant that patients could be given copies of letters about their care, and patient advocates were set up in every hospital. Patient surveys and forums became more patient-centred. As a result of this plan, patients encountered shorter waiting times for treatment and more staff were recruited to care for them.

Specifically, treatment for the main killers of the 21<sup>st</sup> century such as cancer, heart disease and mental health was expected to improve. The plan targeted deprived areas and introduced screening programmes for women and children such as extending the existing breast screening programme to include all women up to the age of 70. There were also plans to step up smoking cessation programmes and to provide rapid access to chest pain clinics and a shorter waiting list for heart operations.(1)

In view of these goals, set out in the NHS's forward-looking plan, an assessment of patient care and doctor-patient interaction in the past seems crucial. The aim of this thesis is to assess two major areas where these aspects are of particular significance. It directly addresses the treatment for breast cancer and patient perception of that treatment. Essentially, information about the development of breast cancer treatment involves two perspectives, that of the clinician and that of the patient. In medical history, breast cancer treatment is analysed largely from the perspective of the clinician and there is abundant material available for the assessment of surgical treatment, including case reports by early practitioners and series of case reports from one surgeon or one hospital. Developments progressed to the 'gold standard' of comparative research today: the double-blind randomised controlled trial. An imbalance of material was identified when looking at the second perspective of the assessment of breast cancer treatment, that of the patient. In this thesis an attempt has been made to redress this problem. A more complete historical assessment of the developments in breast cancer treatment can be achieved when treatment evaluation includes the voice of the patient. Scientific and clinical developments are perceived differently by different patients, reflecting their individual coping mechanisms and belief systems.

This study begins with the case of a cancerous breast treated by Lorenz Heister (1683-1758) in 1720. His work provides material and insight into the 18<sup>th</sup> century treatment of breast cancer. Heister was one of the leading surgeons in the treatment of breast cancer and became an advocate for the development of surgery, making it more accessible to other practitioners by using German rather than Latin for his publications.(2-5)

In the same period there are three narratives highlighting individual patient's needs and choices: *'For it takes two to make a medical encounter - the sick person as well as the doctor; and for this reason, one might contend that medical history ought centrally to be about the two-way encounters between doctors and patients.'*(6) The narratives have been set in context by exploring the standard of living of each patient and the influence their belief systems had on their experiences of living and dying. More specifically, their experience of falling ill and the woman's expression of pain as reflected in the written narratives have been analysed. Roy Porter's research agenda suggested that one should explore the remedies offered, i.e. why and when medical skill was required. Special emphasis was placed on the importance of accepting medical authority or seeking alternative treatment offered by 'quacks'. Porter suggested that 'quacks' offered treatment which might have been perceived as less invasive, cheaper or quicker.(6)

Not every woman whose narrative is included was in the position to seek a medical opinion or agreed with the suggested treatment. The narratives explore different approaches to the treatment of breast tumours from the point of view of the patient, or of her partner/friend. The novelist Fanny Burney (1752-1840) summoned the courage to have a mastectomy in 1811. She recorded her feelings and the details of her surgery in a letter to her sister. Emily Gosse (1806 – 1857), wife of the naturalist Phillip Gosse, refused a mastectomy and opted for a new, alternative treatment with caustics. Her husband and a friend recorded the experience in separate accounts. A French woman, Zélie Martin, did not receive any treatment for her breast tumour and her narrative explores her suffering until her death.

Fanny Burney underwent a mastectomy on 30<sup>th</sup> September 1811. Her narrative provides the patient's view of an operation similar to the one described by Lorenz Heister in his case report. The only instrument available was the knife. The success or failure of the operation was dependent on the skill of the surgeon. Fanny Burney portrayed her mastectomy experience in great detail, and included evidence of her relationship with her surgeons, as well as the treatment, and her fear and pain prior to and during the operation. Her account emphasizes the pressure women were under to behave with dignity, even in the face of the most horrendous pain.(7)

In view of the agony and the risk of postoperative death, it was understandable that some women were not willing to have a mastectomy. Evidence for this is found in the narrative by the naturalist Phillip Gosse, *'A memorial of the last days on earth of Emily Gosse'*, which was published shortly after his wife's death.(8) The booklet was intended for private circulation amongst friends and was only later put on public sale. Emily Gosse was unable to summon up the courage to agree to a mastectomy for her breast tumour. She and her husband sought a second opinion from another clinician, who apparently was able to cure breast tumours without the need for surgery. They were both Brethren and they identified more with this seemingly gentler kind of treatment. The narrative offers an insight into Emily Gosse's suffering whilst her breast tumour was treated using caustic and acid applications after small cuts were made in the breast tissue. In the absence of anaesthesia, it showed the desperate need of patients to seek out alternative methods to mastectomy, which carried extremely high morbidity and mortality due to bleeding and infection. An American surgeon, Dr J W Fell, probably administered Emily Gosse's treatment in 1857, but he was not named in the narrative. Henry T Butlin described this kind of treatment in 1887.(9)

A third narrative of a woman who died from breast cancer without receiving any form of treatment is that of Zelig Martin, entitled '*Purgatory on Earth*'. She discovered her breast lump in 1865 but did not consult a doctor until 1876, by which time it had grown and was painful. Her doctor told her that in his opinion an operation was impossible. She continued to lead a 'normal life' for as long as she could. Martin's narrative includes a detailed description of her pain and feelings of desperation once the tumour became debilitating and she was unable to fulfil her role as a mother and wife. She unsuccessfully attempted alternative treatments suggested by her brother, a pharmacist, and drew strength from her Catholic faith. She died in August 1877.

On reviewing the history of surgical techniques and their echo in the narratives of patients, major watersheds in breast cancer treatment are highlighted. The expansion of treatment incorporated new medical advances. Short-term survival of patients was improved by the introduction of anaesthesia and infection control, while long-term survival improved with a more accurate method of diagnosing malignant tumours and a reduction in local recurrence due to radiotherapy. Major changes are apparent in the developments related to the work of Theodor Billroth (1829–1894), William Stewart Halsted (1852-1922) and Geoffrey Keynes (1887-1982), who not only incorporated major change into their practice, but were instrumental in recording their data on a whole series of operations rather than one case report. Heister described one case, and the description of his technique was valuable to his colleagues. Surgeons in the 19<sup>th</sup> century began to record statistical data on all their patients, which made it possible to assess the new methods of treatment.

This thesis explores the major innovations over many years and their consequences for both treatment and patient care in breast cancer. First the significant changes in treatment from those of a traditional surgeon of the 18<sup>th</sup> century, such as Lorenz Heister, to those of the late 19<sup>th</sup> century are reviewed. Initially significant changes in the pattern of treatments are highlighted. Then the specific impact of these changes on patients' perceptions of their treatment is explored. Over two centuries, the skills available through modern medicine are reflected through the eyes of patients. Patient involvement has a varied influence depending on the degree of understanding of the intended treatment. During the first part of the 19<sup>th</sup> century, patients were involved in their treatment, but suffered severe pain; with the introduction of anaesthesia, operations became pain free, but patients were comatose and unable to communicate during surgery.

The use of anaesthesia allowed surgeons to perform more detailed operations on patients who were not suffering extreme agony. William Thomas Green Morton (1819-1868) attempted the first operation under ether anaesthesia on 30th September 1846 when he removed a tooth. Horace Wells (1815-1847) made a second claim to fame by attempting anaesthesia with nitrous oxide. James Young Simpson (1811-1870) introduced a third type of anaesthesia in Edinburgh, after which chloroform replaced the use of ether in Great Britain and some European countries, but in the United States the use of ether prevailed. Anaesthesia offered a fantastic opportunity to operate without causing pain to the patient. Operations could take longer and be more precise. On the other hand, in the early years, anaesthesia caused some alarm amongst clinicians and patients. Few safety measures were in place and the dangers of anaesthesia were not reported until 1854. Patients worried about losing consciousness and perceived anaesthesia as a kind of dying.(3) (10) (11)

The second important development in surgery was infection control. Ignaz Phillip Semmelweiss (1818-1865) in Vienna first developed a procedure for infection control in midwifery in 1848/9. In 1867 Joseph Lister (1827-1912) demonstrated the antiseptic system of treatment and surgery. Surgeons became aware that they were responsible for the postoperative survival of their patients and began to take steps to avoid infection. Surgical operations were more exact and postoperative survival increased, indicating that better cleanliness on the part of the surgeon resulted in better survival of patients.(12)

Long-term survival was affected by two further developments. Rudolph Virchow published his '*Cellular Pathology*' in 1858.(13) The diagnosis of cancer was confirmed by pathological evidence and clinicians were now able to define a tumour as benign or malignant after a sample of tissue was taken for microscopic examination.(14) Patients were given a differential diagnosis and treatment planning was influenced by the outcome of pathology.

A new way of controlling local recurrence was made possible by the discovery of x-rays in 1895 by Willhelm Conrad Roentgen (1845-1923). This opened the door to alternative radiotherapy. Initially this new development caused severe casualties amongst the operators, as the developers were unaware of the extreme dangers of radiation.(15) Additional limitations to this technique were the high cost of radium and the technical equipment required. Research into radiotherapy was increasingly undertaken in bigger centres in London such as St Bartholomew's Hospital.(16)

For the purpose of this thesis, three surgeons have been chosen as representatives of the important innovations of the 19<sup>th</sup> century. Theodor Billroth (1824-1867) was one of the most influential pioneering surgeons.(17) (18) He included major innovations such as employing Virchow's advances in pathology, anaesthesia and infection control into the later years of his practice.(19) He was one of the first surgeons to publish not just a case report, but a whole series of his operations, expanding his methodology to deliver a full retrospective review of cases. He established a centre of surgical excellence in Vienna between 1867 and 1894.

Billroth opened the door to radical surgery and medical students from the US came to train with him in Vienna. One of his pupils, WS Halsted (1852-1922), took his newly gained knowledge back to the US and expanded Billroth's operating technique further when he developed the technique for radical mastectomy in 1894.(20, 21) This involved removing the whole breast including the axillary nodes and pectoral muscles, and was extremely disfiguring surgery. It was based on the belief that breast cancer spread in a centrifugal pattern and that the tumour remained localised at first. Essential local control was achieved by this procedure. Halsted's operation remained the standard treatment for breast cancer until 1970. Surgeons from all over the world accepted that local control of breast cancer was achieved by an extended mastectomy.(22)

Concerned about the gross mutilation inflicted upon his female patients treated by radical mastectomy, Geoffrey Keynes (1887-1982) was one of the first surgeons to suggest that less radical treatment was an option for breast cancer.(23) (24) He believed that a lumpectomy and radiotherapy would achieve similar survival rates. Geoffrey Keynes embraced the use of radiotherapy by developing a method of

implanting radioactive material directly into the breast tissue. This enabled a conservative approach to the surgical treatment of breast cancer.(25) His position was later supported by the radiologist S Mustakallio in 1953.(26) Lumpectomy and radiotherapy remains the treatment of choice for small breast cancers today.

The doctor-patient relationship changed significantly during this time. It is possible that the new methods used made patients into objects on which operations were performed. This is also indicated by qualitative data being replaced by quantitative data. Statistical data were used to ensure that new treatment methods could be assessed in terms of their safety and efficacy. Understanding of the disease was now more complex for the average patient. Surgery had developed into a science and a new type of clinical medicine had evolved.(27)

The patient was no longer the main source of information about the illness. Physicians diagnosed patients accurately and gave a differential prognosis, administering treatment that had a good chance of success, but often alienated patients. Ultra-scientific-trained physicians of the 1950s were accused of a loss of interest in their patients. Porter suggested that the balance between patient power and doctor power had got out of control, and that the patient needed to make a comeback.(6)

Finally it was acknowledged that patients needed supporting through their cancer journey. Douglas Macmillan founded the National Society for Cancer Relief, today Cancer Relief Macmillan Fund (CRMF) in 1911, after his father died of cancer. He identified the need for information and practical support for cancer patients and the aim of his charity was to support patients at every stage of their personal cancer

journey. Betty Westgate was diagnosed with breast cancer in 1968 and founded the Mastectomy Association in 1973. Today this organisation is called Breast Cancer Care and works closely with CRMF. Breast Cancer Care offers help to women and men with breast cancer. It supports the patient, family and friends, providing advice to people who are worried about their breast health or need support during their breast cancer treatment.

CRMF was fundamental in highlighting the 'patchy' access to breast cancer services in the UK. A report was published by Sir Kenneth Calman, the government's Chief Medical Officer, in 1994. He reorganised cancer services in the UK, introducing designated cancer units and cancer centres.(28) (29) CRMF published an (initially) controversial directory of breast cancer services for the benefit of patients in 1996.(30)

By the end of the 19<sup>th</sup> century, the role of the patient narrative had diminished. Diagnostic technologies such as mammography were increasing, which indicated that doctors' reliance on instrumental aids for diagnosis was at a premium. This had a positive effect on the treatment possibilities for breast cancer, as radiotherapy offered an alternative to radical mastectomy. From 1930 onwards surgeons were able to offer a less radical operation and to treat the affected area with additional radiotherapy.

In 1976 a trial by the National Surgical Adjuvant Breast Project (NSABP) reported that treatment with lumpectomy and radiotherapy offered an equal chance of survival and recurrence to treatment by mastectomy.(31) Two further systemic treatments

were developed in the second half of the 20<sup>th</sup> century encompassing the new theory of cancer as a systemic disease.(32)

A need emerged to control cancer not just at the tumour site through surgery and radiation, but also throughout the body. Chemotherapy was developed in the 1950s and administered by tablet form or intravenously. It was designed to stop cancer cells from regenerating themselves. Adjuvant chemotherapy was initially administered to women who had demonstrated lymph node involvement at the time of lymph node sampling. Today it is still not clear whether chemotherapy should be given routinely to all women with breast cancer. There is a definite benefit for women with stage II/III breast cancer with lymph node involvement, but no clear benefit for women without lymph node involvement, except young women. Chemotherapy has been used as palliative treatment to shrink advanced tumours. Its commonly reported side effects are nausea and vomiting, the possibility of hair loss and early menopause in pre-menopausal women. Some patients suffer constipation or diarrhoea, depression and extreme fatigue, hot flushes, mouth ulcers, weight gain, hair loss and excessive bleeding or bruising.(33)

Endocrine therapy or hormone therapy provided a means of ovarian ablation without the need for surgery. In 1896, George Beatson established that some breast cancers reacted to hormones from the reproductive system. He started to remove ovaries from women who developed breast cancer, which caused shrinkage of the tumour in about 50% of cases.(34) During the 1970s, oestrogen receptor analysis was introduced, which defined whether a tumour was oestrogen receptor positive or negative. The growth of tumours that were oestrogen receptor positive was enhanced by oestrogen. Tamoxifen was developed as a non-steroidal anti-oestrogen compound

in 1966 and is used today in adjuvant therapy for women who have oestrogen receptor positive tumours. It is also used in postmenopausal women to prevent tumour recurrence and is currently being tested to see whether it might prevent the development of breast cancer in high-risk women. Serious side effects with Tamoxifen are uncommon.

During the latter part of the 20<sup>th</sup> century, an increasing number of women with breast cancer considered complementary and alternative therapy (CAM) as a less invasive method of dealing with disease. Usually CAM encompasses a form of treatment that is not normally offered in hospitals. Women choose CAM treatments because they want to improve their survival rate or to deal with the potential side effects and toxicity of chemotherapy, radiotherapy, endocrine therapy and surgery. Heather Boon suggested that women are either pushed into CAM treatment because of their negative experience with conventional treatment or they are pulled towards it because they generally believe in a holistic way of treating themselves.(35) There is no scientific evidence which would enable clinicians to give clear advice on the use of CAM, and it is an area where women must rely on their own judgement and develop their own treatment plans.

In the early 20<sup>th</sup> century, cancer was still perceived as a sinister disease and patients considered it incurable. This prevented many women from seeking early diagnosis. In contrast, in the United States, the Women's Field Army (WFA) raised awareness and enlisted the support of women in their roles as mothers and wives, in the hope that they might look after themselves for the sake of their families, even if they were reluctant to do it for themselves.

World War I and World War II deflected medical involvement away from breast cancer treatment. The move towards more conservative surgery and adjuvant therapy was halted as surgeons were involved in the war effort. Although theoretically a choice of treatment for breast cancer was available, most surgeons still employed radical mastectomy.(22)

The feminist movement in the 1970s raised concerns about such radical treatment. The options offered to women were changing. There was an increase in attention to the individual patient because it was realised that women reacted differently to breast cancer and each woman faced her own battle in living with it afterwards. There was a realisation that some women identified their breasts with their femininity, while others saw their breasts as just another organ of the body. It began to be accepted that women were entitled to be given a treatment choice if clinical presentation and long-term survival allowed.

Women increasingly found their own voice and wrote about their breast cancer journeys. In the wake of these discussions, published stories were readily available and public opinion was engaged. The narratives chosen for this thesis cover a period of thirty years from the 1970s to the 1990s. They do not provide a complete set, but were chosen with a view to covering each decade, with opinions from the United States, Great Britain and Germany. They cover the time of diagnosis and treatment and, in some cases, recurrence of the cancer, palliative care and death.

Three narratives have been chosen to cover the period from 1970 to 1980, two from the United States and one from Germany. All three provide an insight into the breast cancer journey of these women, from the time of discovering their lump and a

malignant diagnosis through their treatment with surgery and adjuvant therapy. In two cases, recurrence and death are part of the story.

The period from 1980 to 1990 is covered in two narratives, one from the United States and one from Germany. The first provides a good insight into how treatment was perceived by the cancer sufferer and the perception of that experience by her closest partner/friend. This narrative covers the time of recurrence and metastases and the experience of dying. The other narrative, by a German author, is written as a third person narrative and ends when treatment is completed.

A further two narratives represent the 1990s. They have been chosen to provide an insight into the breast cancer journey of a woman living in New York and another being treated in London. Both narratives cover the whole cancer journey, i.e. diagnosis, treatment and follow-up.

This thesis aims to address tensions between the clinician and the patient. It will demonstrate that there was a change in the doctor-patient relationship and argue that this has come full circle. Until the beginning of the 19<sup>th</sup> century patients were all-important and at the centre of diagnosis and treatment because they provided essential information for the case history. With the development of surgery and new scientific techniques, the patient became less important and the patient's perspective diminished. In the past two decades, clinicians have realised that, regardless of their advanced diagnostic techniques and treatment, they cannot succeed without involving the patient.

More recently, narrative-based medicine has become a specialty. It encourages a holistic approach to management, rediscovering values from the past. It now offers a different foundation to the doctor-patient relationship. There has been a realisation, that in a diagnostic encounter, narratives encourage understanding between clinicians and patients. Narratives enable a holistic approach to illness management and are themselves intrinsically therapeutic or palliative.(36)

## **METHOD**

The history of medicine substantiates that new treatment options are traditionally evaluated through the success rate of a surgeon or a hospital. This approach continues to be influential today, although research methods have progressed from single case reports by one surgeon to the double-blind randomised controlled trial, regarded as the gold standard for studies of different treatments today. The successful outcome of a treatment is regarded as paramount, with little or no importance being placed on the patient's perception of that treatment. It is still presumed that patients will be happy with a treatment as long as it is successful.

In recent years this changed, with more emphasis being placed on patient-focused evaluations of new treatment options. The methodology of the present study focuses on this development, using the example of breast cancer treatment. Research was undertaken with the aim of linking significant periods in the scientific development of breast cancer treatment with patient narratives. The framework of the study was dictated by the availability of written and published patient narratives and major developments in the treatment of breast cancer. Narratives were limited to written and published material from patients or their carers, i.e. relatives/friends.

A picture of the clinical developments in breast cancer treatment is presented here in historical perspective. Scientific and clinical progress forms the framework, contrasted with relevant patient narratives, which offer a necessary alternative evaluation and highlight the significance of personal insight.

A literature review identified primary and secondary sources. Data were collected using the 'Endnote' reference manager. Search criteria were set to 'breast cancer', 'breast neoplasm', 'breast tumour' and 'mastectomy'. This was further refined to the treatment of women; male breast cancer was excluded from the study. The search was linked with the terms 'history of medicine' and 'patient satisfaction', 'patient view', 'patient narratives', 'patient manuscripts' and 'psychology'. Individual surgeons and developments considered relevant to the study were cross-referenced.

The search was conducted in all languages in an attempt to identify major areas of development world-wide. The main languages for relevant material were identified as German, English/American and French. English and German language texts were used in the original where possible. French texts were used only when available in a translated version. This search was conducted using major databases:

Medline	Major clinical trials database
ASSIA	Applied social science database
CINHAL	Cumulated index to nursing and allied health literature
Cochrane Collaboration	Evidence-based health care, system reviews, methodology, trial register, since 1995
GPGP	General Practitioners database
HLTH	Health Periodicals database
ERDB	European Research and Development database
SCIN	SciSearch: a cited reference science database – 1996
Mantis	1997- to date
COPAC	A union catalogue; 24 of the largest university research catalogues in the UK and Ireland & British Library and National Library of Scotland
Cancerlit	Cancernet A service of the National Cancer Institute
Dipex	Database of personal experience of health and illness

No time period was specified in order to allow for a source-guided development of the chronology with regard to the changes in the clinical development of breast cancer treatment.

The library and archives of The Wellcome Unit for the History of Medicine in London and the British Library were searched and provided source material for this study. Contact was made with Fanny Burney's biographer, Kate Chisholm, to discuss source material with a specific view to identify the report of the chief medical pupil caring for Fanny Burney after her mastectomy. The New York Public Library was contacted to find this account in the Berg Collection. The archives of the Johns Hopkins Institute were searched to find a patient narrative or letters from patients who were treated by radical mastectomy. The archives of St Bartholomew's Hospital in London were searched for narratives or letters from patients who had been treated by Henry T Butlin and Geoffrey Keynes. Cancer Relief Macmillan Fund in London and Breast Cancer Care in Glasgow provided information on the current situation of women suffering from breast cancer.

Core texts were identified and determined the infra-structure of this study. Core texts included the first case report of the amputation of a cancerous breast by one of Germany's leading surgeons of the Enlightenment, Lorenz Heister (1683 - 1758).(37) This case report (1720) provided the starting point for the study. It reflected the scientific background and surgical practice of early modern breast cancer treatment. Heister was a trend-setting surgeon and his procedure was exemplary for surgeons until the late 19<sup>th</sup> century.(14)

A second literature review was undertaken, specifically to search for patient narratives contemporaneous with Heister's case report. The criteria were to find a narrative written by either a woman or her carer with details of breast amputation or mastectomy as explained in Heister's case report. The search criteria were set as above. This identified three sources. The first was a narrative by Fanny Burney (1752

- 1840). She was diagnosed with breast cancer in 1810 and her narrative was published in the form of a letter to her sister and formed part of her diaries and letters (1778 - 1840) published in 1842 - 1846.(7) Fanny Burney's narrative is a significant document reflecting mastectomy as encountered by patients prior to anaesthesia.

The second narrative highlights the endurance required by a woman with breast cancer at that time. In the face of horrendous pain and mutilation, many women found themselves unable to face such treatment. Despite the fact that surgeons advocated mastectomy as the best clinical treatment for advanced breast cancer, women tried to avoid this, even at the risk of their lives. Phillip Gosse wrote about his wife's experience and published it shortly after her death. The publication is entitled '*A memorial of the last days on earth of Emily Gosse*'. It was intended for private circulation, but was later published.(8) (38) A publication called '*Tell Jesus*' by Anna Shipton provided the perspective of the friend.(39)

The third narrative is that of Zelig Martin, a French lace maker who suffered from breast cancer and died without treatment in 1877.(40)

The narratives of breast cancer patients offer an inside view into the personal experience of their authors and address the main issues of their treatment and care. Common themes were identified, such as the doctor-patient relationship during diagnosis and treatment, as well as the importance of friends and relatives as initiators in seeking medical advice and offering support. Narratives were set into the context of the woman's life and her belief system. Martin and Gosse were both influenced by their religious beliefs, Catholic and Brethren, respectively. Material was searched to link religion with the experience of illness.

When women found a breast lump they were confronted with emotions of fear and anxiety and what implications this might have. Predominant was the fear for their lives if they did not seek treatment. Then the fear of horrendous pain and mutilation

with only a slim chance of survival preyed on their mind if they were to agree to mastectomy.

The narratives were set into the context of clinical papers and the teachings of the time. Differences in the approach of the clinician and the patient's narrative are contrasted in the description of the treatment. In the case of Lorenz Heister and Fanny Burney's description, the language used was entirely different. Heister's case report reflected the scientific nature of this operation written from the surgeon's perspective. The language used was objective and emotionally restrained as this was part of a professional ethic trained into health professionals. Doctors were not to be entangled in emotional matters. Fanny Burney provided a subjective and emotional account. Her narrative provided a perspective from the patient looking up to the surgeon who was about to amputate her breast. Every detail of her fear and horrendous suffering was shared with the reader, almost functioning as a valve to release emotion by sharing it with others. She provided her sister with a detailed description of her ordeal, although she initially did not want to write about it at all. She felt originally that word of mouth was all she needed to get the facts over to her family in order not to worry them unduly.

Most clinicians advocated mastectomy only for advanced breast cancer and were aware of the extremely high morbidity and mortality of this treatment. These operations were only carried out when the cancer was life-threatening. Some clinicians advocated medical treatment for breast tumours without the necessity for surgery and desperate patients would often seek alternatives. The narrative by Phillip Gosse provides the voice of a patient who was not able to face the daunting prospect of mastectomy. The narrative details the Gosses' search for an alternative treatment and offers an insight into the difficulties a patient faced when assessing which clinician and which treatment were best.

The chronology of the study was determined by key developments in the area of medical science. Pioneering surgeons in the development of breast cancer treatment were identified by new developments in medical science.

Theodor Billroth was chosen because he recognized that the introduction of anaesthesia and methods of infection control increased the short term-survival of a patient.(18) He realised that they could make a big difference by reducing morbidity and mortality rates after surgery. After the introduction of antiseptic methods in 1877, the operative mortality for mastectomy dropped by 10%.(3, p82)

American medical students often joined Theodor Billroth in Vienna, as it was regarded as one of the centres of excellence in the world. William Stewart Halsted (1852 - 1922) was greatly influenced by his visit to Europe and the teachings of Professor Billroth. At the end of the 19th century, surgeons had different ways of dealing with a lump in the breast. Some surgeons removed the lump and others removed the segment of the breast containing the tumour. Others excised a central mass and removed wider margins or performed a mastectomy. Some would preserve a skin flap, which included the nipple, to close the wound. Little importance was placed upon the cosmetic results; the emphasis was placed instead on a woman's chance to live free from recurrence for as long as possible.

Professor Billroth taught Halsted to remove the whole breast for cancer, although Billroth stated that he was not totally sure if local excision of small tumours with a safe margin might serve the same purpose. Billroth excised the pectoral fascia together with a substantial layer of underlying muscle. Halsted extended this operation and started to remove the underlying pectoralis muscle as a matter of routine after 1882. He reported on it in 1890 and 1894. This 'radical mastectomy' became the standard operation for breast cancer. The idea of breast cancer as a localised disease was born.(20)

It was not possible to find a narrative reflecting the developments at the end of the 19<sup>th</sup> century despite an extensive search. This is explained in the literature by what has been called the 'the disappearance of the patient narrative'.(27) The decreasing dialogue between doctors and patients highlighted the need for a different kind of support for patients. This was demonstrated by the development of a first cancer charity, CRMF.

Surgeons were primarily concerned with finding a way to treat breast cancer that maximised years of survival free from recurrence. Most research projects were engaged in finding the best treatment, with little consideration given to the patient's perception of treatments such as radical mastectomy.

Geoffrey Keynes was one of the first surgeons to disagree publicly with Halsted's radical mastectomy. Despite the fact that he had been taught radical mastectomy as the standard treatment for breast cancer, he was unable to accept this operation.(25) He introduced a new way of thinking about the body image of women with breast cancer and concentrated on research projects that sought an alternative way of treating the disease. This was the starting point of a debate that dominated clinical research in breast cancer for many years.

The discovery of x-rays was seen as offering an alternative treatment method. Initially Keynes used radium implants in addition to conservative surgery, i.e. the removal of the lump together with a margin of healthy breast. Over the following years this developed into a standard treatment for early breast cancer. Some patients could now have the choice between mastectomy or lumpectomy and radiotherapy. Initial trials comparing mastectomy with lumpectomy and radiotherapy were designed in order to establish the effectiveness of this alternative treatment both in the short and long term.

The fact that there was a choice of treatment was an important factor for enthusiasm for early detection. Women had previously delayed seeking medical advice as they were afraid of cancer and the radical operation it entailed. Now there were different options available. Unfortunately, surgeons of the time were not forthcoming about this in their discussions with patients.

The feminist movement liberated women to speak out for themselves. Women realised that their bodies were of value and they should therefore have a say in how they were treated by a surgeon. A broader communication amongst women about their experiences began. The second half of the 20<sup>th</sup> century saw significant expansion in the number of patient narratives, with special emphasis on women writing about their experience with breast cancer. Many women published diaries of their breast cancer treatment. This encouraged a more patient-focused approach by surgeons and their teams.

Patients' perception of their treatment was beginning to be considered an important aspect of their care. Women were starting to take charge of their own destiny. They were given the opportunity to voice their feelings about their treatment. Published diaries highlighted these objectives and encouraged others to become more aware of their rights and the need for support. Seven narratives have been chosen to highlight patient perceptions of breast cancer treatment since 1970.

**Table of narratives**

<b>Name</b>	<b>Title</b>	<b>Year</b>	<b>Location</b>	<b>Treatment</b>	<b>Palliative</b>
Lorde Audre	'The Cancer Journals'	1973	US	Radical mastectomy	Yes Liver metastases
Kushner Rose	'Breast Cancer – A Personal History and investigative report'	1975	US	Modified radical mastectomy	No
Wander Maxie	'Leben wär' eine prima Alternative'	1976	Germany	Radical mastectomy Oophorectomy Radiotherapy Chemotherapy	Yes Liver metastases
Rosenblum Barbara & Butler Sandra	'Cancer in two voices'	1985	US	Chemotherapy Mastectomy Chemotherapy Radiotherapy Chemotherapy	Yes Liver and lung metastases
Mechtel Angelika	'Jeden Tag will ich leben'	1987	Germany	Lumpectomy Radiotherapy	No
Wadler Joyce	'My breast'	1992	US	Lumpectomy Radiotherapy Delayed chemotherapy	No
Segrave Elisa	'The diary of a breast'	1994	UK	Lumpectomy Chemotherapy Radiotherapy	No

The analysis of surgical progress from patient experience as expressed in these narratives has now come to an important development. Advanced diagnostic procedures offered women with breast cancer a better chance of survival. The prospect of less painful and mutilating surgery encouraged women to seek medical advice at an earlier stage.

Doctors seek an active exchange with their patients when discussing options for treatment. Women today are able to access a broader experience through publications and the Internet. Patients are better treated and supported today and the development of narrative-based medicine encourages doctors and their teams to treat patients as human beings with individual needs.

## RESULTS

### 1 Breast Cancer treatment in the 19<sup>th</sup> century

#### 1.1 First case report of the amputation of a cancerous breast

##### Lorenz Heister (1683 - 1758)

Lorenz Heister (1683 - 1758) published one of the first case reports on the amputation of a cancerous breast in a series of collected cases in 1720. This is the starting point for this study.(37) (41) He wrote the first complete and systematic approach to the science of surgery, his '*Chirurgie*' (illustrated with 38 copper plates) in 1718. It was translated into English in 1743 as '*A General System of Surgery*'. He was Professor of Surgery at the University of Helmstadt, then part of the Duchy of Brunswick, where he remained for 38 years. His work was translated into English, Spanish, French, Italian and Dutch, as well as three Latin editions.(5) Heister was the leading professional surgeon of his day.

Heister was born in Frankfurt/Main and studied at the University of Giessen, close to Frankfurt, Leiden and Amsterdam. In 1707 he became an army surgeon in the Dutch war against the French. He took his doctoral degree in the summer of 1708 and then returned to his duties as an army surgeon. He visited surgical centres of importance in Great Britain, coming to London, Glasgow and Edinburgh, and was appointed Professor of Anatomy and Surgery at the University of Altdorf/Nürnberg (Bavaria) in 1710.

In 1720 Heister wrote a description of the amputation of a cancerous breast. Because anaesthesia was unknown, the operation was performed as quickly as possible to minimise the patient's suffering.

The case report begins with a short medical synopsis of demographic and clinical details. Heister describes the way he consented the patient and gives details of pre-

operative preparation and an exact description of the mastectomy. Postoperative care and information about nutritional aspects concluded his report. He stressed that a surgeon should only consider an operation for a tumour at an advanced stage, which seriously threatened a woman's life.(37) Surgical intervention carried a high risk of uncontrolled bleeding and infection causing postoperative death.

Heister's patient was the wife of a farmer who came to him in January 1720 with a tumour of the right breast. This woman was about 48 years of age and described as having a '*...thin habit of body and of melancholic temperament,[she] had been delivered of eight children;...*' (5, p174)(37) The term 'of melancholic temperament' referred to an advanced interpretation of the four humoral imbalances dating back to Galen and referring to a specific typology of tissue and related psychological character. The diagnostic assessment detailed the size, colour and texture of the cancer. This was illustrated on an accompanying copper plate. The appearance of the woman's breast pointed to an advanced breast tumour. The size was indicated as '*...of prodigious size, nearly as big again as her head...*' (5, p175) (37) The breast appeared deformed and painful. There was discoloration, described as dark brown, with several large, bloated veins.

The patient told Heister that she had been to many 'quacks', who had applied ointments to resolve the tumour or to bring it to suppuration, but without success. Heister informed his patient of the dangers of amputating her breast but said that in view of all her symptoms this was her only hope of survival. The tumour was pressing upon her thorax and respiration was affected, making it difficult for her to breathe. He pointed out that despite the danger there was some hope of cure and some hope to save her life through surgery.(41)

This assertion of hope for survival was innovative at a time when breast cancer was considered incurable. For most patients a mastectomy was considered more dangerous than the disease - a belief common since antiquity. Heister offered the

woman some hope of survival and she asked him for the operation. He decided to operate immediately as he feared the woman would grow weaker because of her constant pain. Usually surgeons would avoid operating during the winter months and wait for the spring, which offered a kinder postoperative setting with less extreme weather conditions. Heister explained:

*'... there was no other method of cure but amputation; and that this operation would of course be attended with danger, but that if she was to submit to it there was some hope of cure...for without taking off her breast, she would, in all probability, soon expire...'* (5, p177) (37)

Pre-operatively Heister prepared and checked his necessary instruments and materials, which included a large knife to enable him to cut the breast off quickly. Bleeding control was achieved with a cauterising iron and compresses dipped in spirit of turpentine, generally used as a detergent and for the contraction of blood vessels. Several other types of lint in different sizes were needed.(5) (37)

For the operation itself, Heister positioned his patient in an armchair in the middle of the room and stood behind her on the right. One assistant extended and raised the woman's right arm while the others held her head and diseased breast. Another assistant helped with the instruments and a further assistant with the medicines.(5) (37) The description was detailed and offered other surgeons clear instructions on how to prepare for this operation.

Similar attention was paid to technical details of the procedure. Heister took hold of the woman's breast with his left hand and applied the knife to the inferior part, while directing his assistant, who held it, to pull the breast towards him. He carried on the incision tracing the line that was to be cut with the finger of his left hand till the breast was removed. This, Heister stated, should not take longer than one minute. The bleeding arteries were treated by an application of compresses dipped in oil of

turpentine and the assistant had to apply pressure to the compresses and change them when necessary.(5)(37)

Postoperatively a compress of lint covered with astringent powder was applied to the rest of the wound, which was gently compressed by the hands of the assistant until the bleeding stopped. While the dressings were applied, Heister gave the patient some cordial and smelling salts which prevented her from fainting (he did not want his patient to fall into a coma as it was perceived as a kind of dying). The dressing was fixed with 12 long strips of plaster and over this a large square compress was placed. To finish, two more large compresses were wetted with hot beer and butter and applied. This was a dressing technique previously described by Helvetius, a classical surgeon. The patient was put to bed and an assistant was ordered to sit by her bedside to compress the dressing with his hand in order to prevent fresh bleeding. The assistants were relieved every two hours. After a few hours, blood oozed through the dressings and it was necessary to apply another compress, which was then fixed with a roller. Each time the operation site showed some discharge, the dressing was changed. Compresses soaked with hot beer and butter were applied for 14 days postoperatively. In this case the wound was clean and showed signs of healing. In the fourth and fifth week, the wound was dressed only once a day and the skin began to regenerate. By the seventh week, some powder was strewn on the wound and a dry dressing applied. The whole postoperative period took from January until May and was supervised by Heister.

Heister also gave dietary directions. For the first fortnight the patient was given thin soup and jellies. Afterwards, when her appetite increased, she was permitted veal, boiled prunes, apples, pears and soft-boiled eggs. He allowed her to drink a small beer when thirsty, a glass of wine at four weeks and, later on, some stronger beer. She was advised to keep herself quiet and had recovered her strength by the end of May.(5)(37)

This cancerous breast was the heaviest tumour ever reported or removed by any medical author.(41) After the operation Heister recorded the weight of the breast as twelve pounds.(37) There was, however, no histological confirmation of it being malignant. Meyer suggested that this tumour might have been a cystosarcoma phylloides and not an infiltrating ductal lesion (i.e. not malignant). Heister was obviously aware of the dangers of mastectomy without sufficient control of bleeding, and the risk of infection. However, he could not see any chance of survival for this patient without an operation. He made careful pre-operative preparations and placed great importance on the need for the right equipment.(42)

The mastectomy and postoperative control of bleeding were detailed, using scientific language other surgeons would find easy to follow but offering little insight into the feelings of the patient. It was made clear, however, that the patient was at a desperate stage of her illness and was given hope by the prospect of having the breast removed. However, little detail was given regarding the reassurance of his patient once the operation was underway. The only reference to the patient was immediately prior to the operation. The patient was encouraged to behave with resolution and given cordial julep and smelling salts to keep her from fainting.(37)

There are no indications of the woman's perception during her ordeal and immediately after the operation. Her feelings did not feature in Heister's case report. It was only as she recovered that he mentioned anything with regard to her state of mind: *'[She was] able to get up and walk about, was brisk and cheerful, had a good appetite, and complained of no pain...'*(5, p180)(37)

Somewhat later, in 1731, Lorenz Heister reflected on the intense suffering:

*'some women suffer this operation with great resilience but others scream so terribly that even the bravest surgeon will sometimes be shocked and might be*

*prevented from doing the operation; therefore a surgeon who is willing to undertake this operation must have the courage not to be prevented by the screams of the patient ' (14, p108)*

It was surprising to find so little written about the patient in this case report. The woman provided some history about the development of the lump as well as various alternative treatments she had tried, such as home remedies and on the recommendation of empirical practitioners. It was a large tumour and the diagnosis not difficult. The opinion of the woman was quoted during the process of decision for or against the operation, but then her voice disappeared from the case report. This could be explained in two ways. Heister wrote this report intending it to be a technical manual to be used by other surgeons. As such, he might have considered the feelings of his patient of lesser importance once the decision to operate had been made. Alternatively, Heister might have considered it a show of weakness to describe his patient's suffering during the operation. He obviously believed that a surgeon had to rise above the suffering, otherwise it would become impossible to operate.

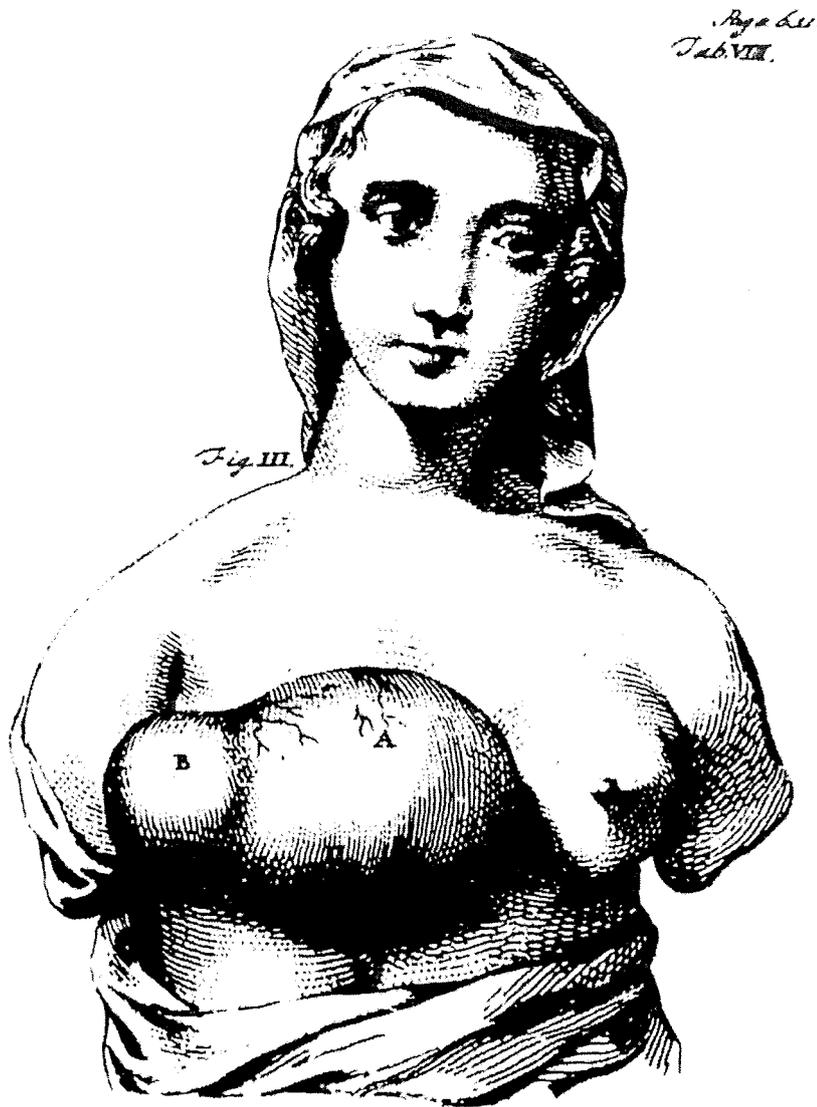
Lorenz Heister (Courtesy of the Wellcome Library London)



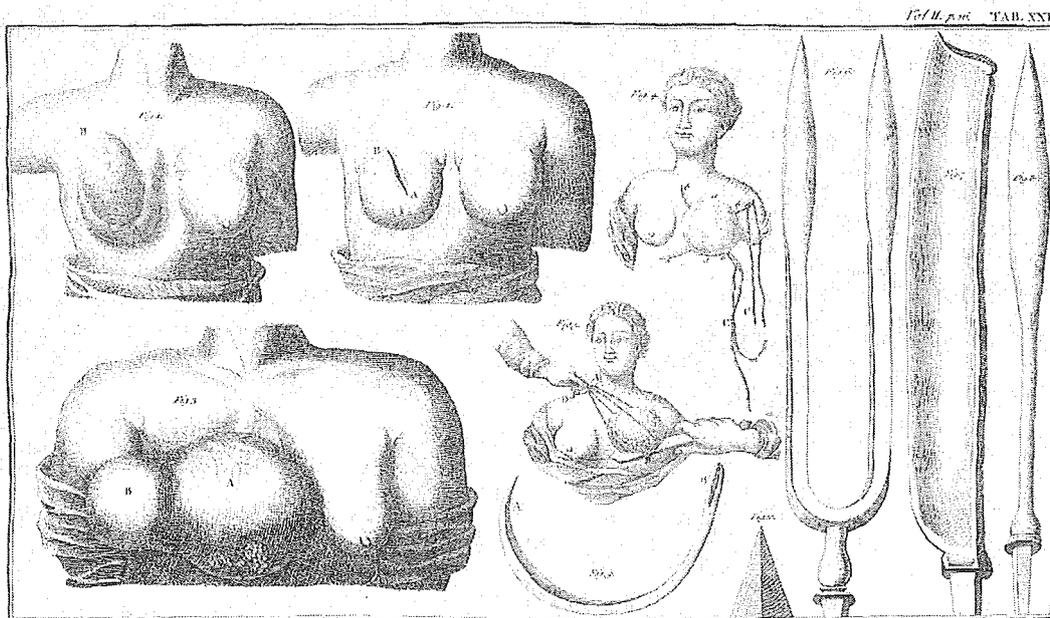
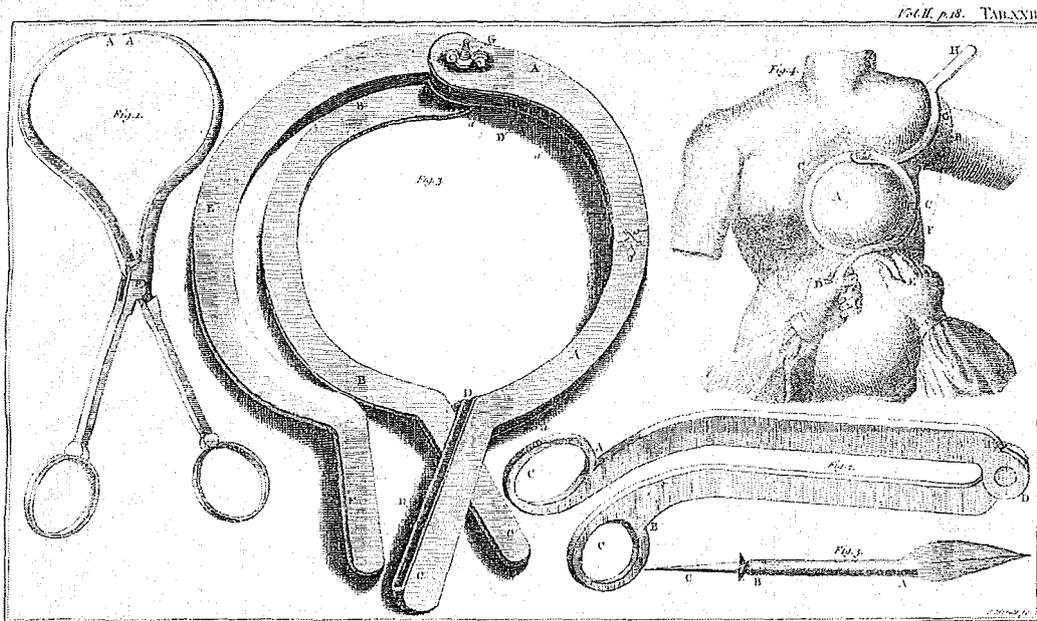
*D. Laur. Heister  
Medicinae Chir. ac Botanicae  
Prof. Publ. Helmstad.*

*J. W. Bannister del. 1742*

Breast tumour of farmer's wife (Courtesy of the Wellcome Library London)



**Instruments for the amputation of a breast**  
**(Courtesy of the Wellcome Library London)**



## 1.2 The patient's perspective

### 1.2.1 Fanny Burney (1752-1840)

One of the first patients to write about her experience of mastectomy was Fanny Burney (1752 - 1840), who discovered a lump in her breast in 1810 when she was 58 years old.(7) Burney was born in 1752 in King's Lynn, the daughter of Charles Burney, who was a well known music teacher and critic. She kept journals from the age of 15 and these have been called the diaries of 'a first royal reporter' by Burney's biographer, Kate Chisholm.(43)

By the time Fanny Burney underwent her mastectomy in 1811 she was 59 years of age. She had established herself as a writer with the successful publication of her novel *'Evelina'* in 1778. Fanny wrote this novel in her early twenties under anonymous authorship, as female novelists were not easily accepted into society at that time. Her brother Charles approached a publisher on her behalf, and Thomas Lownders in Fleet Street accepted the novel for publication. After publication, Fanny was paid £20. The novel was well received and eventually her authorship was revealed.

In her early years Fanny decided against marriage, as would have been expected of the women of her time. Initially she worked for her father, who was supportive of his independent daughter. Despite gaining considerable social and literary standing after the publication of her first novel, it remained difficult for Fanny to support herself on the small income from her writing. Frequently she depended on her family and friends to support her. The publication of her second novel *'Cecilia'* brought an income of £250, but this was still not enough for independent living. This novel, however, opened the doors of the court to her. An influential lady at the court of George III, Mrs Mary Delany, admired Burney's writing, and they became friends. Because of this friendship she met the King and Queen and was offered a royal appointment as Second Keeper of the Robes to the Queen, with a yearly income of

£200. For almost five years (1786 - 1791) she served Queen Charlotte. This meant she had to be available from 7 a.m. until midnight, waiting to be summoned by the Queen to help her to dress for engagements. Evelyn Farr wrote that Queen Charlotte said of Burney that she was *'true as gold'*. Fanny's duties included more than just attendance as a dresser; she soon started to read to the Queen and to keep her up to date with political events through her contacts outside the court.(44) She retired from her appointment at court after 5 years and was promised a pension for life of £100.

Beyond her retirement, it was her charming personality that helped her secure a special position at court during the rest of her life. Initially shy and proud, Fanny's *'powers of entertainment were considerable'* once she got to know people better.(44, p19)

She found love late in her life when she met Lafayette's Adjutant-General, Chevalier Alexandre d'Arblay. D'Arblay was a senior officer in the national guard formed by Lafayette and accompanied him into exile. The French Revolution in 1789 challenged the absolutist regime and nobility sought refuge in exile. Fanny fell in love with the tall, handsome 40-year-old refugee from France. She loved his openness and intellect as well as his perfect manners. She married General d'Arblay in 1793. Her diaries give the reader a glimpse of the love she felt for her husband, but also the equality sustained between them. It did not bother her that he was an impoverished French exile with little hope of employment in England. Their financial situation was secured by the knowledge that Fanny's Royal pension was to continue even after she married. Fanny Burney became the main earner. Their son Alexander was born in 1794.

Money problems persuaded her husband to attempt a return to France in order to claim his pre-Revolutionary inheritance and the d'Arblays uprooted and moved to France. Burney worried about how her relationship to the English court would be affected, as

relations were still strained between the two countries. General d'Arblay thought he would be better able to support them in France, possibly by seeking to claim some of the military pension to which he thought he was entitled and finally persuaded Fanny, who arrived in France in the spring of 1802, when the peace treaty between England and France was announced. Her husband met her after a long and tiring journey and they moved into a small apartment in Paris. By May 1803 her husband had secured his pension, providing them with a regular income.

It was hard for Fanny to leave England because she was close to her family and friends, but she decided to make the best of her situation in France. Again, her personality charmed her husband's friends and family and the d'Arblays were received well in French aristocratic society even though they were only just managing financially.

Burney gave up her hope of moving back to England when hostilities with Britain began again and she lost the pension provided by the English court. As an English citizen, Fanny felt uncomfortable in the French capital; she and her husband led a secluded life.

It was at that time that she first mentioned problems with her breast in her diary. She had experienced 'breast attacks' since 1803. These became more serious in 1810. Fanny did not seek medical advice until the pain seriously incapacitated her. She tried to deal with her attacks using natural remedies such as fasting and avoiding any protein except rich fatty milk. In letters to her family that were smuggled out in a diplomatic bag, she revealed that she felt the episodes of pain in her breast were the same recurring painful abscess that she had experienced after the birth of her son. Only when the pain became so severe that she was unable to move her arm did she listen to her husband's advice to see a physician. Initially her doctor, Professor Antoine Dubois

(1756 - 1837), advised her to rest and avoid anxiety of any kind. Antoine Dubois was a leading obstetrician of the French Empire and known for inventing the Dubois forceps. He was Professor of Anatomy at the École de Chirurgie in Paris and in 1794 he was appointed to the Chair of Anatomy at the newly founded École de Santé. He had served in the army as chirurgien-major with Dominique-Jean Larrey (1766 - 1842). Burney was privileged to have consultations with the court physician Dubois and the surgeon Larrey. It was due to her husband's connections to the court in France that these men agreed to attend her.

Large tumours were commonly perceived to be incurable and Fanny must have been aware of the implications of the recurring breast attacks. Only when her quality of life was seriously affected did she seek medical advice. It is not clear from her diaries whether she feared the problem was cancer and was unwilling to deal with the situation, or if her positive outlook on life would not allow her to admit defeat in her attempts to control the pain. Once the diagnosis of breast cancer was made, she dealt with it in an enlightened way, which seemed to have been her way of dealing with life in general. She was prepared to take action and to make decisions, including the most frightening of all, that of undergoing surgery. She was prepared to shape her own destiny on her own terms.

Even her surgeons must have been amazed by her strength. Larrey was used to the horrors in the battlefield but this was a very different situation for him. One of Burney's biographers, John Wiltshire, described the situation as follows:

*'...this was an agonizing operation to be performed, without anaesthetic, in cold blood, upon a lady of 59 who was a distinguished novelist of sensibility, with connections to the English court, who was, in short, a cultural treasure'* (45, p255)

Both doctors did not take the decision to operate on Burney lightly. Initially they tried a variety of non-surgical treatments. Her pain, however, was gaining in intensity and she no longer had even the stamina to walk up the three flights of stairs to their

apartment. At this point the surgeon Larrey and the physician Dubois came to the conclusion that surgery was the only way to preserve her life. It is significant that only at a terminal point were they prepared to perform mastectomy, reassuring themselves of Burney's consent, despite the fact that they supplied her with little information about the procedure itself.

Fanny faced the ordeal with amazing courage (and some ignorance), which only failed her when she realised the extent of the operation. She felt violated by her lack of knowledge and the compromising situation of the operation. She had always been a woman of strong moral values, eager not to damage her reputation in society. For this operation she was asked to reveal her body to surgeons and assistants who were, in her eyes, ignoring even the slightest attempt at observing etiquette. Burney was not informed about these requirements until the time of the operation and this left her feeling abused and isolated. These concerns and the pain she suffered outweighed any concerns for her body image. Before the operation she kept focusing on a positive cure for her disease and on surviving the operation. Fear of death was acknowledged only immediately prior to the operation when she wrote goodbye notes to her husband and child in case she did not survive.

The tumour seems to have been removed completely and Burney's strong and positive attitude saw her through the postoperative period. The support of friends and family ensured an amazing survival after such a major operation. She was now not just a literary celebrity but also a medical success story. The news of the successful removal of a large breast tumour spread fast as it was such an astonishing and unexpected outcome.

She found strength for her ordeal from inside herself and through the support of her husband and friends. There is no mention of her seeking help through religious belief. Indeed, later in life when she cared for her ill husband she applied a similar positive focus on life, leading her to a total denial of the fact that her husband was

terminally ill. She was a woman who had all through her life insisted on achieving her aims. She succeeded as a female writer at a time when this was highly unusual but her positive thinking and determination did not allow failure. During her own illness she fought for her survival and exceeded the expectations of her doctors. She was driven by her overwhelming need always to find a positive outcome; this caused friction between her and her husband during his terminal illness, when he was obviously aware that his life was coming to an end. Burney was unwilling to acknowledge this. To her it was admitting defeat and she rebelled against that. '*... he intent, resigned, controlled; she active, gesturing, dramatic*' (46, p220)

Her husband, a Catholic, agreed to see the priest, whereas Fanny could not envisage seeking comfort from prayer and religious ceremony. She wrote:

*'I had no faith in Confession to Man, & none in the pantomimic parade of their last & unaccountable shew of a Communion'* (46, p222)

In her mind, doctors and priests were taking away the hope that her husband might survive and undermining her wish and continuous efforts to remain positive about the outcome. Later, looking back to this time, she wrote that she was still wondering at this denial, as well as perceiving it as the source of the strength that enabled her to carry on.(46)

During her own ordeal it was her denial of the seriousness of her condition that enabled her to feel positive about the outcome. She attempted to apply a similar coping mechanism during the time of her husband's illness. Parallels can be drawn from the doctor-patient relationship, too. During the time of her own illness she portrayed Dubois as an emotionless clinician, while Larrey seemed almost a friend. Larrey himself must have felt in a predicament, being confronted with Fanny's constant optimism while trying to retain his professionalism. At the time of her husband's illness Burney found one physician willing to go along with her constant

focus on a positive outcome. Others who denied her the delusion and her dream of her husband's recovery were portrayed as cold and cruel.

**Fanny Burney (Courtesy of The National Portrait Gallery)**



### **1.2.1.1 Napoleon's chief surgeon, Dominique Jean Larrey (1766 - 1842)**

#### **Amputation technique and wound care management**

In 1809 Dominique Jean Larrey had just returned from the battlefield and lectured in Paris until 1812. He operated on Fanny Burney in 1811 with a wealth of experience behind him, gained in Germany, Italy and Spain under Napoleon Bonaparte.

Larrey's parents were French peasants. His father died when he was 13 and he was sent to Toulouse to live with his uncle, Alexis Larrey, the chief surgeon at a large hospital. In Toulouse he attended the school of medicine and surgery and worked at the same hospital as his uncle as a dresser, starting at 15, and later as a house surgeon.

Larrey's first military appointment was in the navy as a chief surgeon in 1797, but he was troubled by seasickness. Therefore, on his return he applied for a position in the military as surgeon of the first class. In the battles of Mayence and Frankfurt he developed his ideas about the 'flying ambulance' that saved the lives of many soldiers. The idea was still in use during World War I and World War II. Today cars and helicopters have replaced the horse and cart, but Larrey's original idea of a fast, mobile field ambulance service has survived. The 'flying ambulance service' was a quick response mobile field hospital bringing first aid to wounded soldiers on the battlefield. It ensured that wounded soldiers were removed quickly, rather than having to wait on the battlefield, often for more than 24 hours, until medical services (heavy vehicles requiring 40 horses) could get to them. Military regulations dictated that these had to stay 3 miles behind the front. He returned to Paris to organise this service in the different army divisions of the new republic.(47)

His next deployment was to Eastern Spain, as the chief surgeon of the army of the Pyrenees. On his return from the battlefield he opened a school of anatomy, physiology and surgery for army and naval officers. In May 1797 he became the chief surgeon for the army of Italy and organised the medical division in Montabello, Northern Italy. His tireless teaching ensured that the training of French army surgeons was extremely good. The peace France had agreed with England was broken in 1803 and Larrey was recalled as chief surgeon. He travelled to Munich and Berlin, lecturing in anatomy and surgery whenever time allowed. He attended the battle of Eylau in Poland in February 1807. The medical conditions of this war were described as unimaginably bad because of the intense cold. Larrey was one of the few surgeons caring for the wounded and dying, regardless of his own needs. Napoleon recognised Larrey's services and gave him the rank of Commander of the Legion of Honour, presenting him with the Iron Cross. He returned to Paris after the battles of Wagram and Essling in July 1809.

Larrey was highly regarded for his loyalty and commitment to his patients and was appointed Inspector General du Service de Santé and chief surgeon at the *Hotel Invalid* in Paris. Thus, when Larrey attended Fanny Burney for her mastectomy, he was both a well-known and experienced military surgeon. He had mastered limb amputation techniques and wound care management. Larrey advocated early operation for battlefield injuries that necessitated amputation. This went against the trend of the time, when most surgeons advocated that the body of the patient should first be given time to overcome the shock of the traumatic injury before an amputation was attempted. Larrey, however, realised that an early amputation would use the fact that the body was still in shock and patients often felt less pain. In his

thesis of 1797 he recommended that '*when an extremity is badly damaged, immediate amputation is life saving in a large number of cases*'.(49, p221).

In 1817 Larrey wrote that most patients who had a primary amputation recovered, while those who had delayed amputation often did poorly. He indicated that about 75% of his patients who had a primary amputation recovered, which is an astonishing figure in view of the extreme morbidity connected with amputation at that time.(49) Some decades later, in 1842, the Paris surgeon J F Malgaigne was still quoting statistics of an overall mortality rate for lower leg amputations in 9 Paris hospitals as 52% and for amputations through the thigh 62%.(48, p435)

Larrey was described as an excellent operator who would instil trust in his patients and work with a calm hand and amazing quickness. An amputation was finished within minutes and sometimes even seconds.(50) Larrey emphasised the importance of a very sharp knife to facilitate his work, as he believed that a dull instrument would increase the pain for the patient. He favoured circular amputation instead of the flap technique, which he reserved for amputation through joints. He ligated bleeding vessels rather than cauterising them. Most importantly, Larrey did not believe in suturing wounds. He used wound closure without skin suture and used bandages of linen, which were previously dipped into sugar, honey and wine. The use of styrax, vinegar and turpentine was mentioned in his papers.(49)

Larrey has been described as a passionate surgeon, concerned almost solely with contaminated wounds and care of the injured. His skill as a surgeon encompassed not only his operative techniques, but also his attitude towards his patients, the planning of the treatment, the preparation of the patient and the postoperative care of

the patient.(50) Incidentally, he was probably preventing sepsis long before Lister invented it.

Larrey would have performed Fanny Burney's mastectomy with the speed and the skill of an experienced surgeon who was used to cutting flesh and bone. Burney's narrative indicates that Larrey tried to avoid the amputation of her breast. He proceeded to surgery only as a last resort to save her life. He planned her operation carefully with Professor Dubois. Larrey's attitude towards her was compassionate and her postoperative care was undertaken with attention to detail.

Fanny Burney was an English lady married to a French man and living in France at a time of hostilities between the two countries. Larrey was a French army surgeon and Burney was fortunate that he believed that his surgical abilities should be used for the benefit of patients regardless of their nationality. Burney described him as a compassionate man who she was willing to trust with her life.

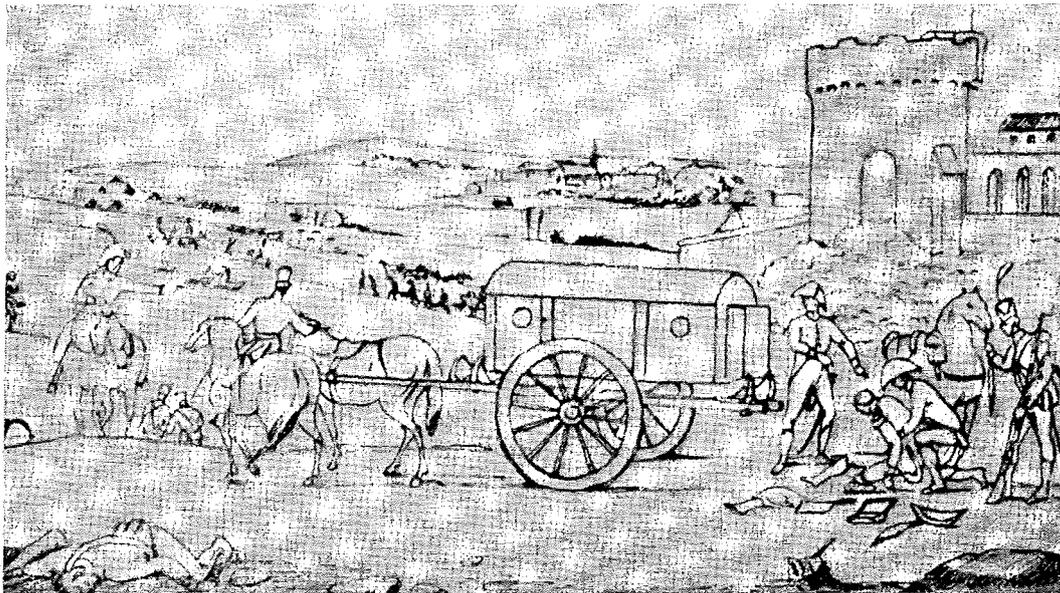
Dominique Jean Larrey (Courtesy of the Wellcome Library London)



*Dollé*

LARREY.

**'The ambulance' (Courtesy of the Wellcome Library London)**



*Larrey's ambulance. Sketch by Duplessis-Bertaux (Val de Grâce Museum, Paris).*

### 1.2.1.2 The mastectomy 1811

Burney's mastectomy experience is to be found in her journals and letters, which she kept since she was a teenager to reflect on events; it was later published. She had initially not intended to write about her illness and operation to her family, to spare them the worry. Unfortunately news of her ordeal travelled fast and she felt it necessary to write to her sister informing her about the 'whole history' herself. She did not want this news to be conveyed to her father.

*'...nevertheless, if they should hear that I have been dangerously ill from any hand but my own, they might have doubts of my perfect recovery which my own alone can obviate. And how can I hope they will escape hearing what has reached Seville to the South, and Constantinople to the East? from both I have had messages - yet nothing could urge me to this communication till I heard that M.de Boinville had written to his Wife, without any precaution, because in ignorance of my plan of silence. Still I must hope it may never travel to my dearest Father - ' (7, p598)*

She dated the entry 30 September 1811 but it was a written account of events which took place at her home in Paris over a period of 4 months. She had started writing this entry on the 22 March 1812, six months after the operation and finished it in June 1812.

Her moving account of what a patient had to endure in the days before surgical anaesthesia created a vivid picture of a time when a breast tumour was treated without analgesia, infection or bleeding control. It offers an insight into the feelings of patients during a time often referred to as that of 'traditional surgery'.

In the letter to her sister, Burney gave an emotional description of the time of her diagnosis, the failed attempts at conservative treatment and finally pre-operative preparation, the operation and postoperative care. The description of the operation points to a procedure quite similar to that described by Lorenz Heister.(see chapter 1.1)

By the time Fanny Burney had discovered her lump, she had been in Paris for eight years. It was her husband and two close friends who insisted that she should seek medical advice after a delay of several months, during which time she had hoped the lump might just go away without treatment. Her lump had become increasingly painful and her arm had become useless. Finally Professor Antoine Dubois was asked for a consultation. Burney had met him earlier at the court of the Empress and Dubois had cured her of an abscess. With the approval of the Empress, this prominent clinician agreed to attend at her home. He gave her a prescription she was to use for one month when he was unable to attend her and told her *'to be tranquil and to suffer no uneasiness'*. He did not give her a diagnosis but instead informed her husband in her absence of the severity of the disease. Fanny herself was left in a state of anxiety and her husband's shocked look after the departure of the clinician confirmed Burney's worst fears: *'his looks were shocking! his features, his whole face displayed the bitterest woe.'* (7, p600) About her own feelings she wrote to her sister:

*'I had not, therefore, much difficulty in telling myself what he [her husband] endeavoured not to tell me - that a small operation would be necessary to avert evil consequences!... for this I felt no courage - my dread and repugnance, from a thousand reasons besides the pain, almost shook all my faculties, &, for some time, I was rather confounded & stupefied than affrightened'* (7, p600)

The couple were told about Dominique Jean Larrey (1776 - 1842), a famous army surgeon noted for his courage and sympathy as well as his surgical skills. It was said that he had cured a Polish woman with a similar breast disease.

Burney described him as follows:

*'M Larrey has proved one of the worthiest, most disinterested, & singularly excellent of men, endowed with real Genius in his profession, though with an ignorance of the World & its usages that induces a naiveté that leads those who do not see him thoroughly to think him not alone simple but weak'.(7, p601)*

Larrey was reluctant to interfere in the treatment of a patient of Professor Dubois and insisted that Fanny Burney request in a letter to Professor Dubois that she would like to be transferred to Larrey's care, citing the professor's over-commitment. Larrey sought advice from two further clinicians with a view to treating Burney conservatively. Unfortunately things got worse within a short period of time and Fanny became unable to climb the stairs to her apartment, making it necessary for the couple to move to a ground floor flat. Larrey insisted that Professor Dubois should see Burney again, and the clinicians made the final decision about the operation that now seemed inevitable.

Burney describes Larrey's reaction after he told her that the operation seemed unavoidable if they were to save her life: *'the good Dr Larrey, who, during his long attendance had conceived for me the warmest friendship, had now tears in his Eyes; from my dread he had expected resistance.'* (7, p603)

After she consented to the operation, there was a delay of three weeks, which kept her in a nervous state of waiting, without a clear idea of when and how the operation would take place. The surgeons told her that they would give her only four hours' notice as it was considered to be better for her not to have any longer to prepare. She

was not given any information about pre-operative preparations, but a friend, who seemed experienced in 'nursing care', arranged to fill her cupboards with compresses and bandages. At Burney's request, the surgeons agreed that they would not tell her husband about the actual timing of the operation. She wrote about her husband and son:

*'Yet my poor M.d'A was more to be pitied than myself, though he knew not the terrible idea I had internally annexed to the trial - but Oh what he suffered! - & with what exquisite tenderness he solaced all I had to bear! My poor Alex [her son] I kept as much as possible, and as long, ignorant of my situation.... I desired, therefore, that M d'A might be kept in ignorance of the day till the operation should be over.'*  
(7, p604-605)

Finally she received a note one morning informing her that the operation would take place within the next two hours. She was horrified that she was given such a short time for her preparations. She arranged for her husband to be called away on business without his suspecting that her ordeal was to take place imminently. She also sent her son away. After two hours she was informed that the surgical team had been delayed and she had to wait another two hours for Larrey and his assistants to arrive. During this time she found it increasingly difficult to occupy herself. She wrote some parting notes to her husband and child in case the operation proved fatal, and finally the surgical team arrived at her house, where the operation took place.

She perceived the entrance of the team as extremely threatening. They entered her room without being announced by one of her maids; she was alone in the room at the time. Professor Dubois acted as 'commander in chief' to the operation. Larrey performed the mastectomy with the assistance of her previous doctors and an unnamed pupil.

In her letter Burney left no doubt that she was kept in the dark about most of the details of the operation. She had been under the impression that she would be sitting in an armchair for the operation and thought that she would be able to wear her long robe de chambre. In order to protect her dignity she had arranged for two maids to be present throughout the operation. Professor Dubois brushed all her preparations aside. She was ordered to lay down on a mattress in the middle of the room and he sent her maids away. She had to insist that at least one be given permission to stay.

The medical team was portrayed as threatening in every way. Burney felt that etiquette was not observed, though one lady was allowed to stay in an attempt to preserve her dignity. A possible reason for this might be the concern of the clinicians for the other ladies and the safety of the operating 'theatre'. Larrey probably wanted to keep control of his operating field and was perhaps worried that the ladies would be shocked and might prevent him operating once he started to cut and they became aware of Burney's immense suffering.

Burney was lying on the mattress waiting for the operation to begin when she realised that Professor Dubois' intention was to remove the whole breast. She had seen through the veil covering her face that he was signalling to his team what should be done and she was horrified. She stopped the professor and explained to him that her sufferings emanated only from one point in her breast and, although the professor listened to her, he made no comment, nor did he give her any explanation. Larrey proceeded to start the operation, leaving her feeling defeated, desperate and hopeless.

She suffered her ordeal with all the courage she could find within herself. She wrote that she did not move, nor did she stop them, nor resist, nor remonstrate, nor speak except once or twice during the dressings. In the face of the most excruciating pain she remembered: *'I needed no injections not to restrain my cries. I began a scream that lasted unintermittingly during the whole time of the incision - & I almost marvel that it rings not in my Ears still! so excruciating was the agony'* (7, p612)

She fainted twice and when all was done she was lifted up and put to bed, not able to control her body. Her last impression was of her surgeon, Larrey: '*& I then saw my good Dr. Larrey, pale nearly as myself, his face streaked with blood, & its expression depicting grief, apprehension & almost horror*' (7, p614)

In her account she described the following sequence for the mastectomy: first she felt the knife plunged into her breast - cutting through veins, arteries, flesh and nerves - the pain she suffered was excruciating. '*When the wound was made & the instrument was withdrawn, the pain seemed undiminished, for the air that suddenly rushed into those delicate parts felt like a mass of minute but sharp 8 forked poncurds, that were tearing the edges of the wound*' (7, p612)

Second the knife cut around her breast in a curve. '*cutting against the grain..., while the flesh resisted... the hand of the operator, who was forced to change from the right to the left*' (7, p612)

Third, just when she hoped that the operation was coming to an end, she realised that the procedure was to be carried on. She wrote that it felt worse than ever when the surgeon: '*to separate the bottom, the foundation of the dreadful gland from the parts to which it adhered-*' (7, p612)

The knife was raking against her breastbone, scraping it and leaving her feeling tortured. She was aware of Larrey asking Dubois whether all remains of the tumour had been removed, but there was still more to endure until Professor Dubois was happy that all had gone. The whole of the operation including the surgery and the dressings lasted 20 minutes.

Fanny Burney's narrative is a precise document written by an articulate woman who had to undergo a mastectomy in the years prior to anaesthesia. The only instrument

available at the time was the knife itself and it was the skill of the surgeon that rendered an operation successful or unsuccessful, and that could increase or decrease her suffering.

Fanny Burney was a life-loving person who, according to her biographers, wanted to maintain positive beliefs at all costs. She could not imagine a permanent state of ill health and was determined to survive.

Burney's narrative shows evidence that the medical team was aware of her distress and that it was by no means trivial to them. Larrey had seen much suffering in the battlefield, but even he was emotionally exhausted after the mastectomy had been performed. He had tried other ways of treating the tumour, always hoping for a successful non-surgical option, but was left with no alternative when these attempts failed. His men in the field perceived him as compassionate and sensitive and operating on a woman must have aroused even more intense feelings. Burney did not seek alternative treatment for her tumour after her own attempts at controlling the disease with diet had failed, and she was quite willing to accept medical advice from Dubois and Larrey to undergo surgery in order to save her life

While accepting surgery as inevitable, Burney still felt threatened by the medical authority displayed by Dubois. She felt threatened as a woman amongst so many men in her house. She fought for a nurse to be allowed in the room during the operation and was horrified to find that she would be lying on a bed, not sitting on a chair as originally expected, without as much as an undergarment.

Her relationship with the surgeon Larrey was more emotional than that with her physician. She described feelings of deepest sympathy for Larrey, who had looked

after her before the operation. She was aware that he had tried every possible option to avoid it.

Modern surgeons, such as Dr Rocke Robertson, who assessed Fanny Burney's case retrospectively, are not convinced that her tumour was consistent with the presentation of a malignant breast tumour. In his view the presentation did not suggest a malignancy; however, the scraping of the muscles beneath the breast might indicate that there was a cancerous invasion after all.(7, footnote 26) The fact that Burney referred to a painful lump points, in the opinion of modern surgeons, to an inflammatory condition. The fact that she survived her ordeal by more than ten years supports the questions raised about the malignant diagnosis. Contemporary knowledge, however, dictated that a large tumour like hers could only be cured by mastectomy, removing as much of the tumour tissue as possible in order to prevent recurrence. Physicians of the early 19<sup>th</sup> century did not differentiate a tumour as either malignant or benign. A tumour was defined as a swelling, and advanced tumours were considered sinister.

### 1.2.2 Emily Gosse (1806-1857)

Because the horrendous pain and the risk of postoperative death after a mastectomy were well known, it is understandable that some women were not able to face surgery to remove a breast tumour. P H Gosse wrote about the experiences of his wife after she was diagnosed with a breast tumour. This is now a rare book and only five copies are in existence.(8) The book was intended for private circulation amongst friends after Emily Gosse's death in 1857. It describes in detail her painful illness and unsuccessful treatment by an American practitioner, 'Dr. F', not identified in the narrative, but believed to be Dr Jesse Weldon Fell. (51)

Emily's friend, Anna Shipton, a writer of religious verse, wrote the story of her friend's suffering using some of Phillip Gosse's material, provoking much attention.(39) It was sold in religious circles and excerpts were published in *'The British Messenger'* for 1 July 1857.(51) Later their son Edmund Gosse (1849 - 1928) also wrote about his mother's death from breast cancer.(38)

Emily Gosse was an established writer of religious verse and belonged to a religious group called the 'Plymouth Brethren'. The Brethren were founded in Germany in 1708. They defined themselves as a Christian group mainly focused on the teachings of the New Testament:

*'The early Brethren were committed to fellowship in community, mutual aid, obedience to the New Testament as their only creed, and rejection of force and violence. They followed ordinances of simple living and dress, the Lord's Supper, feet-washing and anointing for healing of body, mind, and spirit.'* (52, p40)

At one of their meetings Emily Bowes met her future husband Phillip Henry Gosse. When Emily was 42 in 1848 they married, and their son Edmund William Gosse was

born in 1849. The relationship was described as extremely happy, sharing both intellectual and religious interests. The family lived in London.(38)

Emily Bowes' life before her marriage to Philip Gosse is not well documented, but she presumably lived as a single woman in London. She was obviously spiritually anchored in the Brethren's religious community. Her religious writings enabled her to live a financially independent life, true to her religious faith. She was described by her friend as '*a child of God*', following the Lord fully, in happy, cheerful confidence. Her physical appearance was fair and delicate, more youthful than would be expected at her age. She became a caring mother.(39)

P H Gosse was a famous naturalist who published many popular books about natural history and religion. His publications about the seashore, such as 'The Aquarium', published in 1854, were innovative and well received. Gosse had a considerable social standing in London society, but was not rich. He had an income through publishing serials and journals, but it was not easy to earn a living from book royalties. '*Gosse is beyond all comparison the most voluminous writer on Natural History among the present generations of men: his powers are as inexhaustible as his subject. Volume follows volume with a rapacity that is marvellous.*' (51, p8)

Emily became aware of a breast lump in the spring of 1856. She was seen by a Brethren physician who told her bluntly that this was cancer. Mr Gosse recorded that his wife came back in the afternoon with her usual quiet smile and an unbroken calmness but told him that the physician said she was suffering from cancer. Her diagnosis was confirmed by Dr Henry Salter (1823-1871). She was referred to James Paget (1814-1899), who suggested that a mastectomy was necessary. Emily was terrified by the brutality of the operative procedure for breast cancer. Her non-violent approach to life would have made it difficult for her to accept such a procedure for herself. Therefore it was not surprising that she looked for alternative treatment, perhaps drawing again on her religious faith that God would provide

everything from nature's own resources. This, together with her husband's inquisitive naturalism or his belief in Natural Theology, attracted them to the American Physician 'Dr F.'. He offered hope to the couple, who were desperate to find some positive solution for Emily's illness. He quoted them an 80% success rate. (8)

Anna Shipton wrote that she was impressed by the bright hope expressed in her friend's face after she had seen the American doctor: '*The American doctor spoke with confidence of the case as one that promised a happy issue. When I saw her, and marked the vigour of her frame, and the bright hope in her face, I took hope also.*' (39, p57)

To the Gosses his treatment must have seemed like an answer to their prayers. The physician was obviously convincing and gained their trust in the way a surgeon had not been able to. The treatment offered by 'Dr F.' sounded less violent and in line with their fundamental religious rituals of anointing for healing of body, mind and spirit. For the naturalist Gosse, the treatment promised all the hope of a secret cure with elements of native Indian remedies. They had found an alternative way to treat Emily's illness and it was close to their own beliefs and secret hopes, taking away the cold, brutal and violent aspect of death from cancer or mastectomy.

Emily found considerable strength to persevere with the treatment used, as her own beliefs supported it. She endured months of agonising applications of various ointments and had to make frequent journeys, often with her small son, to the surgery of 'Dr F.'. The confidence of their physician seemed to keep the Gosses' spirits high and they even started to make plans for travelling together on one of Mr Gosse's field trips.

Unfortunately the very much hoped for cure did not materialise. At that stage, Emily even agreed to the removal of the tumour, which caused her rapid deterioration.

They continued paying heavy fees, which pushed them to their financial limits, in the desperate hope that all would be worth it in the end. Surprisingly, PH Gosse was still expressing his gratitude to 'Dr F.' even after the treatment had failed and Emily had died having suffered horrendously. It is unclear whether the Gosses ever had any doubts about having made the right choice in refusing a mastectomy. It seems that both Emily and her husband felt that they had made the only choice possible for them and that, although the failure of this treatment was terrible, in their eyes it had been the only way forward. Their son later suggested that he had some doubts about 'Dr F.'s' treatment and did not share the parental view. However, he was too young at the time of his mother's treatment, to influence their decision.

Religious belief played an important role in the shaping of Emily Gosse's breast cancer experience. The Gosses felt that they had found a treatment in line with their beliefs, and were able to fully support that treatment, whereas the mastectomy violated every aspect of what life meant to them.

### **1.2.2.1 Alternative treatment for breast cancer with caustics:**

#### **Dr Jesse Weldon Fell (1857)**

Dr James Paget advised Emily Gosse to have immediate surgery but she and her husband hesitated, as they were aware of the brutality of the procedure. The fear of sepsis and the only slight possibility of cure frightened them.

The fact that anaesthesia under chloroform had been available since Simpson introduced it in 1847 did not help them in their decision about surgery. Anaesthesia with chloroform was still under suspicion in the minds of the general public, and even some of the medical profession. It was seen as a form of dying, and patients would rather undergo the pain of treatment without anaesthesia than face being unconscious.(53)

The fear of pain and infection and the fear of anaesthesia motivated the Gosses to seek alternative treatment. They were advised to try an American physician, not named in the narrative appearing only as 'Dr F, but likely to have been Dr Jesse Weldon Fell. A relation, Dr Salter, had attended an open day in his surgery and was considering alternative treatments to surgery. Fell had trained in America but the medical schools had a poor reputation and were often run solely for profit, and competed for students. Fell was able to gain his MD in two years rather than three. He left America after a dispute with the New York Academy of Medicine, having been accused of accommodating a notorious 'quack', Dr Gilbert, who claimed to have discovered a new cure for cancer. Fell decided to settle in London, hoping to establish a lucrative medical practice. He wrote to a friend stating that he intended to make his fortune by introducing an ointment cancer cure he used in New York.(38) Fell moved quickly

from premises described by Gosse and Shipton as gloomy and in a dull small street with a waiting room full of very poor people to more extravagant lodgings.(8) (39)

Fell set up a clinic one day a week and opened it to any member of the medical profession for observation. Soon the Middlesex Hospital asked him to demonstrate his treatment on the cancer wards. Fell began a trial at the Middlesex Hospital, which was mainly serving the poorer sections of the working class, allowing him to experiment more easily.

Emily Gosse was one of those patients. Having rejected James Paget's advice to have surgery she sought out Fell instead, believing treatment with his ointment would be milder if not also cheaper and quicker. The Gosses met Fell, who introduced to them one of his patients who told them that the pain of the procedure was not worth speaking of. They were reassured by Fell's success rates described as greater than 80%, and Emily Gosse placed herself under his care a month after her diagnosis, hoping that there was no need to extract the tumour. Her treatment lasted almost four months. Despite the fact that the ointment was supposed to be painless, it induced a severe aching of her breast. Her friend wrote '*Many of the applications of the American treatment were of the most painful nature, and these were continued without intermission...*' (39, p70)

She travelled three times a week from her house to receive treatment, obviously a tiring journey: '*Emily's attendance on Dr.F- involved the necessity of a wearisome journey from her house in Barnsbury to Pimlico, three times a week.*' (39, p57)

However, the tumour grew bigger despite four months of treatment and had to be extracted 'surgically'. Emily Gosse and her son found accommodation near Dr Fell's surgery:

*' The long journeys to and fro had now to be discontinued, and a lodging taken for her at Pimlico, near to the doctor's residence...accompanied by her little son, her companion and assiduous nurse.'* (39, p76)

The extraction of the tumour involved the application of nitric acid on the whole surface of the breast on the first day. After that, a series of scratches half an inch apart across the surface of the breast were made with a scalpel and gradually deepened each day.(38) During this time Emily Gosse was said to be distressed and experienced permanent aching, piercing pain and she deteriorated rapidly. The only sleep she could find was induced by opiates. Her friend Anna Shipton described her suffering:

*' Sleep, which up to the present time had not failed, now went from her, and it was seldom that she slumbered but for fitful seasons, and these disturbed by the moan that never escaped her patient lips, except when wrung from her in the extremity of anguish. Unable to find ease in any posture, she wandered up and down her chamber, resting her head from time to time upon the mantelpiece or against the wall. '* (39, p76)

This procedure was repeated twice and when the physician advised her of a third and possibly fourth extraction, she found herself unable to undergo the treatment again. The pain had worn her down and, in discussion with her husband, she decided to adopt a homeopathic approach. She was delighted with the comfort of her own home, but already too weak to survive for much longer.

*' Her nerves were shattered by unceasing pain, and the enfeebled body worn by sleeplessness and the semi-recumbent position which she was obliged to maintain. The powerful remedies, used to combat the disease and produce sleep, had acted on the susceptible nervous temperament, so that the once strong brain and vigorous thought could no longer be concentrated upon a subject, and many days she could*

*look no farther than to the cessation of the present paroxysm of pain, to the hope of relief.*' (39, p85) She died in 1857.

Emily Gosse was advised that Fell's treatment would be less radical and less dangerous than having her breast removed surgically by James Paget. Perhaps, as has been suggested, the naturalist and zoologist Gosse was also attracted by the offer of a secret remedy, often the trademark of a 'quack' practitioner. In his publications, Fell said he derived his remedy from the Cherokee Indians. This was close to the heart of the naturalist in Gosse, who might have been intrigued as to the background of this remedy. He presumed it to be based on plants and animal ingredients, linking it to his belief of Natural Theology which stated that the creator had a remedy from nature for all diseases. Later PH Gosse quit the Brethren sect, as he was no longer able to believe after the death of his wife.

In 1887 two cases of cancer of the breast treated with caustics were published by Henry T Butlin as part of the St Bartholomew's Hospital reports. This description of treatment was very similar to that described by Gosse as having been performed on his wife. The main difference from the narrative by P H Gosse was that Butlin clearly stated that his patients experienced severe pain while he was applying Vienna paste and there was no mention of a secret ingredient in Butlin's case reports.

When Dr Fell realised that Emily Gosse's tumour was still growing despite the application of caustics, he decided that it had to be removed. It was only later that it became known that Dr Fell's claim of an 80% curative rate was exaggerated and that many of his patients had a recurrence within one year. He also failed to warn his patients of the severe pain involved in caustic treatment.

Emily Gosse and her husband were caught in the controversy related to surgical treatment of breast cancer and treatment with caustics by 'quacks'. Despite James Paget's advice to Emily to have surgery, the Gosses' fear of this treatment led them to Dr Fell, who promised them a successful non-surgical option. Treatment with caustics was offered as mild and almost pain free.

#### 1.2.2.2 Treatment for breast cancer with caustic paste: HT Butlin (1887)

In 1887, HT Butlin published as part of the St Bartholomew's Hospital reports the treatment of breast cancer with caustics of two patients who were described as '*one of advanced age, the other of very weakly constitution*'.(9, p57) Both cases were unsuitable for surgery.

The first case report offered a straightforward description of the procedure consisting of the application of two pastes. Vienna paste was applied with a brush as the initial coat. This paste consisted of equal parts of caustic potash and caustic lime, which were made into a paste with alcohol, forming a mixture of calcium hydroxide and potassium hydroxide used as an escharotic. The paste was used to destroy the skin around an ulcerated cancer without being applied to the ulcer directly. Within ten minutes of application the skin became red, then black and was completely destroyed. The Vienna paste was then removed with cotton wool and the surface dried. Where bleeding occurred, it was treated with a nitrate of silver stick.(9)(54)

Bougard's paste was then applied as a second coat over the whole surface of the malignant ulcer and the blackened skin. The full recipe for Bougard's paste was given in the article. In essence, it was a paste made out of wheat flour, starch, arsenic, simoniac and a solution of chloride of zinc; reference was made to prior use as published in Brussels in 1882. This paste was applied for five to six hours, held in place by lint, a compress of cotton wool and bandaging. Twenty-four hours later, Butlin was able to cut the burnt tissue with scissors and separated it easily from the parts below. The treatment was repeated for about 12 days until all diseased tissue appeared to have been removed. A month later, the first patient left hospital and remained healthy for more than 15 months after the operation.

The second case report contained a warning. This patient developed a severe reaction to the treatment. She had a high temperature and her pulse became weaker.

Further treatment was not commenced for a few days until the condition of the woman improved.

The application of Bougard's paste did not seem to be painful; however, the application of Vienna paste caused severe pain. Butlin observed *'During the application of the Vienna paste she (the patient) undoubtedly experienced severe pain, but being a courageous woman, bore it without murmuring.'* (9, p59)

Butlin was a surgeon by trade but stated in his article that caustic treatment, traditionally administered by 'quacks', should be used more frequently in surgical practice, especially in circumstances in which surgery might carry a high risk. He wrote that it was important to give patients the choice between caustics and the knife:

*'Under these circumstances it seems only reasonable that we should avail ourselves of it in cases in which there were reasons to dread a surgical operation, and that in many other cases we should at least give our patients the choice between caustics and the knife, setting before them as clearly as possible the amount of risk to life on the one hand, the pain and slow course of the treatment on the other hand.'* (9, p63)

This statement was revolutionary at a time when surgeons were not seen to advocate non-surgical procedures and their relationship with so-called 'cancer quacks' was strained. Butlin compared it to the relationship between surgeons and 'bone-setters' as described by Roger Cooter.<sup>(55)</sup> Bone-setting was regarded as a family trade and the knowledge was passed on from father to son, but surgeons questioned the treatment and considered it dangerous.

Butlin advocated that the knowledge of 'cancer quacks' should be absorbed into surgical practice. This would limit the remit in which quacks could function. Butlin warned that many patients who feared surgery sought help from quacks: *'... many of*

*our patients with cancer fall, through an apprehension of the knife, into the hands of cancer-quacks...'* (9, p63)

Butlin's aim was to defeat the 'cancer-quacks' by learning their successful methods and incorporating them into his own practice:

*'... so must we meet and defeat the cancer-quacks, not by ridiculing his methods and refusing to credit the accounts of his success, but by making his methods our own and by employing them with a far better knowledge of disease than he is ever likely to attain to.'* (9, p64)

**Henry T Butlin**

**(By kind permission of St Bartholomew's Hospital Archives & Museum)**



### 1.2.3 Death from breast cancer without treatment:

#### Zelie Martin (1877)

Zelie Martin was a French lacemaker who died from breast cancer in 1877. She lived with her husband and five daughters in Normandy. In an analysis of her diary, she was described as a living example of the values of the Catholic middle classes of northern France.(40)

Zelie Martin wrote regular letters to distant relatives. In her letters she enjoyed idealising herself and her life as she wanted to see it. She used these letters to express herself, in addition to her role as mother and wife. Zelie discovered her breast lump in 1865 and mentioned it in a letter to her brother. She asked his advice about seeing a surgeon in Paris, but her brother, who was a pharmacist, advised her instead to use tonics and scented oils. Despite the fact that Zelie doubted the value of those ointments, she did not question his advice, and the visit to a surgeon in Paris was never made. She said herself later: *'I knew that there was nothing to be done but an operation, and the thought of it made me shiver, not because of the pain but because I was sure that from that moment onwards, I would be bedridden and would not recover.'* (40, p385-386).

Zelie believed that a traumatic incident was the origin of her breast tumour, a belief that was a common explanation of why a patient developed a disease. She remembered a blow to her chest when she was a young girl and, although she had paid no attention to it at the time, she believed that it had caused the lump in her breast. Initially, the lump did not hurt and Zelie did not mention it in her letters for ten years, although she wrote about other illnesses, such as those of her children. She sought a second opinion from doctors when four of her children were taken ill,

but unfortunately nothing could be done to save them. Reference to this episode in her letters indicated that she had frequent contact with doctors after she had discovered the lump in her breast, but she never asked for a personal consultation and neither her brother nor her husband or friends encouraged her to do so. After the discovery of her breast lump in 1865, she gave birth five times and remarked that she had difficulty in nursing her babies by 1870. It was not until December 1876 that she finally decided to consult a doctor. In her letters it had become clear that the breast lump had grown and become painful. Her consultant told her that she had a fibrous tumour and that, in his opinion, an operation was not really a possibility. He gave her a prescription, but both Zelig and her doctor were fully aware that it was not going to help. When she asked him what good it would do, he replied: *'It is of no use, it is just to please the sick.'* (40, p389).

After this consultation, Zelig concluded, *'I am very grateful to him for his frankness, because I know now that I must wind up my business affairs, so as not to leave my family with any debts'*. (40, p389).

She told her husband about the consultation and he was devastated. He had only recently become aware that there might be a problem and it is possible that Zelig never spoke to him about her disease, as she would have seen it as unfitting for a wife to discuss discomfort in a female organ.

Zelig Martin described her tumour only in the early stages. After her tumour had become ulcerated, she referred to it in her letters as 'my wound'. There were minimal descriptions of her feelings about the tumour or the pain it caused her. The disease must have spread to her bones, as her main complaint became that of extreme pain in

her neck, which probably indicates that she had developed metastatic bone cancer. In 1958 her body was exhumed and reburied when she joined the family of saints at the Basilica which was built in honour of her daughters. Her skeleton showed evidence of damage to three vertebrae at the base of her neck and to her left shoulder bone. Zelig tried to conceal her suffering from her family and continued as long as possible as if nothing was wrong. She wrote that she regretted speaking to her family after a consultation with her doctor because they became so worried and wept. This made it more difficult for her to create an atmosphere of normality.

In June 1877 she had a second consultation with her doctor. It was during this visit that the anger and frustration about her situation erupted. Zelig challenged the clinician about why there was nothing to be done and pressed him about when the tumour would break open. She again mentioned the possibility of an operation, but her consultant reminded her that it had already been decided that an operation was not possible. He told her that no one really knew how the disease would progress. She objected to his tone of indifference and boredom, writing that she believed the doctor was heartless: *'I feel such a rage against the man's heartlessness, I cannot express it...even the sight of him makes me sick.'* (40, p392)

During the final stages of her illness she was prescribed a sedative, although at this time doctors and patients were often unwilling to use addictive drugs. She wanted to avoid lapsing into a drugged and unaware state, which she felt would leave her helpless, and in the hands of others: *'I have not yet taken it, for the great crisis is passed, although I continue to feel pain everywhere.'* (40, p393)

On a second home visit she was not prescribed any more sedatives, despite the fact that the illness had progressed and her pain was more severe. She was given a prescription for Eau de Vals, which was really just plain water, an act that was quite inexplicable under the circumstances. It can only be presumed that Zelig Martin was unfortunate in her medical attendant.

Zelig had discovered her breast lump in 1865 but did not seek medical advice until 1876. Despite her better judgement, she accepted her brother's advice and did not seek another opinion, although to do so was customary at the time. During the consultation with her doctor, she portrayed a fatalistic attitude towards his unwillingness to offer treatment. She died in August 1877.

At the time of her first consultation her tumour would have been quite advanced and had become painful. By June 1877 she was referring to the tumour as 'my wound', indicating that it had ulcerated through the skin. She wrote to her sister-in-law that the wound had started to weep, but there was no mention of the smell caused by the advanced breast tumour. It was only when she had become unable to dress herself that she allowed some of her emotions to show in her letters, expressing desperation as the debilitating effects of her disease developed. She wrote:

*' You ask again that I speak to you of my malady, alas! What can I say? Only that the illness advances day by day. I can no longer dress myself, nor undress without help, my arm, on the affected side, refuses to work at all, but my hand, it still is willing to hold a needle.'* (40, p395)

Friends sent her advertisements of alternative treatments but she refused all of them. She perceived 'quacks' who promised a cure through their ointments as witch doctors.(40, p395) The only ray of hope she allowed herself was attached to her Catholic faith. She went to Lourdes to take the water, which supposedly had cured many people, including a woman with breast cancer. She undertook the journey in June 1877, accompanied by three of her daughters. Zelig had some hope, but she was also realistic: *'Why would there be a miracle for me, rather than for this or that other whom I have seen die, leaving numerous family.'* (40, p397).

The journey was strenuous and hastened the progress of her disease, robbing her of her last hope. She wrote: *'I am not cured, quite the opposite, the journey has aggravated the illness.'* (40, p397)

The Catholic Church profoundly influenced the life of Zelig Martin. She wrote extensive letters, preserved by her daughters. Zelig herself did not keep copies and her letters were casually hand-written, most of them to her sister-in-law, Celine Guerin, some to her brother, husband and daughters. Therese Taylor has described Zelig: *'Zelig Martin was a living example of the values of the Catholic middle classes of Northern France. She was conservative, hard working, and consolidated her whole identity with her role as a wife and mother.'* (40, p381)

Zelig and her husband married when she was 26 and lived in Normandy. Her husband had a jewellery store and she had her business as a lacemaker. Their marriage was based on Catholic principles and they had 5 surviving children. Her biographer describes Zelig as a strong woman running her home as a matriarch.

She defined her life through her family and her work. Her breast cancer experience was an unusually long one, from her first mentioning the lump to the terminal stages

of her illness almost 15 years later. It is possible that a malignancy developed in an initially benign lump. She lived her life without ever focusing on the illness and mentioned it in its early stages only once, in a letter to her brother, when she sought his advice on going to Paris for a consultation with a surgeon. She then did not mention the disease again until much later. By this time she had another five children and the disease had become too advanced to ignore it any longer. She herself never believed in her brother's ointments, and despite realising that surgery was the only option, she never pursued the issue further. It was her belief that the operation would speed her deterioration and make her helpless, rather than offering a realistic hope of cure.

Even in her later consultations, she had an unusually open discourse with her doctor, who once more prescribed some ointment, although he was aware it was only a placebo. It was common at that time to let a disease run its course when doctors felt that there was nothing that could be done to cure a patient. Pioneering surgeons like Larrey and Paget had not gathered enough evidence that an operation really did offer a cure for breast cancer.

Zelie's Catholic religion glorified self-sacrifice and limited her ability to express weakness, even during the most painful periods of her illness. On the rare occasion that she wrote in her letters about her suffering, she instantly apologised for her weakness. She did, however, feel much more realistic about the benefit of her suffering in this life as it affected her life after death. Catholic teachings held out the hope that sin would be forgiven if pain was endured in this life, and Zelie agreed with this belief. She felt it was much more important to prepare for death by sorting all family and financial affairs and to leave everything in an orderly state. This to her was of utmost importance and gave her the strength to carry on her work as a lacemaker in the months before she died. She did not want to leave any debts and did not allow herself to show weakness. She believed that she was alive as long as she was working.

Zelie did not hope for a cure from clinicians and 'quacks', nonetheless she was prepared to try Lourdes. Even this trip was seen as hopeless in the end, and with a hint of scepticism and resignation. Zelie had a strong family and although she did not allow herself to burden them with her illness, her daughters remembered her heroic suffering vividly in their own letters. One of Zelie's daughters was to attain posthumous fame as Saint Therese of Lisieux, and the Martin sisters created a 'saintly cult' of their family, rewriting their personal histories. It was only Zelie's death that did not fit the picture of a family specifically chosen by God. How was their mother's suffering to be explained in these terms? Instead, Zelie's saintly courage was praised and she was remembered as part of a 'family of saints'

## **2 The debate at the turn of the century:**

### **radical mastectomy vs. conservative surgery**

Surgical and non-surgical scientific developments influenced the way patients were treated as well as the doctor-patient relationship. Surgical procedures were performed more often and more accurately, with a better short-term survival rate, after the development of anaesthesia and infection control. Long-term survival rates were improved by better diagnostic possibilities due to the publication of 'Cellular Pathology' by Rudolf Virchow (1821-1902) and the discovery of x-ray in 1895 by William Conrad Roentgen (1845 -1923). The Medical Act of 1858 ensured that surgical training was no longer regulated through apprenticeship but through earning a degree from a university. This in turn changed the social standing of the surgeon in society.

Three influential surgeons in breast surgery illustrate that change. Theodor Billroth (1829-1894), a representative of the early days of modern surgery, assessed new developments and adopted changes into his operating theatre when he realised their life-saving potential. He was able to assess the impact of anaesthesia and infection control when he advanced his research methodology. He expanded the common case report to include a whole series of his patients, attempting a first statistical analysis. The American surgeon William Halsted (1852-1922) was greatly influenced by Billroth's surgical skills, research and teaching. He became one of the most influential surgeons in breast cancer surgery. He published the methodology for a radical mastectomy for breast cancer, which remained the standard treatment for breast cancer until the mid 20<sup>th</sup> century.

The discovery of x-ray treatment and the subsequent possibilities of radium implants provoked a debate on radical surgery vs. lumpectomy and radiotherapy. Geoffrey Keynes (1887-1982) was one of the first to demonstrate the use of radiotherapy in breast cancer patients and became an advocate for less disfiguring surgery.

Qualitative data collection was replaced by quantitative patient assessment, which caused the disappearance of the voice of the patient, who up to this time had been a 'key player' in the diagnosis and treatment of cancer. Patients were no longer playing an active role. The need for communication between patient and doctor was replaced by scientific methodology designed to provide objective, often numerical, results that would enable a clinician to find a more specific diagnosis. Treatment was becoming more effective and less painful as patients were anaesthetised. The lack of patient involvement created a void and a need for better support in the form of more information, emotional support and financial help. The charity Cancer Relief Macmillan Fund (CRMF) was founded at the beginning of the 20<sup>th</sup> century by the carer of a patient suffering from cancer who felt that there was a desperate need for better information and patient support.

## **2.1 Major scientific developments in surgery improving the short-term survival of the patient**

The fear and experience of severe pain during breast cancer treatment dominated previous patient narratives. Women delayed seeing a doctor and refused surgery, hoping for a cure by alternative treatment, or accepted death rather than face the excruciating pain of a mastectomy without anaesthesia. There was a lack of effective pain relief, which might be explained in two ways. First there was limited scientific knowledge about the use of natural resources such as narcotic analgesia. In addition, in deeply religious circles, there was a belief that pain was associated with punishment from God and therefore not to be minimised. Advances in surgery during the second half of the 19<sup>th</sup> century addressed the control of pain by the invention of anaesthesia (1846).

Surgical case reports and clinical papers reflected the concern of surgeons for the survival of their patients after major surgery for breast cancer. This was largely due to the difficulties in controlling bleeding and sepsis. Operations were postponed as long as possible and considered only in very severe cases, for example when the life of the patient was in question anyway, such as when a tumour was pressing on the windpipe (trachea).

The introduction of anaesthesia and infection control, first described in 1864, allowed surgeons to consider an operation at an earlier stage of the disease, as survival of a patient after surgery was more likely. After an extensive learning curve, the operations could now be undertaken with fewer time constraints. The surgeon was able to operate more accurately and extensively due to the relative calm

of the operating theatre. Patients were anaesthetised and not screaming in agony. Immediate postoperative survival was greatly increased when infection-controlled theatres and techniques came into practice.

It was now possible to treat a woman with breast cancer at an earlier stage of the disease. During the operation, patients did not endure torturous pain, and postoperative survival rates increased. The operation was performed under anaesthesia and the operating field was sterile. This enabled operations to become more extensive in an attempt to control localised tumours.

### 2.1.1 The control of pain with anaesthesia (1846)

Patient narratives from the first half of the 19<sup>th</sup> century show that the treatments for breast cancer during that time were terrifying for women. Women were afraid of the pain they would have to suffer if they had a mastectomy. Fanny Burney gives the reader a vivid account of the agony she suffered during her operation, while Emily Gosse's account is an example of the desire to escape the severe pain of a mastectomy, whilst enduring the agonising pain of caustic treatment. Zelig Martin shows the suffering involved with a progressing tumour endured without treatment.

Even today we are unable to explain what pain is, but we are better at controlling it. Prior to the development of surgical anaesthesia, attempts were made to control pain with alcoholic mixtures given before or during surgery or to induce loss of consciousness with compounds from roots, barks, herbs, berries, seeds or blossoms, derived from plants such as the poppy, mandragora and hemp.(56) The use of these non-purified agents was dangerous because there was no standard dose, which often resulted in the death of patients due to overdose: *'Probably one of the reasons why anaesthesia in general was so slow in developing was the fact that no drugs were standardized. No attempt was made to purify them or to regulate dosage. Often a drugged sleep resulted in death.'* (56, p8)

The lack of effective pain relief before 1846 can be explained in two ways. First, scientists in biology and chemistry had not yet developed controlled dosages of drugs derived from plants. Second, as pain was unavoidable, a religious view fostered the belief in society that associated pain with punishment from God.(57)

Pain was regarded as an inevitable part of surgery. It was considered something that patients had to bear with courage. This way of thinking inhibited surgical advancements: '*...whatever the viewpoint the practice of surgery was inhibited by the associated pain and suffering until the advent of general anaesthesia a mere five generations ago.*' (57, p70)

Recalling the story of Fanny Burney (1811), she and her surgeon, Larrey, would have welcomed any discovery that avoided pain, but the first operation under ether anaesthesia was only done 35 years later. On 30th September 1846, the dentist William Thomas Green Morton (1819 – 1868) removed a tooth under ether anaesthesia. Days later, Morton approached a surgeon at the Massachusetts General Hospital and performed ether anaesthesia on 16th October 1846. He successfully invented one of the most important developments for the surgical treatment of patients.

Morton used the 'Wulffsche Flasche', with two openings and a glass ball as big as a fist. The glass ball was filled with sponge pieces that were covered in ether. In the bottle was a wooden pipe, which was taken into the mouth by the 20-year-old patient, Gilbert Abbot. The patient inhaled the ether and the surgeon removed a tumour in the neck area. The operation was performed without any screams of pain by the patient although Abbot claimed that he was aware of being operated upon. (58) (10)

Horace Wells (1815-1847), who attempted anaesthetising with nitrous oxide, made the second claim to a different agent for anaesthesia. He was given the opportunity to demonstrate his discovery in an operating theatre, but unfortunately his attempt at

anaesthesia was not successful. The patient developed a typical aggressive reaction phase, quite common to the inhalation of nitrous oxide. Following his failure, Wells did not attempt to demonstrate his discovery in public again, although he continued to use it in his own practice. (59)

James Young Simpson (1811 - 1870) in Edinburgh developed a third type of anaesthesia. Chloroform had been discovered almost simultaneously in Germany, France and in the USA. Simpson assisted childbirth with sulphuric ether on 19th January 1847. On 20th November he published the first preliminary report on the use of chloroform in the Lancet.(60) Chloroform was given to Queen Victoria during the birth of her son Leopold in 1853 and the birth of her daughter Beatrice in 1857. It was argued that this type of anaesthesia could not possibly be conceived as something dangerous, as danger was sure to be kept away from the Queen.

Chloroform replaced the use of ether in Great Britain and some European countries such as Germany, France and Austria. In the United States, however, the use of ether prevailed. D R Kindschi suggested that its use in Europe might have been due to the considerable influence of both Simpson and the Edinburgh school. (61).

Anaesthesia was viewed by some with alarm. It was seen as immense progress of science by some, but challenged by others. Anaesthesia offered an almost unimaginable solution to the cruelties of surgery, but worries about patients' safety during anaesthesia remained. The following is the French response to the publication of Mr Lister's operations performed without pain at the University Hospital London:

*'... you poison patients to spare them pain? But are you certain that they will awaken afterwards? It would be of greater benefit to have them sleep under an UPAS tree or render them dead drunk with the help of a good dose of gin!! ... Sad experiments! Homeopathy and mesmerism shake hands these days in Paris as well as London' (53, p608)*

Safety measures did not feature in the early days of anaesthesia. The use of ether in so-called laughing gas parties did not help to engender a feeling of safety in patients or surgeons. The parties showed that anaesthesia induced insensibility. This caused a high level of anxiety for patients, who felt that they might develop temporary madness. Even surgeons who were able to see the benefits of anaesthesia viewed these side effects with suspicion and were reluctant to adopt a new scientific development without convincing evidence of its safety.(10)

The inventors themselves denied the dangers of anaesthesia, despite the first death of a 15-year-old girl in 1848.(62) Death from chloroform anaesthesia was reported almost on a weekly basis, but its use continued. It was as if surgeons who believed in its benefits were willing to deny the dangers because it made such a difference to their daily operating procedures. They seemed willing to take their chances rather than going back to submitting their patients to the agony and pain of an operation without anaesthesia.(62).

A cautionary note on anaesthesia was published in the Lancet in November 1854 and concern was raised in the United States and in France. The Boston Society for Medical Improvement decided that the use of chloroform was too dangerous. In

France JE Petrequin championed the use of ether, as he was able to provide 15 years of evidence without a single death. (62)

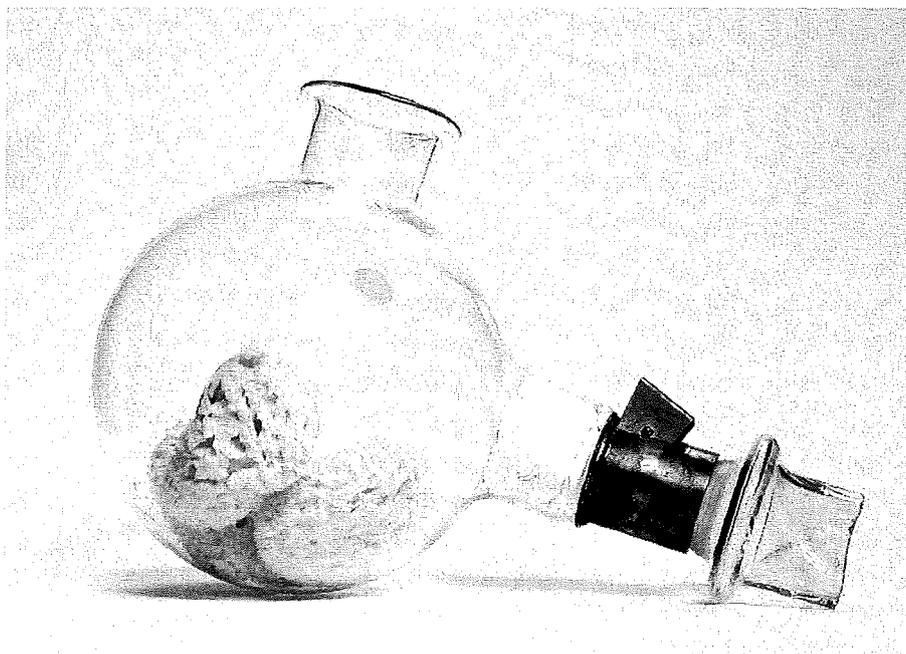
For almost a century after the invention of anaesthesia surgeons practised according to their personal preference, weighing up the risks of anaesthesia against the suffering and potential inaccuracy of an operation under time constraints without it. Statistics for the fatal complications of ether and chloroform anaesthesia were only published in 1934, although results were collected between 1890 and 1897. These showed that ether anaesthesia was safer, with a complication rate of 1 in 14,000, or 1:28,000 if an anaesthesia machine was used. Chloroform anaesthesia had complication rates of 1:3,000.(62, p149)

Anaesthesia could not be used for the mastectomy of Fanny Burney in 1811. However, it was used in the period when breast cancer was diagnosed in Emily Gosse and Zelig Martin. Neither woman mentioned anaesthesia or the possibility of pain-free treatment in her narrative. With Zelig Martin, this might well have been due to a lack of knowledge as she lived in rural France. However, it is surprising that Emily Gosse and her naturalist husband were not aware of the possibilities of anaesthesia, as they were in contact with scientific circles. Given the continuous debate about anaesthesia, the Gosses might have encountered information but felt it was an uncertain development and that they were better served by alternative treatment. In addition, the alternative method seemed to conform to their religious beliefs that God provided the right treatment for a disease from nature if that was the destiny for the person.

William Thomas Green Morton (Courtesy of The Wellcome Library London)



*W. T. G. Morton*



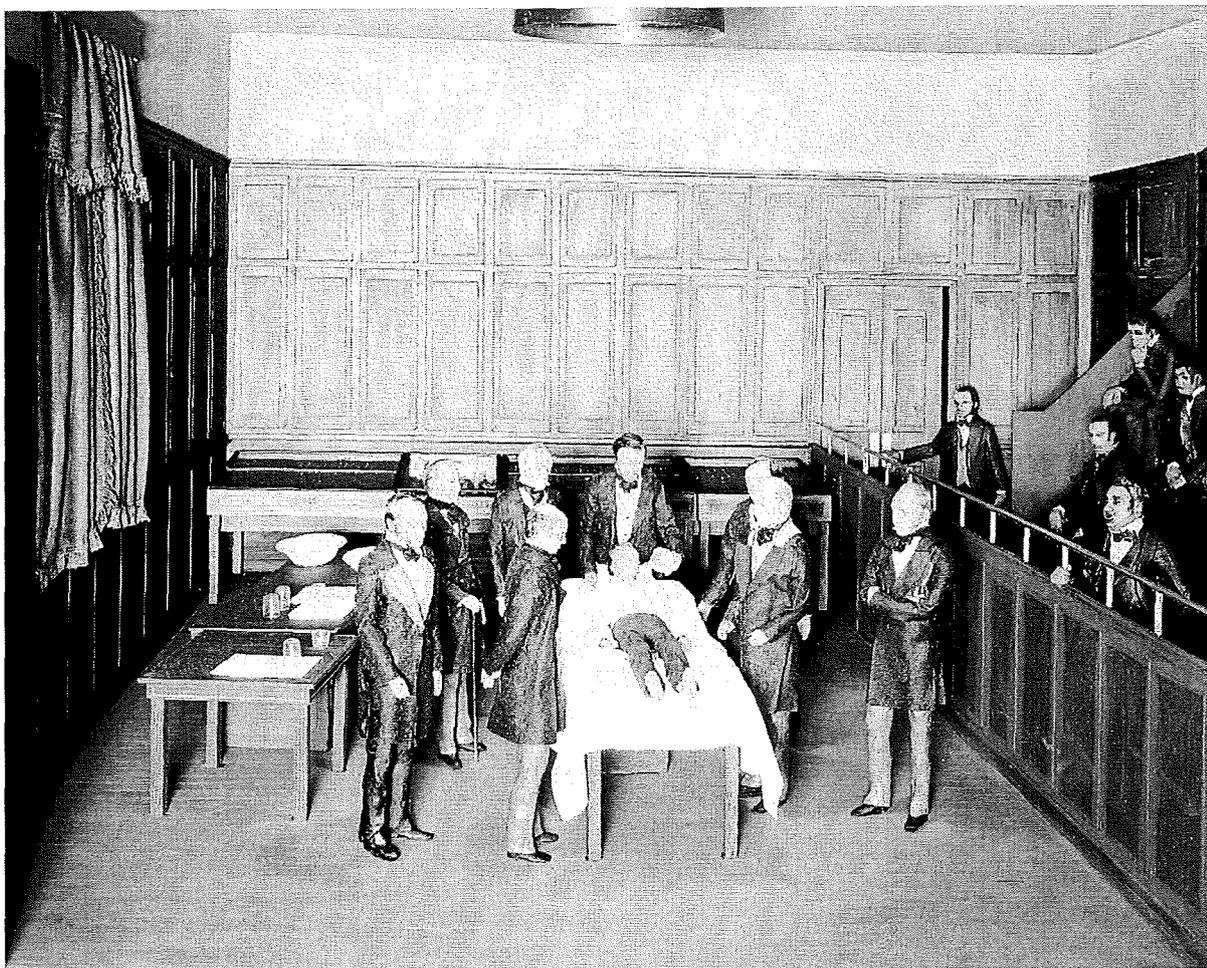
**Horace Wells (Courtesy of The Wellcome Library London)**



**James Young Simpson (Courtesy of The Wellcome Library London)**



**Surgical Anaesthesia (Courtesy of The Wellcome Library London)**



### 2.1.2 Increased survival rates after the introduction of infection control (1864)

Anaesthesia, despite all reservations, opened the door to more surgery, but it did not increase the use of operative interventions dramatically. Short-term postoperative survival was still low due to complications and death from sepsis.

Wound infection remained a major complication in all surgical procedures, including amputation and mastectomy. Cleanliness was not seen as important in surgery. Case reports and patient narratives alike did not emphasise the necessity to wash or use clean equipment. Fanny Burney's mastectomy was performed in her home. Her surgeons were dressed in their street clothes and no special arrangements were made for cleanliness before, during or after the operation. Her home, however, was still a safer place for the operation because a stay in hospital would almost certainly have ended with an infection and possibly postoperative death.

First awareness of a need for increased cleanliness was demonstrated in 1848/9 by Ignaz Philipp Semmelweiss (1818-1865). In his *'Antiseptic system of midwifery'*, published in Vienna, he argued that contagious infection could be avoided by scrubbing with soap and water, using a fingernail brush, and doing a second scrub with chlorine water before examining any patients internally. Semmelweiss used this method to avoid postnatal infection in women, but his theory did not find wide acceptance amongst his colleagues. (12)

In 1867, Joseph Lister (1827-1912), Professor of Surgery in Glasgow, published his *'Illustration of the antiseptic system of treatment in surgery'* in the *Lancet* as part of a series of three essays.(63) Initially he soaked his surgical instruments in a solution of carbolic acid and used carbolic-soaked dressings to prevent contamination through atmospheric bacteria. A picture published in 1882 as an example of complete aseptic precautions still showed the surgical team dressed in their street clothes, without masks and gloves.(12) Lister's discovery coincided with a widespread public health

movement. Hospitals were becoming much cleaner, although bacteriology had not yet been established: *'Surgical cleanliness through soap and water, and frequent changing of dressings, was being widely advocated simultaneously to, but independently of, Lister's antiseptics.'* (12, p135)

Surgeons were confronted with evidence of their responsibility for the postoperative survival of their patients. The success of an operation was now determined by an exact operating technique and awareness of the need for cleanliness to avoid infection. Surgical operations became safer and postoperative survival increased.

The operative mortality for radical mastectomy dropped from 21.3% to 10.5% and the overall mortality from 15.7% to 5.8%. (3, p82) Death rates from leg amputations dropped even more than for other operations after the introduction of infection control and antiseptic procedures.

<b>Amputations performed by Professor Lister</b>	<b>1864 -1866</b>	<b>1867 - 1869</b>
<b>Died</b>	N = 35 16 (46%)	N = 40 6 (15%)

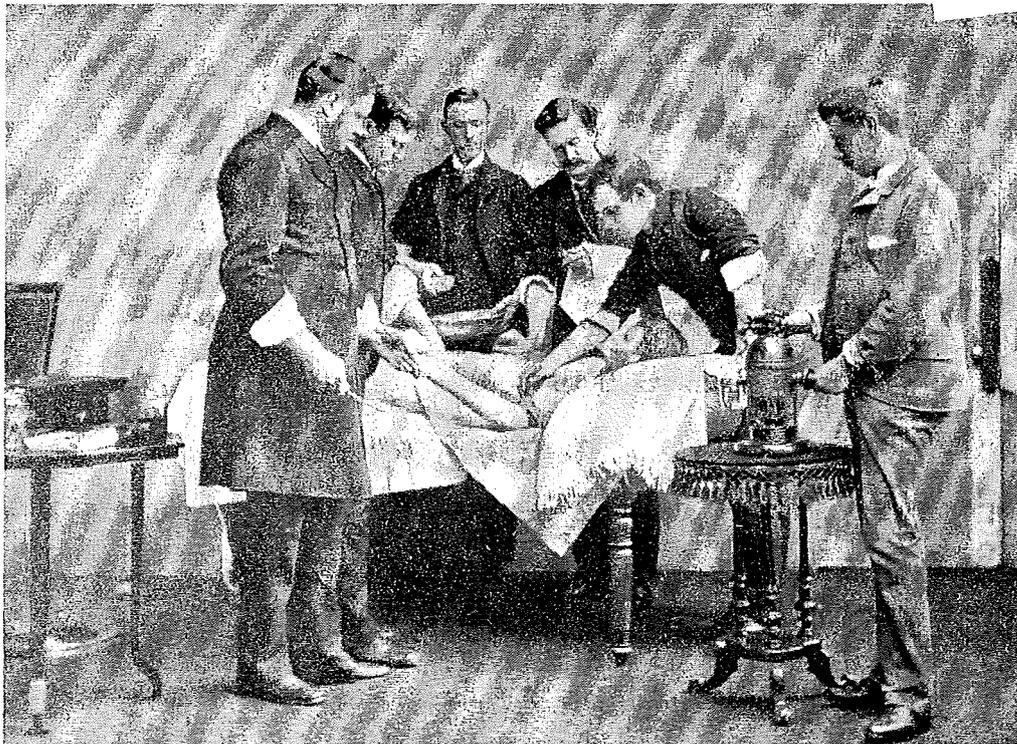
(63, p989)

The responsibility for wound cleanliness lay with the surgeon and the operating team. Before this, pus in a wound was seen as part of the natural wound healing process. Now infection could no longer be seen as part of the natural wound healing process but had to be avoided in order to ensure better postoperative survival.

Operating theatres and hospital wards changed in their appearance. The surgical team wore gowns, gloves and masks. In 1874 L Pasteur (1822-95) started to clean instruments by immersing them into boiling water and K Schimmelbush (1860-91) developed sterilising drums, which were further improved by E Travel (1858-1912) into a pressure steam sterilisation process. The hospital was of *'...spotless purity*

*containing scintillating metal furniture and ingenious electric lights. All concerned in the operation are clothed from nose-tip to toe-tip in sterilised linen gowns, their hands covered with sterilised rubber gloves.'* (63, p992) (64)

Joseph Lister (Courtesy of The Wellcome Library London)



## **2.2 Major scientific developments improving long-term survival of the patient**

As short-term survival was becoming more certain, long-term survival began to play a role in breast cancer treatment. Two major developments influenced the way patients with breast cancer were treated. In 1858 Rudolf Virchow (1821 – 1902) published 'Cellular Pathology'. This publication offered a scientific explanation for tumour development. The cell was described as the bearer of life and therefore also of disease. Disease was explained as life under altered conditions, a reaction of the cell to abnormal stimuli.(13) (3)

The second important development was the discovery of x-rays by Roentgen in 1895. It enabled the development of a concept of adjuvant therapy and surgeons started to question the necessity for radical operations for breast cancer when local control of the disease might be achieved with lumpectomy and radiotherapy or radium implants.

### 2.2.1 The publication of 'Cellular Pathology' by Rudolf Virchow in 1858

The clinical diagnosis of breast cancer was not difficult when a woman presented with an ulcerated breast and complained of intolerable pain. Before the lump penetrated the skin, a clinician tried to determine whether it was benign or malignant. Consideration was given to the possibility of a breast lump being of local origin, i.e. caused by a trauma, by inflammation or milk retention, or whether it resulted from another internal cause.

Pathology was at '*an advanced but curiously helpless state*'(65, p114) when Virchow suggested that the cell was the source of all life and therefore the source of disease. The biological principle of '*omnis cellula e cellula*' (each cell stems from a cell) formed the foundation for further developments in pathology.(13) A new definition of cancer evolved from Virchow's theory. Herman Tillman (1844-1927), for example, developed a new explanation for cancer. He argued that from the epithelium of the skin and the duct cells, cancer breaks through the normal tissue at the early stages of the disease. The main characteristic of the cancer is that it shows a limitless peripheral growth in the form of epithelial metastases, which sometimes move along the lymph and sometimes within the blood circulation. Finally the disease will lead to the death of the patient.(66) (3) (67)

Until the development of experimental surgery or surgical pathology, the diagnosis of breast cancer was determined by physical examination. This was limited to the affected breast and its immediate environment. Attention was paid to the colour of the skin, the presence or absence of swollen veins, the position of the nipple, the consistency of the lump, the degree of irregularity of its surface and its fixation to the

skin or to the chest wall. The examination was completed by surgical palpation of the nodes in the ipsilateral axilla, in the supraclavicular area and in the neck. If the tumour was smooth and mobile and menstruation was unimpaired, it was thought to be benign in nature.

The development of cellular pathology in 1858 made it possible to determine much more accurately whether a tumour was benign or malignant. Virchow explained disease as life under altered conditions and a reaction of the cell to abnormal stimuli. '*Die Krankhaften Geschwuelste*' appeared in three volumes between 1863 and 1867 and dealt with the possible spread by metastases.

### **Rudolph Ludwig Karl Virchow**

Virchow was born on 30th October 1821 in Schivelbein (today Swidwinn).

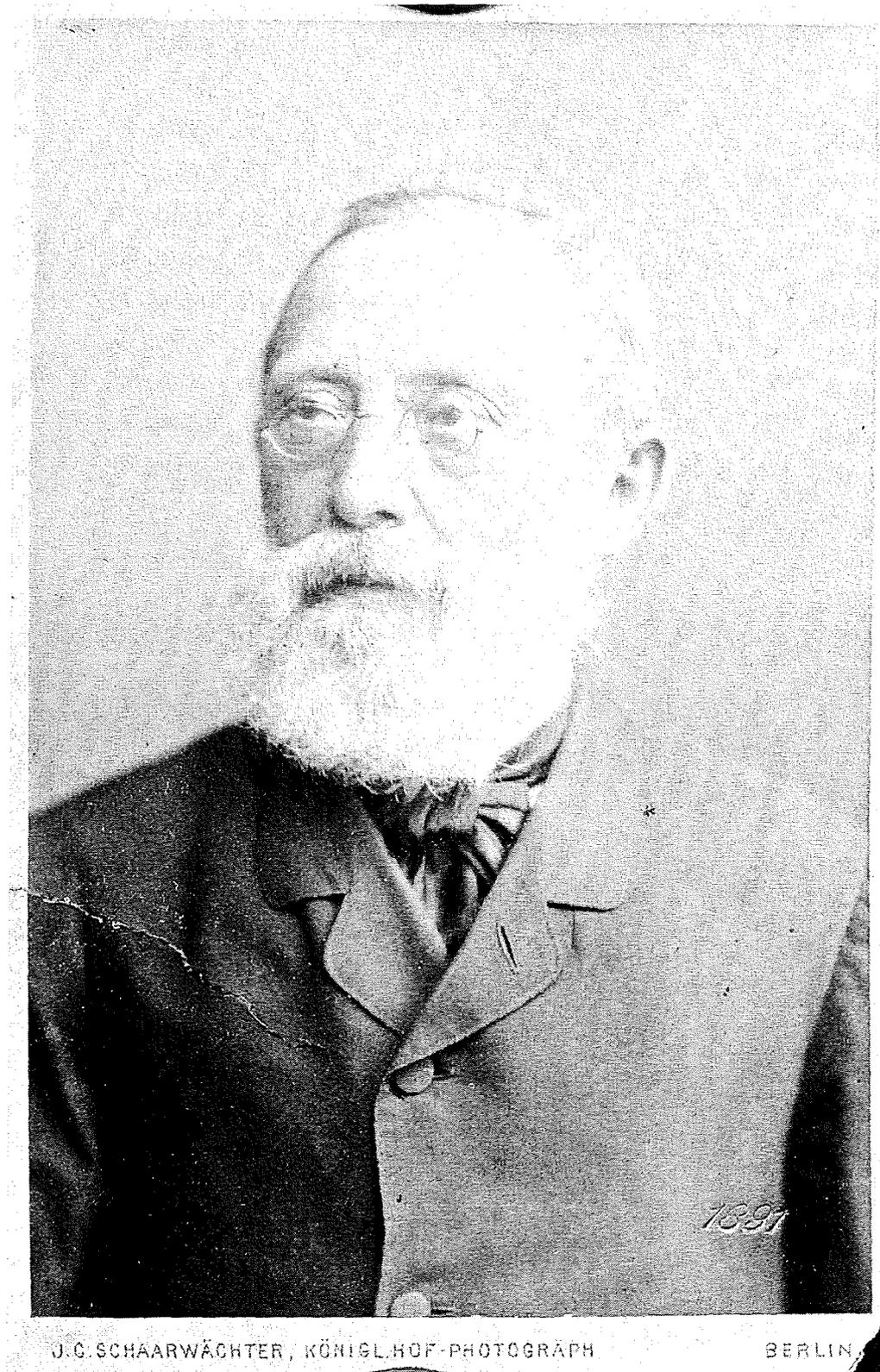
Although he was able to go to school and finish with an A-Level certificate, his limited financial means did not allow him to attend a university. He therefore entered the Military Academy in Berlin where his education and accommodation were free. He went to Berlin in October 1839 and completed a four-year theoretical education and one practical year at the Charité Hospital there. As part of his practical year in the Charité, he gathered work-experience in all specialties. He worked in the eye clinic, on the ward for mentally ill people, in internal medicine, obstetrics, gynaecology and paediatrics.

In 1846 he was appointed as a manager of the newly created Department of Pathology. He introduced courses in pathology and anatomy and began to develop ideas for reform in medicine. He saw medical reform as a necessary social change. During a cholera epidemic, he explained the connection between the cholera

epidemic and living/economic conditions: people who were poorly educated were most frequently infected. Realising that social factors directly influenced medical outcome made him an advocate for better social conditions. His revolutionary ideas for social change on the back of medical reform resulted in his suspension from the hospital in 1849.(65) From 1849 to 1856 he worked in Würzburg as Professor of Pathology and Anatomy, but was allowed to return to the Charité Hospital in Berlin when a new Institute of Pathology was built and he was considered to be the best qualified candidate to head the institution.(68)

Virchow directly influenced William Halsted's views when he explained cancerous cell growth as: '*The disease arose from one single abnormal cell which proliferated, and spread in a centrifugal manner to involve regional tissues, such as chest wall muscles and axillary lymph nodes.*'(69, p82)

Rudolf Virchow (Courtesy of The Wellcome Library London)



### 2.2.2 The discovery of x-ray in 1895 by Wilhelm Conrad Roentgen

Roentgen (1845-1923) discovered x-rays in 1895. He produced the skeleton image of his hand and demonstrated his discovery on his wife. When he showed her the x-ray of her hand she exclaimed: *'Oh my God, I'm looking at my bones. It makes me somehow feel that I'm looking at my own death.'* (15, p121) Her reaction was a good indication of the excitement and anxiety his discovery would encounter. He published his discovery in Germany as a supplement to the 1895 volume of the Proceedings of the Würzburg Physical Medical Society and sent reprints to the most important physicists in Europe to disseminate the news within scientific circles.(70)

Initially this new technology was used for body imaging. The broader application and speedy development of this technique, however, were limited by important factors affecting the safety of patients and clinicians. First, there was uncertainty about the appropriate dose: *'There was the stimulating dose, the erythema dose, the epilation dose, the vesicating dose and all too often the necrotizing dose.'* (3, p98) Second, this newly discovered technology threatened the lives of its operators due to radium overdose, and many died during its initial phase. By 1919, 169 physicians had died and the number was increasing.

Once the dangers of x-ray treatment had been established, it was possible to create a safer working environment by protecting the technicians and their patients, using lead as a shield. This allowed further research into the use of x-ray, and excitement grew when its use was extended to the treatment of tumours with external beam radiotherapy or radium implants. In 1898, Helman Gocht (1869-1938) made a first attempt at using x-rays in the treatment of breast cancer. Two patients, one with advanced ulcerating breast cancer and the other with recurrent breast cancer, were treated with radiotherapy. In both reported cases the pain associated with the ulcerated tumour was controlled. Gocht published these case reports in a newly

established journal, founded with a view to publishing information about medical advances in x-ray treatment.(71) (3)

Radiotherapy saw further technical development, but the high cost of radium and the technical apparatus necessary meant that further research was undertaken only in larger centralised institutes.(72) At the time of World War I, it was possible to generate a maximum voltage of 150 kV. In the 1920s, radiotherapy developed as a medical specialty ensuring considerable progress over the following years.

Apparatus producing reliable, clinically useful x-ray therapy (orthovoltage equipment) with voltages ranging from 170 to 200 kV became available.(73)

Hospitals in Europe and America started to use radiotherapy not just on patients with inoperable breast cancer, but also after breast cancer surgery. 1950 saw the introduction of Megavoltage machines. This opened up choices for less radical surgery and safer radiotherapy treatment, with higher reliability and less skin damage for breast and other cancers.(74)

After initial results with incurable breast cancer, Geoffrey Keynes (1887-1982) began to use radium implants as adjuvant treatment for less radical breast cancer surgery. The development of high-voltage x-ray machines established radiotherapy as adjuvant treatment in the treatment of breast cancer, and randomised trials were performed to determine its benefits.(see chapter 3)

Willhelm Conrad Roentgen (Courtesy of The Wellcome Library London)



*Dr. W. C. Roentgen*



### 2.3 The view of the medical profession and the patient

The medical profession and patients benefited from major scientific advances that improved short-term and long-term survival rates. Surgeons such as Billroth, Halsted and Keynes had the means to diagnose a malignant tumour and offer effective, relatively pain-free treatment with surgery and radiotherapy. In turn, the doctor-patient relationship changed. The voice of the patient disappeared and was replaced by series of case reports from one surgeon or a hospital. Patients were treated less as individuals, but as objects on which operations were performed. This resulted in a situation, described by Foucault and supported by Roy Porter, in which the modern 'patient' was in a sense a fabrication of the 'medical gaze'.(6)

Qualitative/narrative data were replaced by quantitative/statistical data. First, statistics were used to debate the safety of anaesthesia and to prove the effectiveness of infection control and radiotherapy. The whole understanding of disease had become more abstract, as neither the patient nor the surgeon could touch cells of microscopic dimensions or see x-rays. Understanding of these issues required specialist knowledge, i.e. the scientist doctor. This excluded lay people from active participation in their treatment and with that patients lost the empowerment of being in charge of their management. It was increasingly the doctor who diagnosed a disease without the need to involve the patient and who attempted to treat patients without involving them in the decision. Sandra Goebel claimed that patients viewed surgery as a new technology that could eradicate disease.(69) Patients disengaged themselves from their own journey through illness and treatment. It was only in 1967 that Ackerknecht called for increased involvement of the patient. He realised that patients needed to engage with their disease and possible treatments in order to help themselves to overcome their illness.(75)

### 2.3.1 A pioneer in breast surgery Theodor Billroth (1829-1894)

Theodor Billroth (1829-1894) created the foundation for effective cancer surgery by incorporating achievements in anaesthesia, antiseptics, and most importantly, the study of pathology into his practice. He audited his results extensively and was able to demonstrate a better survival rate for his patients.

*' Billroth, it is fair to say, contributed more to the subject of tumours than any other surgeon who ever lived. To be sure, his career embraced the period in which the development of microscopic pathology and antiseptic surgery took place, making effective cancer surgery possible for the first time. '* (76, p84)

Born on 26 April, 1829, on the island of Rügen in the Baltic Sea, his mother and family friends encouraged Billroth to begin a career as a surgeon. When Willhelm Baum, a friend of the family, accepted a position as Professor of Surgery at the University of Göttingen, Billroth joined him in 1848. After an unsuccessful attempt to set up in general practice, he joined Professor Bernard Rudolf Conrad von Langenbeck, Professor of Surgery, as an assistant. He developed an outstanding reputation as a respected clinician, researcher and teacher in surgery and was offered a position as Professor of Surgery in Zurich and Chair of Surgery at the University of Vienna in 1867.(78)

Billroth began his surgical career in 1848, two years after the first successful operation under anaesthesia was performed. He followed the debate on the safety of inhalation anaesthesia, opting for its use as it enabled him to operate more accurately. He believed that aggressive surgery for the treatment of breast tumours was inevitable and performed a total mastectomy for breast cancer. The pectoral muscle was removed if it was involved and axillary nodes were removed if they were enlarged.(77) (79) This kind of operation was impossible without anaesthesia.

He demonstrated a fall in his operative mortality following mastectomy by about 10% when he implemented infection control into his practice. Billroth viewed the introduction of infection control with scepticism, and did not find it easy to accept this drastic change in the operating theatre and hospital environment as it resulted in total upheaval of all his pre-operative and postoperative practice. He was, however, quickly convinced by survival statistics.(3, p82)

Billroth was working at the University in Berlin when Rudolf Virchow published '*Cellular Pathology*' and he was greatly influenced by this research. He realised that Virchow's theory offered a solution to the difficulty of recognising whether a lump was a cancerous tumour. He commenced extensive pathological examinations of breast carcinoma and offered a first pathological classification based on Virchow's theory.

Three publications reflect his achievements in breast cancer surgery. In 1880 he published '*Die Krankheiten der Brustdrüse*', in 1881 '*Clinical surgery: extracts on the reports of surgical practice between 1860-1876*' and in 1888 '*Handbuch der Frauenkrankheiten*'.(17) (18) (19) His publications included all aspects of diseases of the breast and offered a special chapter on cancer of the female breast. Billroth offered a complete review of the cancerous anatomy, aetiology and clinical evaluation of case histories covering the duration of the disease until death. Picture plates were used. He classified breast cancer into four groups, relating his classification to well-known terms, i.e. classifications by Franz Schuh from Vienna (1804-1865), John Birkett from London (1815-1904), Samuel David Gross from the US (1805-1884) and Alfred Armand Louis Velpeau from France (1795-1867). (3, p72)

Billroth was interested in the origin and the course of the disease. Case reports alone were not able to answer his questions. Therefore he was one of the first to audit his results. Dr Alexander von Winiwater (1848-1917), his assistant, recorded Billroth's

patients treated for cancer during his time in Vienna (1867-1876). It was the first time an analysis like this was attempted.(76, p86) He recorded 170 cases of breast cancer seen by Billroth in Zurich and Vienna (1867-1875); 143 had a mastectomy. The operative mortality was 23.7%. Antiseptic wound treatment had not been in place. After three years, only 19 (13%) of the mastectomy patients were alive or had died of other causes. Winiwater recorded a 4.7% three-year cure rate, 85% developed local recurrence.(4, p51) (3, p87)(20) In comparison, Friedrich Esmarch (1823-1908) reported a similar survival rate of 12% in 1878 from a series of 229 patients who had surgery between 1850 and 1878.(3, p87)

In addition Winiwater's observations included demographic data, a detailed history of the disease, and number of children, with a note of whether the woman had nursed them. He found that nearly all women who had children and had developed cancer had not breastfed.(18)

In Billroth's perception, breast cancer developed mainly in women aged 35-60. He thought the younger the woman at diagnosis, the more rapidly the cancer grew. The majority of women died about three years after the diagnosis of the disease and younger women died more rapidly from the disease. In Vienna, Billroth treated 238 patients with the following age distribution.

Age	26-30	31-40	41-50	51-60	61-70	71-77
No. of patients	12	43	93	58	30	2

(18, p216)

Theodor Billroth opened the door to effective cancer surgery using a radical approach. One of his pupils, W S Halsted (1852-1922), described the radical mastectomy in 1891.

Theodor Billroth (Courtesy of The Wellcome Library London)



*Dr. Th. Billroth*

Billroth operating (Courtesy of The Wellcome Library London)



### **2.3.2 The establishment of a standard operation for breast cancer by William Stewart Halsted (1852-1922)**

Theodor Billroth established a centre of surgical excellence in Vienna between 1867 and 1894. William Stewart Halsted (1852-1922) travelled from the USA to learn about his practice.

Halsted was born in 1852, the oldest son of a family with a successful importing business (Halsted, Haines and Company) in New York. He benefited from a privileged upbringing and a good education. He became interested in anatomy and physiology during his last few months at Yale and entered the College of Physicians and Surgeons in New York City after graduation from Yale in 1874.(80) He was an enthusiastic pupil and secured an internship at Bellevue Hospital one year ahead of his graduation from the Royal College.

Halsted encountered the frontiers of modern research. Joseph Lister went to the United States to introduce the technique of antiseptics. Halsted was impressed by the superior results in terms of postoperative survival achieved by surgeons who practised antiseptics.

In 1877 he graduated from medical school and was offered a position as house physician at the New York Hospital. Here he met the pathologist Dr William H Welch (1850-1934), who was to become his mentor and friend in the coming years. Halsted decided to go to Europe to gain further experience. In 1878, Germany and Austria were seen as the medical centres of excellence of the time and were well ahead in specialist training and medical research. Most of Halsted's time was spent in Vienna with Professor Billroth's team. He had access to the operating theatre of Professor Billroth, which was to leave a lasting impression on Halsted's methodology and operating technique.(81)

In 1880 Halsted returned to New York. He was described by his colleagues as '*fired by a laudable ambition to put to use the knowledge he had acquired.*' (82, p224) For four years he worked in the Roosevelt Hospital and became a visiting physician to the Charity Hospital (1881-1883), consulting surgeon to the Emigrant's Hospital (1883-1886), visiting surgeon to the Bellevue Hospital (1883-87) and visiting surgeon to the Presbyterian Hospital (1885-1886).

Halsted enjoyed teaching students in the form of a 'quiz', the standard way to prepare them for important medical exams. His teaching sessions were popular, with about 65 students. He would take them on ward rounds, give them a lecture and anatomic/pathologic demonstrations. '*At the height of his New York career, Halsted was a bold, daring, and original surgeon, an indefatigable worker, and most of all, an inspiring teacher.*' (82, p224)

On 11th October 1894 Halsted heard about a new form of anaesthesia. As a young researcher he was open to new possibilities and willing to undertake research. He saw the potential of anaesthesia and decided to embark on some tests on himself and his colleagues. The result was the development of local and regional anaesthesia. Unfortunately this anaesthetic was cocaine-based and Halsted and his colleagues became addicted. (83) (80) From then on the life of this young and enthusiastic clinician changed dramatically. He tried hard to overcome his addiction. His mentor Dr W Welch was most supportive during this time, and asked Halsted to join him in Baltimore where the new Johns Hopkins Hospital was to be built. In 1896 Halsted moved to Baltimore and lived and worked with Dr Welch.

Despite many attempts he never totally managed to overcome his addiction and the years in Baltimore at the newly founded Johns Hopkins Hospital were overshadowed by his drug addiction. His life was in total contrast to the way he lived and worked during his New York period. He became a man marked by suffering and withdrew

from society. He devoted his life to scientific investigations, the new organisation of a residency system and developing his operating techniques.

He worked in the laboratory using Lister's antiseptic methods. He placed particular emphasis on the careful handling of tissue, and fine silk suturing. He was a perfectionist in every way. '*...it was difficult to think of surgery more carefully conducted.*' (82, p225)

Despite his cocaine addiction, he was offered the position of Surgeon in Chief to the Dispensary and Acting Surgeon to the hospital for one year. He was able to avoid a relapse of his addiction, although his best friend Welch knew that he controlled it with a low dose of morphine. His appointment was made permanent in 1890.

He restructured surgical services and is generally seen as the father of the modern American training scheme for surgeons.(81) From 1890 to 1895 he concentrated his interests on treatments for cancer of the breast, hernia repair and wound healing.

### **Halsted's achievements in breast cancer surgery**

At the end of the 19<sup>th</sup> century, different surgeons still had different ways of dealing with a lump in the breast. Some surgeons removed the lump and others removed the segment of the breast containing the tumour. Others had begun to excise a central mass and removed wider margins or performed a complete mastectomy. Some would preserve a skin flap, which included the nipple, to close the wound. Cosmetic results and concerns about body image were of secondary importance in the quest for women to live recurrence-free for as long as possible.

Since the introduction of antiseptic techniques in 1877, the operative mortality for mastectomy had dropped by 10%. Professor Billroth routinely removed the whole breast for cancer, although he stated that he was not totally sure whether a local excision of small tumours with a safe margin might serve the same purpose. He

excised the pectoral fascia together with a substantial layer of underlying muscle. Billroth's pupil, WS Halsted, advanced this operation and removed the pectoralis muscle as a matter of routine in 1882. This radical mastectomy became the standard operation for breast cancer. After Halsted's publication in 1894, his technique was adopted in Europe and the USA.(20) Halsted believed that breast cancer began as a small nodule and extensive operation at an early stage would prevent local recurrence.

William Halsted based his whole approach to breast cancer on this theory. It was his belief that when surgery was not successful, it was because not enough tissue had been removed and cancer cells which had been left in the breast then spread and ultimately caused metastases all over the body. He thought it necessary to cut out as much tissue as possible to prevent the cancer from spreading. The radical mastectomy began with an incision at the shoulder and the removal of the breast as well as the muscles of the chest wall, lymph glands and all the fat under the skin. Halsted's radical mastectomy became the conventional treatment of choice and remained so until the 1970s. (21) (33)

Halsted's view was influenced by the fact that most of his patients presented with a late stage of breast carcinoma. The breast cancer had usually ulcerated and spread to the axillary lymph nodes. He assumed that breast cancer spread along the lymphatic system. Surgeons such as Willie Meyer and Samson Handley supported this theory.(2, p4) Radical mastectomy controlled the local recurrence of breast cancer. Approximately 70% of women survived the operation. Halsted's main aim was to reduce the high incidence of local recurrence reported by his teacher, Billroth.(20) He reported a local recurrence rate of only 6%, with a late regional recurrence of 16.6%.(32, p212) (21)

Halsted's radical mastectomy was a specialised operation, only to be performed by highly trained surgeons. This in turn led to a change in the way research was undertaken. Whereas previously case reports had been the only way of finding out how surgeons performed, Billroth and other surgeons believed that a review of one particular disease gave a better indication of the benefits of treatment. Statistical reviews of one operation, often performed by one surgeon or in one hospital, were fast becoming the norm for surgical practice.

Halsted's teaching prevailed for much of the 20<sup>th</sup> century and sometimes the operation was extended to involve the excision of a rib or supraclavicular nodes. In rare cases, the arm was amputated, although there was little support for such mutilating procedures in general. Some surgeons were beginning to question this radical procedure and looked for a more conservative approach to surgery, a less mutilating procedure with similar result. Radical mastectomy left the woman with a sunken chest, often restricted movement on one side of her body and frequently a painful, chronic condition caused by a disturbance in the lymphatic fluid system, which accumulated in the arm (lymphoedema). It inflicted maximum deformity, disfiguration and disability onto women.

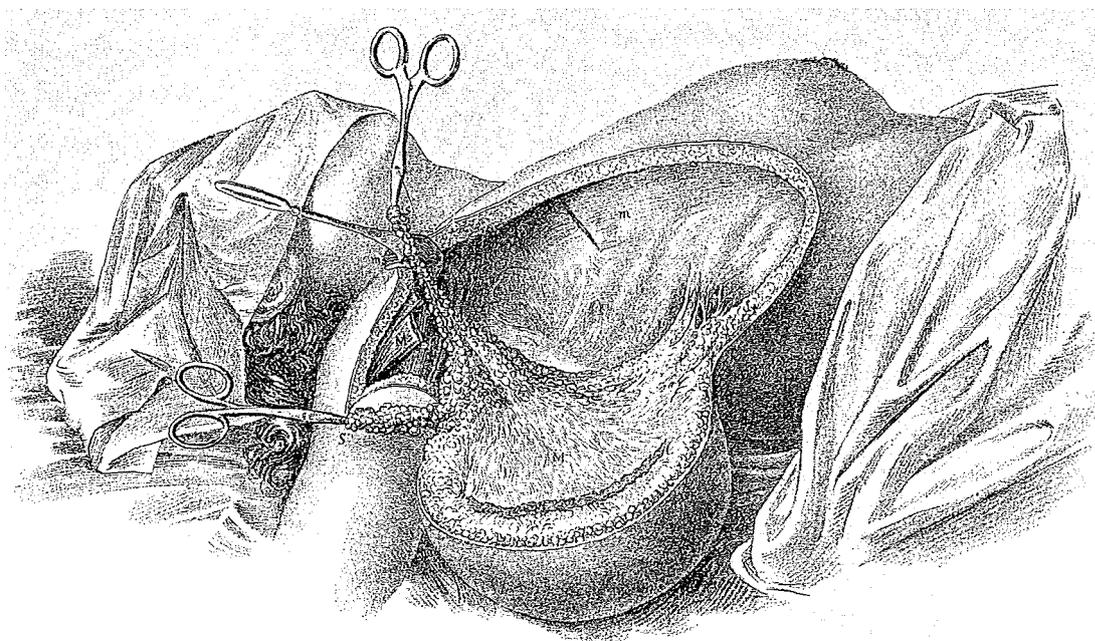
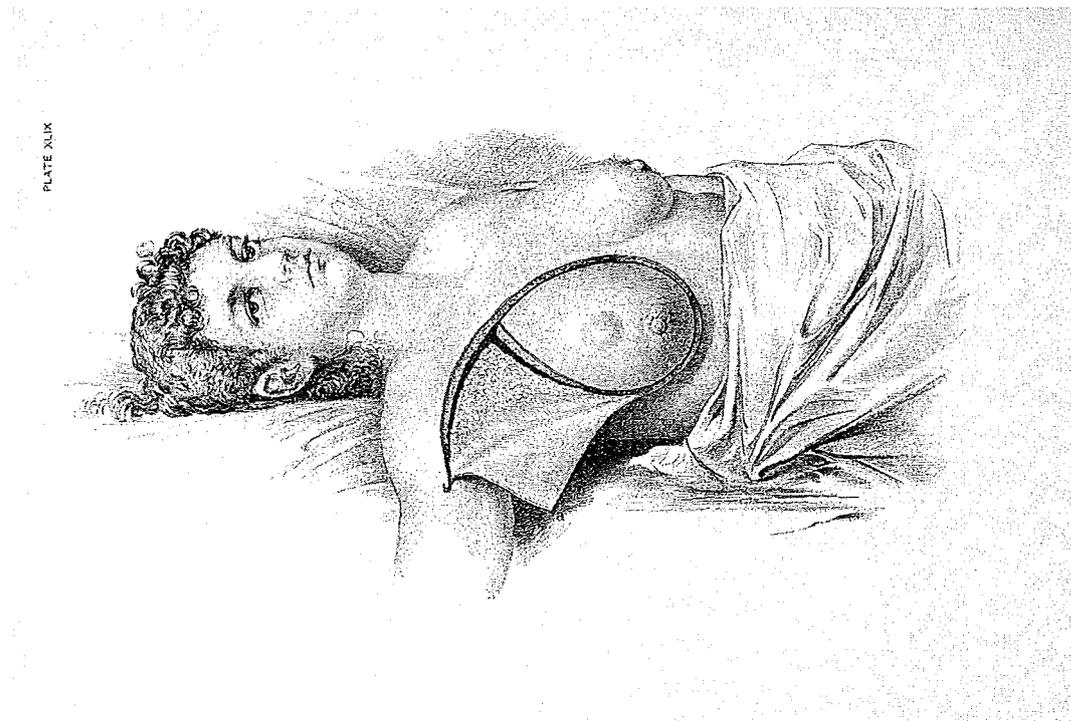
William Stewart Halsted (Courtesy of The Wellcome Library London)



© Jeffers, Baltimore

W. S. Halsted

Haksted's radical mastectomy (Courtesy of The Wellcome Library London)



### 2.3.3 The argument for less disfiguring breast cancer surgery:

**Geoffrey Keynes (1887-1922)**

*'Every patient had become a 'case' and not an individual, whereas in fact there was good reason for regarding each patient as a separate problem for careful consideration according to the individual circumstances ' (84, p215)*

Geoffrey Keynes started his career in medicine with enrolment in the medical school at St Bartholomew's Hospital, London. After three years as a medical student he was certain that he wanted to become a surgeon. He felt that he was literally holding the patient's life in his hands as a surgeon and found it very satisfying when an operation was successful. (84)

In August 1914 he was a senior house surgeon at St Bartholomew's Hospital. When war was announced, he decided to report to the War Office and was given the rank of Lieutenant in the Royal Army Medical Core. During his time in France as a military surgeon, his task was to set up an operating theatre and he practised surgery on a vast scale in a casualty clearing station, gaining experience with wound closure and amputation. (84)

#### **Breast cancer research**

After the war, Keynes returned to St Bartholomew's, which was a voluntary hospital. Despite his war experience, Keynes thought that he needed further experience of major surgery and became the second assistant to George Gask in the surgical unit. Professor Gask suggested he should undertake some research. His first project was to study the common condition of chronic mastitis. Keynes endeavoured to establish a possible relationship with breast cancer, and enjoyed his time as a researcher. After his first success he decided that he wanted to undertake more clinical research work. In 1922 a small amount of radium was given to St Bartholomew's, and Gask and Keynes set up a trial treating patients with recurrent breast cancer. Keynes showed

that nearly all growths disappeared and therefore radium therapy was extended to primary breast cancer; the first patients were treated in August 1924. During the following four and a half years patients with advanced and inoperable tumours were treated in this way. Keynes believed that he might be able to improve the quality of women's lives, although he remained somewhat sceptical.(23) (24) Late results were published in 1937.(25)

In his biography Geoffrey Keynes wrote about his feeling with regards to the radical operation for breast cancer: '*When it came to performing the operation myself I found that it filled me with the utmost loathing and I soon became sceptical about its real efficiency.*' (84, p214) Despite the fact that he was taught the Halsted radical mastectomy technique as the standard treatment for breast cancer, he was unwilling to accept the '*gross mutilation of the patient's body in order to remove every scrap of tissue that might be infected by the spread of the disease through the lymphatic channels supposed to drain the breast.*' (84, p214) He felt that a combination of radium treatment and less radical surgery might be equally effective.

### **The method of treatment with implanted radium needles**

This method involved removing a tiny piece of tissue for examination under the microscope for confirmation of the diagnosis. The radium implants were inserted under general anaesthetic in the form of radium-filled needles, which could be removed without pain after seven days. Patients described discomfort rather than pain. Each needle contained a 3mg radium element, which was placed in a parallel series from each side and overlapping in the centre. In addition the axilla was irradiated with four to seven needles; three short needles were introduced into the area above the clavicle and one short needle was placed in each of the upper three or four intercostal spaces. All needles were usually left in position for seven days. Keynes worked in close collaboration with the physicists. Together they devised a pattern in which the needles should be placed to give a standard dose of irradiation

covering the whole of the diseased area and those areas immediately concerned in the lymphatic drainage of the breast, such as the axillary lymph nodes.(85) (84)

Usually there was no surgical intervention. If lumpectomy was necessary, this preceded irradiation and was done with a diathermy needle. No dissection of the axilla was carried out. Radium treatment was regarded as a failure if the primary tumour did not disappear completely, or if it recurred in the breast or in the skin. On examination of the patients in whom the radium needles were not effective, it became apparent that the penetrating power was strictly limited and that some tumours were too bulky. The gamma rays could not penetrate and therefore cancer cells did not receive a lethal dose. The decision was taken to remove large tumours of the breast before irradiation. Any operation undertaken was as conservative as possible and never involved removal of the pectoral muscle or dissection of the axilla.

In 1927, Keynes published an initial report documenting five years' experience of the use of radium, and was able to demonstrate that there were a number of patients in whom the local disease had come to a complete standstill.(23) Some women had remained healthy for up to five years. He reported a refined protocol for radium therapy, which was published in 1937.(25) This included, first, the local removal of the tumour if it was large or the diagnosis was uncertain; mastectomy was only required for very large cancers. The axilla was never dissected. Radium was given to prevent recurrence. Radium therapy alone was used for small tumours or if the patient refused operation.

### Five year results

Keynes divided women with breast cancer into 3 groups: Group 1, where the cancer was confined to the breast; Group 2, where the disease was confined to breast and axilla; and Group 3, where the disease was advanced and inoperable. He treated 250 patients.

Survival rate	Group 1 n=85	Group 2 n=91	Group 3 n=74
3 yrs	83.5%	51.2%	31.4%
	Group 1 n=75	Group 2 n=66	Group 3 n=60
5 yrs	71.4%	29.3%	23.6%

(25)

His results compared favourably with those of W H G Jessop (1936) from University College Hospital, who reported 79.2% three-year survival and 69.1% five-year survival for Group 1.(86)

Keynes understood that his results required confirmation, but that the combination of less radical surgery and radiotherapy was an effective treatment for breast cancer. During his research he became increasingly confident that his survival rate compared favourably with that of surgeons using a more radical approach to breast cancer. Keynes, however, believed that he was able to address additional factors which influenced earlier detection and the quality of life of his patients.

Keynes no longer undertook radical operations and practised conservative surgery adapted to the needs of each patient, taking into account all relevant circumstances. He removed small segments of the breast for small tumours and did a mastectomy without axillary dissection for large ones. All his patients were kept under close supervision. He felt it was an achievement that all his patients were spared both

serious mutilation and the complications that followed radical mastectomy, such as the swelling of the arm following the removal of the lymphatic channels. Keynes argued that he had improved the quality of their lives and perhaps prolonged life in some instances. Many women might have delayed going to their doctor, taking away their chances of an early diagnosis, because they were worried about a radical mastectomy. Keynes thought that if this became a thing of the past, more women would seek advice sooner.

In his biography he explained that the belief in radical operations had become a dogma and he resented the fact that every patient had become 'a case' and was not an individual. There was good reason to believe that each patient should be regarded as a separate problem with careful consideration according to the individual circumstances. He felt that it must be the ambition of every conscientious surgeon to assist in the gradual elimination of any operation so extensive and severe as the radical operation for cancer of the breast. (84)

### **The argument/case for conservative surgery and radiotherapy**

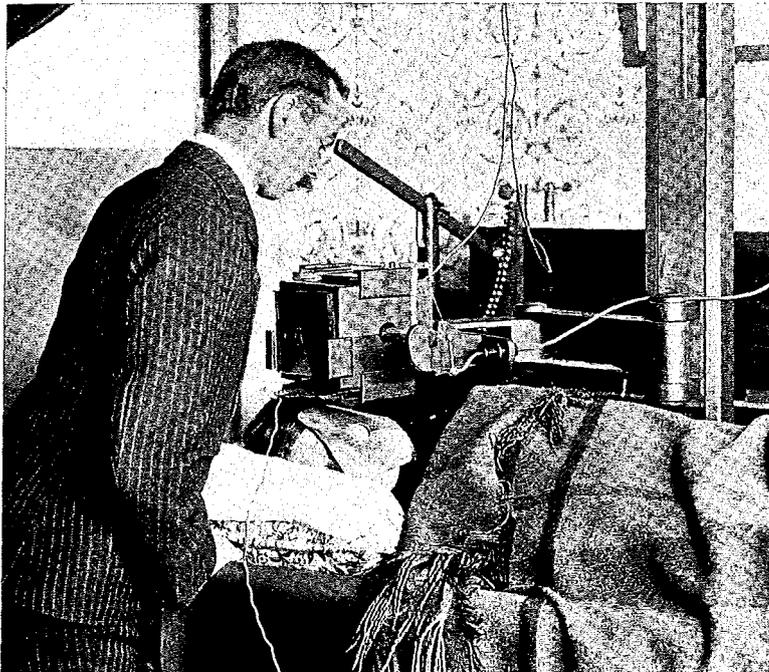
Geoffrey Keynes challenged the need to perform a radical mastectomy for breast cancer. Halsted's theory was based on the common belief that the disease spread by '*centrifugal permeation*'; that it proceeded from the outset to permeate lymphatic channels in all directions, to reach distant organs such as the liver and the bones. Keynes examined this pathological theory on which the treatment was based in his paper of 1937. He denied there was evidence for the theory of '*centrifugal permeation*'. It was his belief that if the axillary lymph nodes were extensively affected, dissection of the axilla might even be harmful. If the axilla did not appear to be affected, dissection was unnecessary because radical irradiation was carried out in every patient.(25)

Keynes' view was followed with keen interest and he was invited to speak at the American Association of Surgeons in New York. Conservative surgery was adopted

in centres such as Edinburgh, and the younger surgeons at Keynes' own hospital started to look for an alternative to radical operations. His approach was a major step in changing the approach to breast cancer treatment. During the 1930s and 1940s the Finnish radiologist Sakari Mustakallio started to treat his patients with early breast cancer routinely with a tumorectomy and external irradiation. He stated in a paper from 1953 that he arrived at his decision to use breast-sparing surgery by challenging the theory of '*centrifugal permeation*'.(26) He examined patients who had a radical operation for breast cancer and later developed metastases and died. Most developed distant metastases without showing any local recurrence in the skin or glands. He therefore concluded that distant metastases had not spread postoperatively by way of local lymph nodes or the operative field, but had obviously already developed before or during the operation. Therefore he felt that local metastases were more likely to be controlled or cured with radium therapy than radical surgery.

Despite its growing acceptance, conservative treatment for breast cancer was hindered by the fact that effective radiotherapy was limited by the rudimentary equipment, which produced low-energy x-rays with poor penetration, and the cost of radium. Eventually conservative surgery and radiotherapy for breast cancer offered a real alternative to radical mastectomy, which disappeared as the standard operation. Keynes wrote in his biography about a very gratifying incident in 1967. An American surgeon, George Crile, of Cleveland, whilst writing a book on conservative treatment of cancer of the breast, discovered that the work had all been done before by Keynes himself and therefore dedicated the book to him.(84)

Geoffrey Keynes (Courtesy of The Wellcome Library London)



#### **2.3.4 A move from qualitative to quantitative data and the disappearance of the patient narrative**

*' Medicine is not only a science, it is also an art. Science is primarily analytic, art primarily synthetic. Medicine is likely to remain an art, however hard we may try to make it more and more scientific, and however much we may attempt to master its scientific contents. For medicine deals not with impersonal atoms, elements, plants with tropisms or animals with instinct mechanisms, but with humans with a "soul" and "free will". In order to fulfil his mission, therefore, the physician has to be more than a mere technician and man of science. He must be a well-rounded human being, humane and humanistic. ' (87, pxvi)* This was the critical assessment of the medical historian EH Ackerknecht.

The introduction of anaesthesia and infection control and the developments in pathology changed the experience of the doctor-patient relationship. Traditionally the patient had been the chief witness to and the interpreter of the events of an illness. It was a personal account and not an objective description. The doctor was drawn into the human drama of the illness. New scientific developments allocated the patient a role with less involvement. Emphasis was moving away from the patient's story towards so-called 'objective evidence'. Differential diagnosis was possible with minimal communication between patient and doctor. Laboratory results spoke for themselves. During the consultation the patient was no longer the prime source of information about the illness, and during treatment he/she was now anaesthetised and recovered in a sterile hospital environment. The latter was strictly regimented and did not allow much personal interaction between doctor and patient.

Prior to this development the patient was usually treated at home. The doctor or clinician was invited into the home and into the family. He was provided with food after the journey and the consulting room was usually a room in the house.

Patients of the most recent past were given little information about their treatment and were often unable to understand what was going on. Clinicians were viewed as scientists and semi-gods. Patients were fearful of anaesthesia and viewed skills such as pathology and microbiology as far beyond their understanding. The later development of x-ray by Roentgen at the end of the 19<sup>th</sup> century increased the alienation of the patient.

At the beginning of the 20<sup>th</sup> century patients had become 'objects' who were treated with all scientific skills and means available but who had little or no influence. As beneficial as the new scientific developments were to surgical performance, they had negative influences on the doctor-patient relationship. This deteriorated from a close, life-long doctor-patient relationship with a general practitioner to an anonymous unsupported relationship between the doctor and patient in a hospital environment. Increasing medical autonomy made the patients' narrative of illness redundant.(27, p93) Previously the words of the doctor and the words of the patient reflected a shared communication and often the patient's 'voice' was found in the doctor's case report. Increasingly doctors sounded like anonymous scientists and the voice of the patient disappeared. Doctors started to change the patient's own words and interpret them into their own medical equivalent. The patient's perception in the medical case history had almost disappeared and was replaced by the results of the physical examination and laboratory tests. Respiratory sounds, temperature, pulse and the condition of the blood evaluated the progress of the patient. Doctor and

patient did not meet as equals, indeed the physician gained overall authority over the body under their care.

This emphasises that the doctor-patient relationship had come full circle. In earlier times it was characterised by detailed history taking; the doctor was reliant on information provided by the patient. In the 19<sup>th</sup> century it was not common to perform a physical examination of the patient.(88) Physicians took the pulse, looked at or tasted the urine and looked at the tongue. Most of the time was spent talking to the patient in order to develop a clear picture of the natural history of disease. A specific diagnosis was not yet possible.

In the later 19<sup>th</sup> century doctors gained prestige in the eyes of their patients. They were still taking a detailed history, concentrating on the information given by the patient, but they were also using hands-on examination techniques to establish an accurate anatomical/clinical diagnosis. Treatment options, however, had not improved much. Slowly barriers diminished, and women who before this time did not allow clinical examination permitted the scientific doctor to examine them.

Research and medical treatment moved away from the individual case report to a presentation of a whole series of patients. Scientists such as Rudolph Virchow combined a new understanding of society with their dedication to medicine and medical research. The spectacular progress of histology, pathology, physiology and pharmacology led to the development of a new type of clinical medicine at the end of the 19<sup>th</sup> century. This period is characterised by medication, which for the first time really worked. Unfortunately the psychosocial dimension, i.e. individual patient care, became neglected. The doctor-patient relationship moved away from

qualitative patient-orientated data collection to quantitative statistical data analysis. Patients felt on the outside and not involved with their treatment. They felt treated as objects and were angry with their physicians, and considered alternative healing in an attempt to be treated holistically. The ultra-scientific physician of the 1950's was accused of a loss of interest in the patient as a whole person.(89)

History taking became less important and was only practised as part of the admission to hospital. The publication of patients' stories became more a thing of the past, and the physician relied on laboratory and diagnostic results. Physicians of that time were able to make accurate diagnoses and give differential prognoses. For the first, time treatments were available to them which actually worked, but often alienated their patients.

In surgery the social rehabilitation of the surgeon and the abolition of the distinction between medicine and surgery, as well as the development of anaesthesia and asepsis, facilitated a scientific approach to surgery.

*' The beginnings of their rise to their present-day authority originated, without doubt, in the momentous scientific advances of the mid- to later nineteenth century such as germ theory, asepsis, and the introduction of various specifically effective remedies. Medicine's increasing capacity to cure, mitigate, and prevent the ravages of many diseases led to the elevation of physicians to a commanding position. '* (90, px)

Roy Porter suggested that there was an imbalance between patient power and doctor power and that the patient needed to see a 'comeback'.(6) Clinicians began to realise

that they were unable to achieve good results without the support of the patients they were trying to cure. Patients needed to take control of their own bodies; they wanted to be listened to. They did not want to be treated as yet another case but as an individual. The way forward must include a qualitative doctor-patient relationship combined with all the latest scientific improvements.

*'Sickness cannot be seen in isolation; rather it is important to view responses to health and health and sickness as constitutive parts of whole cultural sets... we should never underestimate the key role of the family in sickness care and therapeutics in ages before doctors and welfare organisations were common.'* (6, p193-194)

### **2.3.5 Patient support networks and palliative care. The example of the first patient support charity Cancer Relief Macmillan Fund (CRMF) and Breast Cancer Care.**

Charities, dispensaries and friendly societies were established in the UK to aid the poor. They were not established to offer medical assistance, with the exception of a few, such as the Coventry District Nursing Institution, which was founded in 1883 and aimed to provide trained nurses for the sick and poor.(91) There were no charities to support cancer sufferers.

The reports of breast cancer patients in Western Europe and the USA did not mention the help of professional charity organisations until 1973 when Betty Westgate founded 'The Mastectomy Association' today Breast Care and Mastectomy Association/Breast Cancer Care: *'Because I'd had cancer, people felt they could talk more freely to me. I found they needed information and non-medical help. Using volunteers to help other women in the same situation just seemed common sense.'* (92, p165)

Betty Westgate was diagnosed with breast cancer in 1968 and expected information and support from the treating hospital and the consulting doctor but was disappointed. Medical training, until recently, did not specifically focus on help and support for cancer patients. Until recent changes in palliative care education, palliative training in the United Kingdom was incoherent rather than systematic and comprehensive.(93) Therefore, help for breast cancer patients was limited to medical and scientific advice by a sympathetic doctor/surgeon or nurse.

Douglas Macmillan founded the National Society for Cancer Relief, today Cancer Relief Macmillan Fund (CRMF) in 1911 after he witnessed the painful and distressing death of his father. Little support and information was available for

cancer patients, but CRMF now offers educational support at a time when many doubts, fears and questions need an answer. Access to information plays a vital role and this is made possible in the support units. Douglas Macmillan's concept was that *by 'improving the knowledge of cancer among the public and amongst health professionals, the needs of cancer patients would be better understood and their quality of life improved'* (94, p1)

This concept prevails today, and formed the foundation of the charity. CRMF will support patients at every stage of their personal cancer journey.(94) It has developed community nursing to care for terminally ill patients at home, making it possible for patients to avoid admission to hospital. The nurses aim to improve the quality of life for people with cancer. CRMF has three main areas of activity:

- (i) working with patients offering care and practical support
- (ii) sharing skills especially with regards to symptom control and pain relief, with other health care professionals, and (iii) researching ways to improve care for patients with cancer. It offers practical and emotional support to patients and their families. Within this framework, CRMF has been a responsive charity seeking a partnership with the NHS and other organisations in the UK.

Grants were the first step towards helping people with cancer to meet their financial needs, therefore offering practical support. The procedure was quick and simple. All people with cancer or who were experiencing the after-effects of cancer were eligible for a grant. Applications for the grants came from Macmillan nurses and other health care professionals. The grant was given for a specific purpose such as clothing, furniture, heating, holidays, home-care, telephones, travelling and miscellaneous reasons.

By 1994 more than 1200 Macmillan nurses were in post; 110 new posts were created in 1994 alone. Nursing care had expanded from community care to the hospitals and specialised cancer units. CRMF responded to a need for specialist nursing care in

breast cancer and other specialised areas. Posts were linked to a teaching engagement. These developments ensured a continual improvement in the standard of care for cancer patients at the hospital or in the community.

At the same time, the nursing establishment agreed that nursing services should become more specialised. This move to specialist nursing was initiated by the need for breast cancer nurses. A breast cancer nurse explained her role as follows:

*'My role is to help women make informed decisions about their treatment and to support them at all stages. I can discuss treatment options and give advice and counselling to women and their partners.'* (Macmillan Nurses leaflet) Karen Cox

examined the views of patients, carers, district nurses and general practitioners.(95)

A general emphasis was given to the supportive and educational role of the Macmillan nurse.

The Macmillan charity grew in the early 1970s and 1980s developing new dimensions of support with a special focus on patients who were terminally ill with cancer. New hospices were built all over Britain and staffed by CRMF in partnership with the NHS when the voluntary sector was unable to cope with the demand for hospice places.

Both charities developed in parallel until Breast Cancer Care became a professional association funded by CRMF with a high degree of autonomy. Breast Cancer Care offers help to women and men with breast cancer, as well as support for partners, friends and relatives. Women are able to obtain advice if they are worried about their breasts or if they specifically need support during their breast cancer treatment. Help is available from volunteers, women who have had breast cancer themselves but are at least two years post treatment. All volunteers are trained in counselling

skills. Advice is offered in hospital, at home, or on the telephone. There is also a prosthesis fitting option.

Charities today provide essential support and information to patients, friends and relatives as well as health professionals. CRMF was instrumental in working with the government on restructuring cancer services with the Chief Medical Officer, Sir Kenneth Calman, in 1994. A first 'cancer directory' was published. The system of care has levels, starting with the family doctor, who has the responsibility for appropriate and timely referral and for offering long-term support. The next levels are the cancer unit and cancer centres, each offering different degrees of expertise. Initially this caused much discussion by health professionals as the labelling involved different levels of financial support.(28)

### **3. Breast cancer treatment in the 20<sup>th</sup> century**

#### **3.1 The increased choice of treatment with the development of new surgical techniques and adjuvant therapy**

##### **3.1.1 First trials evaluating lumpectomy and radiotherapy vs. radical mastectomy**

Radiotherapy offered local control in the treatment of breast cancer without radical mastectomy - the treatment advocated by Geoffrey Keynes at the turn of the century. The further development of radiotherapy was restricted by the limited availability of radium and extremely high costs for research organisations. Five grams of radium cost £72 500. At that time the MRC (Medical Research Council) received only £76 000 per annum in an overall grant from the Treasury to cover research projects. A study at the Middlesex Hospital during World War I examined the effects of small doses of x-rays on behalf of the MRC.(16) It concluded that radium might have hazardous side effects that needed to be eliminated by establishing a safe dose for patients and safe working conditions for clinicians. Because of the competitive nature of a limited supply, researchers were under pressure to show clear benefits of this treatment.

Eventually the second half of the century saw a change in the use of radiation therapy. New radiation equipment and techniques ensured that this treatment was used increasingly to treat patients with cancer. Further trials showed the potential of radiation therapy to avoid radical operations. The introduction of mega-voltage radiation studies showed that the five and ten year survival rates were similar for lumpectomy and radiotherapy, and mastectomy. Today radiation therapy is used mainly as adjuvant therapy to surgery, but is playing an increasing role in both the primary and palliative treatment of breast cancer. It is an essential diagnostic tool for early detection with mammography screening. It is beyond the scope of this study to enter into the screening debate.

Until 1948, clinical trials did not provide evidence regarding the best treatment for primary breast cancer. Before this, anecdotal evidence influenced clinical practice. (96) Initially adjuvant radiation therapy was used postoperatively to reduce the incidence of locoregional recurrence. In 1976 a trial by the National Surgical Adjuvant Breast Project (NSABP) aimed to determine the effects of radiotherapy as compared to mastectomy. Patients were randomised to either a mastectomy or lumpectomy with radiation therapy. This trial involved 1843 women who were followed over five years. The results of the trial indicated that segmental breast resection or lumpectomy followed by breast irradiation was appropriate for women with stage I or stage II breast cancer who had a tumour of less than 4 cm in diameter and clear excision margins. All women underwent axillary node sampling and, where this was positive, they received adjuvant therapy. Lumpectomy followed by radiation therapy resulted in a five-year survival rate of 85%, compared with 76% for the group who had been randomised to a total mastectomy. The NSABP trial showed that radiation therapy had reduced the local recurrence rate, but was not able to prevent metastases.(31)

Trials showed that in general three important factors influenced the degree of local control. These were the adequacy of the surgical excision, the total radiation dose, and the specific histological findings. In the surgical setting it proved to be important that the tumour was excised with a healthy margin of breast tissue, as this influenced the local recurrence rate. If the tumour was excised with a healthy margin, the recurrence-free survival was 86 - 89%, compared to 66 - 72% when excision margins were involved. The optimal radiation dosage was determined to lie between 4500-5000 rad to the entire breast, with an additional boost of 2000-2500 to the tumour site using a radioactive implant, electrons or a combination of both. The dosage was calculated to offer the greatest chance of controlling local recurrence at the tumour site and avoiding the complications of radiation treatment to the breast, which included fibrosis and breast retraction. (97)

In all, five prospective randomised controlled trials were published comparing conservative surgery and radiotherapy with mastectomy as a treatment for stage I/II breast cancer. These trials did not demonstrate any difference in local recurrence or survival rates.(98)

Radiation therapy was also used in the advanced stages of breast cancer. Breast cancer often metastasises to the bone, and radiation therapy is used here in a palliative capacity. Breast cancer cells are highly sensitive and respond well to radiation. Patients usually experienced partial or complete relief of the bone pain.

### 3.1.2 The development of chemotherapy

Chemotherapy was developed in the 1950s and given as an adjuvant therapy to surgery and radiation therapy for the systemic control of the cancer.

Chemotherapy is administered either in tablet form or intravenously and usually consists of a combination of cytotoxic drugs. It allows healthy body cells to regenerate but prevents cancer cells from doing so. Most commonly, patients with early stage breast cancer are treated with the combination of cyclophosphamide, methotrexate and fluorouracil, (CMF). Generally the CMF combination works better than any single drug alone, and administration over a six-month period has been proven to be most effective. Usually CMF is started within a few weeks of surgery. Other combinations and variants of chemotherapy are still under consideration and going through trial phases today. It is beyond the scope of this study to discuss this line of research.(99)

Adjuvant chemotherapy was initially administered to women with primary breast cancer who had been shown to be lymph node positive. Since 1957, the National Cancer Institute has been involved in chemotherapy research. Professional competition between groups and rivalry developed.(33)

One group in the USA was the National Surgical Adjuvant Breast Project (NSABP) led by Bernard Fisher in Pittsburg. Early results in the mid 1970s showed that women who were given a chemotherapy drug after surgery had fewer recurrences of their breast cancer than women who had only surgery. Gianna Bonadonna at the Milan Tumour Institute reported that women who were given the three-drug chemotherapy cocktail after surgery had one quarter of the recurrence rate of the women who had surgery only. However, long-term follow-up results of patients in these two studies did not confirm these results. The debate was continued in 1988 when the National Cancer Institute made an announcement stating that all women

with breast cancer should receive chemotherapy, not just those staged as lymph node positive. The physician William Maguire weighed the improvements in disease-free survival against the toxic effects and financial cost per patient of treatment and came to the conclusion that studies had published a disease-free survival between 4% and 15% higher than that of patients who were treated with chemotherapy. Therefore according to Batt only a maximum of 15% of women benefited from the treatment.(33, p98)

It is still not clear whether chemotherapy should be given routinely to all women with breast cancer. As it stands today, research has shown that there is definitely an indication for adjuvant chemotherapy in a pre-menopausal woman who has lymph node involvement and a stage II or higher breast cancer. For a woman with primary breast cancer and no lymph node involvement there may not be a need for chemotherapy and systemic treatment to prolong disease-free survival.(33) Recent meta-analysis in the Lancet showed that young women particularly should receive chemotherapy.(100) (101)

Neo-adjuvant chemotherapy can also be used as palliative treatment to shrink advanced tumours, but its side effects may seriously affect the quality of the final months of a woman's life. Therefore the benefits and drawbacks need careful assessment.

Treatment with chemotherapy is an issue to be decided between the physician and the patient. However, it is difficult for a patient to give informed consent in a situation for which there exists conflicting research. It has to be taken into account that every woman will react differently to chemotherapy. The influences on decision making involve not only the clinical staging of a breast cancer, but also non-medical factors that can play an important role for a woman making an informed choice about her treatment.

The most commonly reported side effects of chemotherapy are nausea and vomiting for the first 48 hours, a varying degree of hair loss and a temporary cessation of periods in younger women. For women closer to the menopause this might result in a permanent cessation of menstruation. Other side effects include constipation or diarrhoea, depression and fatigue, hot flushes, mouth ulcers, weight gain or loss, and excessive bleeding or bruising.

### 3.1.3 The development of endocrine therapy

Endocrine therapy or hormone therapy is achieved by surgical removal of the ovaries (ovarian excision), by radiation ablation or chemically. George Beatson discovered the connection between breast cancer and hormone levels when he introduced oophorectomy in 1896. Beatson removed the ovaries of women who had developed breast cancer and realised that in about half of the patients the operation caused remission or tumour regression. (34) (102) Until the 1960s, young women were routinely offered oophorectomy after mastectomy. Oophorectomy was seen as a radical treatment, especially for pre-menopausal women, with a 50% success rate. In the 1960s a first randomised trial was designed. According to this trial Bernard Fisher showed that: '*The worth of oophorectomy... cannot be denied. The operation resulted in a remission rate of 25 - 30 percent for pre-menopausal women who experienced a recurrence*' (33, p116)

Further research suggested that there might be a link between the hormonal status of a tumour and the development of breast cancer. The experimental use of a test called ERA (Oestrogen Receptor Analysis) was introduced in the early 1970s. This classified tumours as oestrogen receptor positive (ER positive) or negative. ER-positive tumours are oestrogen-dependent for growth and ER-negative tumours are not. It is still debated today whether all tumours start oestrogen receptor positive and then become oestrogen receptor negative as they progress, or if there are actually two kinds of tumour cells. However, evidence suggests that most tumours eventually become independent of oestrogen.

By 1934 scientists had been able to produce purified oestrogen and progesterone. The development of Tamoxifen was characterised in the first instance as a contraceptive pill. Scientists discovered that oestrogen and progesterone suppressed the release of an egg from the ovaries and, in the face of over-population, this became a very attractive option for birth control. Further uses of Tamoxifen were

established. Tamoxifen (Nolvadex) was characterised as a non-steroidal anti-oestrogen compound in 1966. The link between oestrogenic agents and breast cancer became established and the first clinical trial to assess the efficacy of Tamoxifen for breast cancer was reported in 1971.(103) More extensive tests followed. Bernard Fisher from Pittsburgh conducted several large trials in the 1970s. He showed that Tamoxifen could disrupt the growth of oestrogen receptor positive tumours by interfering with protein synthesis. The structure of the synthetic hormone was similar to that of natural oestrogen in the body. Tamoxifen then competed with oestrogen on receptors on the surface of tumour tissue and therefore blocked the effect of natural oestrogen from the body. First trials, undertaken in patients with advanced breast cancer, found Tamoxifen to offer a benefit. Subsequently, Tamoxifen was tested in women with a poor prognosis who were given the drug in addition to other therapies such as surgery and chemotherapy. These trials showed that Tamoxifen helped to prevent recurrence and also prevented the spread of cancer. The final step was to test the drug on women with a good prognosis, such as women with node-negative breast cancer. Even in this setting, Tamoxifen was shown to prevent recurrence. Patients with oestrogen receptor positive or unknown tumours had a significant survival advantage when taking Tamoxifen.(104) Most encouragingly, Tamoxifen prevented the development of breast cancer in the opposite breast. Of the seven trials which had been undertaken with Tamoxifen, all found that the incidence of breast cancer on the opposite side was reduced by 30 - 50%.(33, p119). First results from the International Breast Cancer Intervention Study (IBIS-I) a randomised prevention trial, showed that the use of Tamoxifen reduced the risk of developing breast cancer by 32%.(105)

Two-year results reported in 1981 showed that women with positive nodes who had been given chemotherapy and Tamoxifen did better than those given chemotherapy alone. In addition, Fisher's group identified one specific group of women who particularly benefited from this combination. These were women over 50 with ER-

positive tumours. Women younger than 50 did not benefit from Tamoxifen. (33, p120)

Today, Tamoxifen is given in tablet form of 20 mg once a day and is beneficial both for pre-menopausal and postmenopausal women. Tamoxifen is usually given for at least two years, but it has been shown to be beneficial for up to five years, and sometimes even longer. The Italian Interdisciplinary Group evaluated adjuvant treatment in 2003 and suggested that women with oestrogen receptor positive tumours showed an increased disease-free survival benefit after taking Tamoxifen for five years.(106)

An alternative to Tamoxifen in pre-menopausal women is oophorectomy, either by radiation ablation of the ovaries or surgery. The use of hormonal agents (often called medical oophorectomy) has the benefit of being reversible, unlike surgery or radiotherapy.

Over the last few years a new drug has been developed which is an aromatase inhibitor. This drug works by inhibiting the enzyme aromatase, which usually catalyses the conversion of testosterone and other hormones to oestrogen. Initially the only known agent to achieve this was aminoglutethimide, which always had to be given in combination with a glucocorticoid because it blocked the action of the adrenal gland. Between 1995 and 1997, the active inhibitor of aromatase, called anastrozole (Arimidex) was evaluated against other therapies and first results, published in 2003, showed that Arimidex significantly improved the disease-free survival compared to patients taking Tamoxifen and had fewer side effects.(107)

Tamoxifen therapy induces an early menopause and induces all the symptoms a menopausal woman might experience. Menstruation will either stop completely or be interrupted. Menopausal symptoms such as hot flushes, depression and vaginal discharge or dryness may occur. More serious are the carcinogenic effects, which

include a small increase in the rate of endometrial cancer, blood clots and vision problems. The evidence of Tamoxifen's long-term effect is being studied. Women usually take the drug for 2 - 5 years and serious side effects are often attributed to the underlying malignant disease. Cancer of the liver, if caused by Tamoxifen, might take up to 20 years to develop. Even if these are recorded as long-term effects of Tamoxifen, the evidence is inconclusive as women with breast cancer might develop liver tumours anyway, which are usually thought to be metastases and are not biopsied routinely.

Serious complications of Tamoxifen are uncommon and must be set in the context of the benefits in ER-positive tumours in postmenopausal women. Doctors and patients should be aware that certain risks and complications might become apparent. Recently, Tamoxifen has been found to have some protective effect against osteoporosis (brittle bones) and coronary heart disease.

### **Conclusion**

Adjuvant radiotherapy in the treatment of breast cancer has enabled women to undergo more conservative surgery. This combined treatment is associated with the same survival rate in stage I and stage II breast cancer as radical mastectomy. Radiation therapy offers good locoregional control of the tumour, but does not control the cancer systemically. The addition of chemotherapy or endocrine therapy was established in order to achieve systemic control. In patients with positive axillary nodes, adjuvant chemotherapy offers encouraging results to pre-menopausal woman, while endocrine therapy with Tamoxifen remains the treatment of choice for postmenopausal women.

The physician and the patient must decide together which adjuvant therapy to choose. Different women will react differently to treatment and have individual side effects.

### 3.1.4 Complementary and alternative medicine (CAM)

Many attempts at defining complementary/alternative medicine (CAM) have been made.

*'CAM encompasses both the use of natural health care products (including herbs, homeopathy, and nutritional supplements) and the process of seeking health advice (i.e. regarding treatment, prevention of disease, as well as health maintenance) from individuals who are not generally considered conventional health care professionals (i.e. herbalists, homeopaths, naturopathic practitioners and acupuncturists).'*' (35, p639)

*'Complementary and alternative medicine (CAM) is defined as methods used in the diagnosis, treatment, or prevention of disease that complement mainstream medicine, as opposed to alternative therapies, which are used as a direct substitute for mainstream medicine.'*(108, p1445)

*'...we defined CAM as treatments that are available to patients outside conventional medical settings and that are not normally used in conventional settings to treat breast cancer or its associated symptoms or treatment side effects.'* (109, p668)

All the definitions indicate that complementary and alternative medicine is a form of treatment not usually offered by orthodox medicine. Most clinicians are not trained in the application or use of CAM.

In 1995 the OAM (Office of Alternative Medicine), today called NCCAM (National Centre for Complementary and Alternative Medicine), defined it as follows:

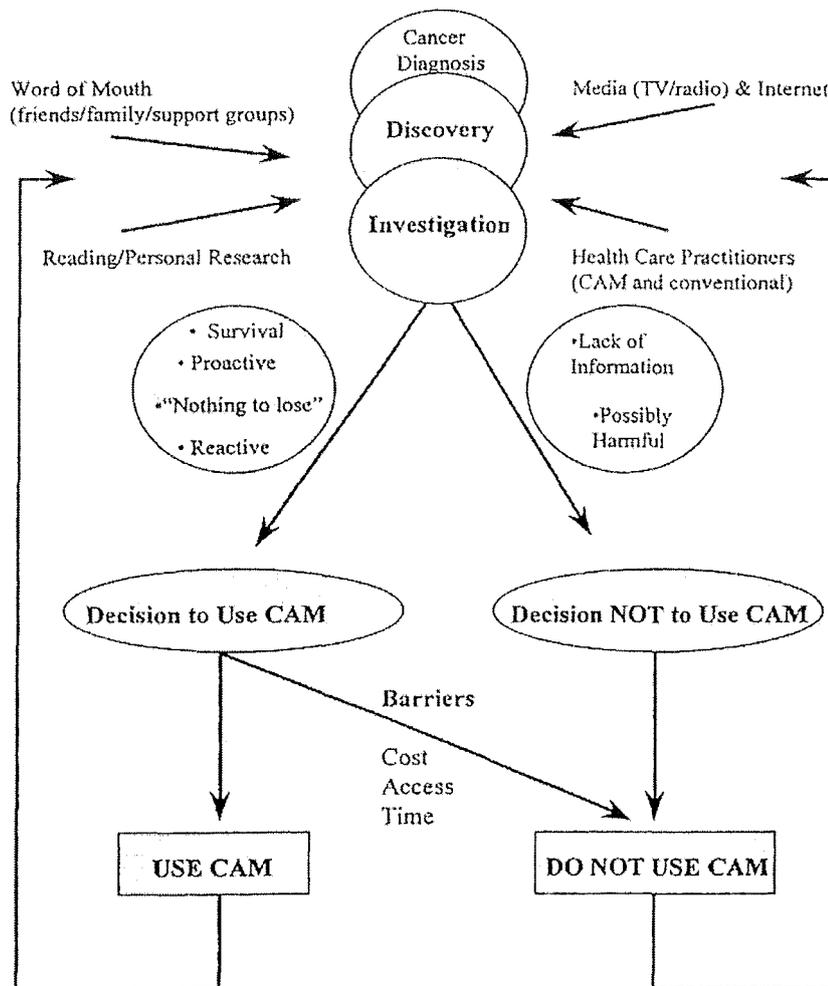
*' Complementary and alternative medicine is a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historic period. CAM includes all such practices and ideas self defined by their users as preventing or treating illness or promoting health and well-being. Boundaries within CAM and between the CAM domain and the domain of the dominant system are not always sharp or fixed.'*(110, p36) The OAM grouped numerous therapies into seven broad categories:

<b>CAM Practice</b>	<b>Examples</b>
Diet and nutrition therapies	Gerson diet, macrobiotic diet, specific vitamins and minerals
Mind-body techniques	Biofeedback, relaxation and guided imagery, meditation, hypnosis, yoga, support groups
Bioelectromagnetics	Acupuncture, homeopathy, laying on of hands
Traditional medicines from other cultures	Indian Ayurvedic medicine, Traditional Chinese medicine
Pharmacological and biological therapies	Shark cartilage therapy
Manual healing	Physical therapy, massage, chiropractic practices, Therapeutic Touch
Herbal medicine	Practices by indigenous healers such as Native American shamans

(110)

Orthodox treatment, i.e. surgery with or without adjuvant therapy, is recommended on the advice of a clinician. CAM is something that a woman who has just been diagnosed with breast cancer usually researches herself and finds through the media or personal investigation. Women choose these kinds of therapies for a variety of reasons, but mainly to enhance their chances of survival. They want to be pro-active

to prevent further illness. Some women also believe they have nothing to lose and that these therapies can do no harm.(35) Women want to boost their immune system or to deal with the side effects of the toxicity of orthodox therapies, such as radiotherapy, chemotherapy and endocrine treatment, or to mitigate cancer-related symptoms. The choice of treatment gives them a feeling of being in control as they design their individual treatment protocols.



(35)

Various studies have shown that many women with breast cancer use at least one form of complementary or alternative medicine. A study in San Francisco showed that 72% of women with breast cancer used CAM. The therapies included dietary treatment in 27%, spiritual healing in 24%, herbal remedies in 13%, physical methods in 14% and psychological methods in 9%.(111, p121) Dietary supplements (anti-oxidants, vitamins) were used in order to improve the immune system and reduce chemotherapy or radiotherapy side effects. Meditation and yoga were used to reduce stress and enhance the immune system; acupuncture for symptom management, immune enhancement and stress reduction; herbal therapy for symptom management and immune system enhancement; metabolic therapy (detoxification) to eliminate potential cancer-promoting toxins; and bio-electromagnetic healing of damaged tissue.(111, p122)

Marianne Richardson claimed that 73% of patients combined CAM with conventional therapy. Most used was prayer 62%, imagery 31%, vitamins 29%, herbal medicine 25% and massage 23%.(112) Heather Boon listed vitamins and supplements, herbal products such as Essiac, meditation, visualisation, special diets, Reiki therapy, acupuncture, Traditional Chinese Medicine, homeopathic medicine and massage therapy. She argued that patients were either pushed into CAM treatment because they had a bad experience with conventional therapy or they were pulled into it because they believed in the possibilities of CAM. She also explored the barriers for women who made a choice but encountered problems because it was too expensive, too time consuming or the chosen therapy was not available.(35)

A review of the literature revealed that there was little guidance for patients with breast cancer seeking documentation of the value of popular and conventional

therapies or ideas.(113) Publications do not show a definite benefit, according to a review that was published by Judith Jacobson in 2000, which evaluated literature from 1977 to 1980. She used four end-points, i.e. breast cancer size, disease-related symptoms, side effects, and immune function. Her review article examined more than a thousand citations, but only 51 fitted the category of CAM for breast cancer. Seventeen of those were randomised clinical trials.

The only treatment that produced positive results in two randomised clinical trials was melatonin. This demonstrated a benefit for patients with metastatic cancer, including breast cancer. It can be purchased over the counter. Other areas identified were acupuncture to relieve nausea and vomiting associated with chemotherapy, and massage to reduce lymphoedema after mastectomy. The mind-body methods showed some potential to reduce the pain and stress experienced by women undergoing conventional treatment.(113)

In the absence of scientific evidence, women are forced to rely upon their own judgement in the use of CAM. Often patients develop individual ideas based not on scientific evidence but on the way the treatment feels and whether it affects their quality of life positively. No two women are the same and no two women with cancer will suffer in the same way. The individual programme of alternative treatments is designed to alleviate the symptoms of orthodox medicine. Women are aware that it is not possible to cure the cancer, but that they may be able to control some aspects of their quality of life during treatment.

### 3.1.5 The importance of early detection

Until the end of the 19<sup>th</sup> century, communicable diseases such as tuberculosis were major contributors to high mortality rates. Cancer was not regarded as causing a high number of deaths in a society. The discovery of the bacterium by Robert Koch in 1882 ensured that the risks from communicable diseases were diminished and changed the focus on diseases such as heart disease and cancer.

Cancer was perceived as a sinister, mysterious disease, engendering intense fear or phobia. Information and knowledge about the cause of this disease and its possible treatment were limited in the population. Many women believed, especially during the 1920s and 1930s, that a blow to the breast or tight clothing caused breast cancer. In 1907, Charles P Childe made an attempt to convince women that cancer was controllable as long as it was detected at an early stage: '*[A] period exists in any cancer... when it is local, when it is operable and when it is curable.*' (22, p30) (114) He believed that it was essential to get his key message across to women: the importance of early detection for successful treatment.

Childe became involved with the American Society for the Control of Cancer (ASCC) which was founded in 1913 by physicians and lay people. In 1919 this group established three main focuses for their efforts in the USA:

1. *Cancer is first a local disease.*
2. *With early recognition and prompt treatment the patient's life can often be saved.*
3. *Through ignorance and delay thousands of lives are needlessly sacrificed.*

(22, p30)

The ASCC aimed to raise public awareness about the importance of early diagnosis. In the case of breast cancer this was imperative in order to diminish the threat to life. The debate about radical mastectomy versus lumpectomy and radiotherapy was in full flow and when trials confirmed that both treatments had equal survival rates, a true choice of treatments was available (in theory). So far this issue had not been addressed, as the only possible way of treating breast cancer surgically was through radical mastectomy. Many women were unable to accept such radical surgery. Now it was possible to attempt breast-conserving surgery with adjuvant radiotherapy as long as the cancer was discovered early. It was also possible to offer a better chance of survival while at the same time reducing the risk of the loss of the breast, which threatened the integrity of the patient's body and her identity as a woman.

The ASCC was instrumental in the fight against cancer, continuing to counteract the stigma that surrounded the diagnosis of breast cancer. In 1936 members of this organisation formed the 'Women's' Field Army' (WFA), whose aim was '*trench warfare with a vengeance against a ruthless killer*'. (22, p43) This campaign attempted to address women in the home, appealing to them in their roles as mothers and homemakers. In this role they were enlisted to become responsible for the health and well-being of themselves, their families, and communities.

The effects of World War I and World War II on the development of treatment for breast cancer were discussed in Baron H Lerner's book *The Breast Cancer Wars*. (22, p69) Surgeons still advocated Halsted's radical mastectomy and even suggested that this operation may not be extensive enough in women with axillary metastases. The attitude of the surgeon was to portray courage and valour in the operating room, resulting in super-radical operations for breast cancer. Many breast cancer surgeons had served in World War II and gained a different kind of experience during the war years, such as operating under difficult conditions, removing bullets and shell fragments from almost any part of the body.

Correspondence between Halsted and his patients indicated that women were happy with their treatment regardless of the radical change to their body. Barbara Mueller was treated by Halsted in 1917. After her radical mastectomy she remained under Halsted's follow-up care and was convinced that her doctor had cured her. Her correspondence indicates her gratitude for his treatment and follow-up. She wrote in her letter dated 18th January 1920:

*'... I have only the pleasantest recollections of you and a deep feeling of gratitude. That left arm did give me some worry when the swelling manifested itself, but now I no longer am disquieted, as the swelling has to some extent diminished though the arm still remains considerably larger than the right, and I am suffering no discomfort.'* (115, p102)

Others wrote: *'I still recall with pleasure my brief acquaintance with you and others, and my stay at the Hospital'*.(22, p23)

*'Again I wish to thank you for your wonderful attention and interest, ... and to assure you that the recollection of these favours will never be effaced from my memory.'* (22, p23)

*' You will be interested to know that I have been able to paint with a great deal of ease this summer ... and I owe it all to your skill and am grateful to you every day.'* (22, p23)

Women with breast cancer were in general treated with a paternalistic attitude, but until the 1970s they seemed willing to accept this. Few were aware that doctors were actively discussing other treatment options among themselves, i.e. the debate between Halsted and Keynes. The controversy between radical mastectomy vs. lumpectomy and radiotherapy had started at the turn of the century and was almost forgotten during the war years. It was only in the second half of the 20<sup>th</sup> century that this debate influenced the treatment of breast cancer. George Crile began to offer a simple mastectomy or lumpectomy in 1955 to selected patients and was supported by like-minded surgeons and nurses. Surgeons through this debate began to accept that the management of breast cancer should be decided on an individual basis. Everyone reacts differently to the diagnosis of breast cancer and women who survived the treatment had to find their own courage to live with it afterwards.

The women's movement created a forum for more and more women to find their own voice. Women were beginning to write about their experiences with stories being published increasingly from the 1970s onwards. Some women associated their breasts directly with their femininity and motherhood, while others saw the breast as a more neutral organ. Narratives highlighted the importance of treating each woman

individually, addressing the fear of a potentially terminal disease as well as concerns about body image.

Not all women decided to wage a war against uncaring physicians, but more and more information was disseminated by women, for women. Narratives were published for a variety of reasons. This included the need to inform others about diagnostic procedures and treatment options and the need to share the breast cancer experience. Women were beginning to make their own voices heard in a medical establishment where female patients would almost invariably encounter male doctors, with a more or less condescending or paternalistic attitude.

Early detection remains a major issue with the introduction of mammography and screening as well as the latest advances in gene technology. It would be beyond the scope of this study to explore these aspects.

### 3.2 Women's perception of different surgical techniques and adjuvant therapy since 1970

The examples chosen for this part of the thesis represent a time when women's voices began to be heard from the 1970s to the end of the 20<sup>th</sup> century. They are intended to be examples of published written narratives, which have been chosen because they offer an in-depth examination of breast cancer treatment and reflections on the perception of the patient about that treatment. They are grouped in decades and an attempt has been made to cover the US and Europe in each decade. Some narratives cover the whole breast cancer journey from point of discovery of a lump to the development of recurrence or metastases and palliative care. Others offer the reader an insight into the treatment for breast cancer, stopping when treatment was completed.

The first narrative covers the period of Audre Lorde's life from 1973 to 1986.(116) Audre Lorde was born in New York in 1934. She worked as a Professor of English at Hunter College, part of the City University of New York. She has been described as an 'Amazon Warrior' who also knows how to tell the tale of a battle and is an eloquent outsider who speaks in a language that can touch people everywhere.

In 1980 Audre Lorde was diagnosed with breast cancer. She wrote about her experience in essays, speeches and journals, first published in '*The Cancer Journals*' (1980), '*Sister Outsider*' (1984) and '*A Burst of Light*' (1988). In '*The Cancer Journals*' she published selected entries from her diaries six months after her modified radical mastectomy in January 1979. '*A Burst of Light, Living with*

*Cancer*' is a collection of diary entries from 1984 to 1986. It reflects the passion and courage of a woman who worked as one of the leaders in the feminist movement.

Rose Kushner provides a second narrative; she was a freelance writer for the Washington Post. *'Breast Cancer - A Personal History and Investigative Report'* was published in New York in 1975 and gives her personal experience as a medical journalist diagnosed with breast cancer in 1974.(117)

The third narrative has been chosen from Europe, and is by the author Maxie Wander with the title 'Leben wär' eine prima Alternative' (Living would be a good alternative).(118) Maxie Wander was born in January 1933 in Vienna and was married to the Austrian Fred Wander. She had two children. She worked as a secretary, a photographer and a reporter and also wrote role-plays and short stories. Her diary starts in September 1976 and follows the diagnosis and treatment of her breast cancer through to her death on 20th November 1977. It was edited and published by her husband.

Two narratives have been chosen to represent the perception of breast cancer treatment by women during the 1980s. The first narrative is written as a dialogue between Sandy (Sandra Butler) and Barbara (Barbara Rosenblum). This dual narrative covers the time from February 1985 when Barbara was diagnosed with advanced breast cancer up until 14th February 1988 when she died. A collection of journal entries reflects the perceptions of treatment and records the feelings of the victim, Barbara, and her close friend, Sandy.(119)

Both women were Jewish and had lived heterosexual lives before cohabiting. When they met, Sandy had just moved from San Francisco to Rio Alto after her youngest daughter had graduated and moved to Israel. Barbara was working as a Professor in Sociology at Stanford University.

The second narrative from the 1980s is German and written by Angelika Mechtel with the title 'Jeden Tag will ich leben' (Every day I want to live).(120) The author was born in 1943 in Dresden. Mechtel was a freelance author in Cologne who published novels, short stories and children's books. Her story began in October 1987 and ended in May 1992, covering in diary form her feelings about her diagnosis of breast cancer and her treatment. It creates a picture of her anxiety, doubts and fear of death, balanced with hope and love during that time.

Two further narratives represent treatment in the 1990s. Joyce Wadler, a New York correspondent on the Washington Post, published her story in 1992.(121) Initially her story was printed in a magazine but the response it received prompted her to write a full-length version of her experience. The book was an international best seller and gave a detailed and powerful personal picture of the author as she dealt with the diagnosis and treatment of breast cancer.

The final narrative is that of Elisa Segrave who is a freelance writer. Her story was published in *The Observer Magazine* on 13th February 1994 and in a book version in 1995 with the title '*The Diary of a Breast*'.(122) This is the story of a British woman treated for breast cancer in London starting in September 1991. Elisa Segrave was born in 1949 and grew up in Madrid. She lived in New York, Paris and Peru and published articles and short stories, which appeared in *The Observer*, *The Guardian*

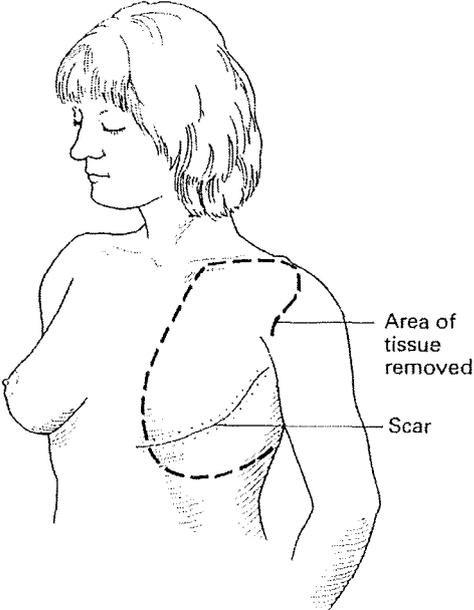
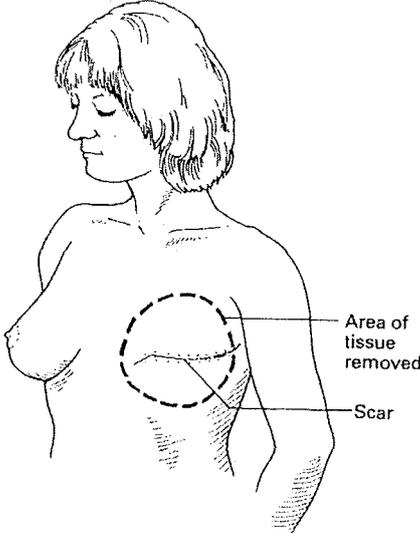
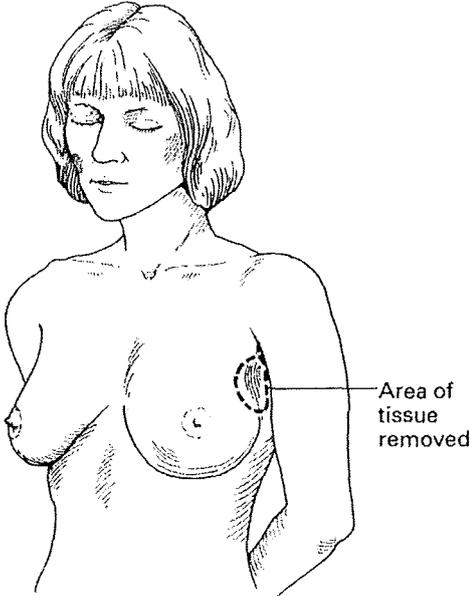
and *The Independent*. Her story covers the nine-month period from September 1991 to May 1992, when she received cancer treatment as an NHS patient.

These narratives are examples of how women perceived their diagnosis of, and their treatment for, breast cancer since the 1970s. Every one is an individual story and every woman managed the diagnosis and treatment in her own individual way. The analysis of these narratives will pay tribute to their individuality, but will also try to identify common themes. Each of these women reacted differently to discovering a lump and being told she had breast cancer. Their reaction depended on their individual perceptions of health and illness, and on their general coping mechanisms in life.

The experience of their doctor-patient relationships influenced their perception throughout. The women perceived their treatment in different ways. For some, their treatment choices and the treatments themselves were adjusted to their individual needs, for others they were not, resulting in different perceptions of their treatment for breast cancer and their fear for their life and femininity.

**Diagram of operating techniques:**

**Lumpectomy, simple mastectomy, modified radical mastectomy (92)**



**Lymphoedema and metastases**

**(Courtesy of the Wellcome Photo Library London)**



### 3.2.1 Audre Lorde *'The Cancer Journals'*\*

*'Each woman's response to the crisis that breast cancer brings to her life out of the whole pattern, which is the design of who she is and how her life has been lived. The weave of her every day existence is the training ground for how she handles crisis.'*  
(p3)

#### **Diagnosis**

Audre Lorde started writing six months after her radical mastectomy for breast cancer. The first entry into her diary shows that the words 'pain' and 'fear' dominate her feelings. She does not mean physical pain, but more a mental pain of coming to terms with the diagnosis of cancer.

*'I handle the outward motions of each day while pain fills me like a pus-pocket and every touch threatens to breach the taut membrane that keeps it from flowing through and poisoning my whole existence'* (p4)

*'Is this pain and despair that surround me a result of cancer, or has it just been released by cancer?'* (p5)

She was aware that she needed to come to terms with her diagnosis and was looking for ways of letting pain go and finding some form of laughter and happiness again. She felt the need to confront cancer as a means to analyse life itself. This way she felt able to incorporate the threat of death into her current living: *'There must be some way to integrate death into living, neither ignoring it nor giving in to it.'* (p7)

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\* all direct quotes from (116)

One year later she felt that she dealt with fear and pain more positively. Slowly these emotions were becoming less important, although they did not disappear. She was beginning to deal with the painfulness of her breast cancer diagnosis in a more positive way, making it a part of her life. This enabled her to overcome the feelings that her life was overshadowed and that all happiness had flown out of it. What remained was the fear of a recurrence: *'Sometimes fear stalks me like another malignancy, sapping energy and power and attention from my work. A cold becomes sinister; a cough, lung cancer; a bruise, leukaemia.'* (p9)

Lorde saw that her fears were most powerful when they were not given a voice. She encouraged herself to deal with them by trying to turn them into creative energy. This enabled her to face the fear of death which might be imminent or come years later. She felt that it was shaping her every moment of living.

In *'The Cancer Journals'*, Audre Lorde allows the reader into her immediate thoughts. In places she provides her own analysis of these entries retrospectively. During her diagnosis she recalled her feelings when she had a biopsy that was termed benign. Even at that stage she faced the fact that she might have cancer. She wanted to live her life to the full:

*'In September 1978, I went into hospital for a breast biopsy for the second time. It all happened much faster this time than the year before. There was none of the deep dread of the previous biopsy, but at the same time there was none of the excitement of a brand new experience.'* (p18)

She opted for a two-stage procedure and when she woke up from her biopsy in recovery she knew that it was malignant because both breasts were bandaged. Her surgeon had told her that she would biopsy both breasts if cancer was found. Shock and fear manifested themselves in a feeling of extreme coldness. She describes it as one of her worst experiences. She was feeling very cold but nobody was offering her extra blankets. Her friend Frances waited for her after she came round from the anaesthetic and confirmed her worst fear that it was malignant. Lorde perceived her friend as a sunflower in the cold, freezing hospital environment, indicating how much of a lifeline her friend was for her. Her friend represented the positive search for light in her dark tunnel. The sunflower will always turn its head to find the strongest sunshine and her friend's presence resembled that search for light and warmth at one of the worst moments in her life. *'Frances was there by the door of my room like a great sunflower. I surfaced from anesthesia again as she took my hand in her deliciously warm ones...'* (p19)

### **Friends and family**

Audre Lorde had a wonderful support network from all her friends and family, who carried her through her experiences lovingly. Friends brightened impersonal surroundings and brought human warmth into the cold and indifference of a hospital environment: *'Our friends came and were there, loving and helpful and there, brought coats to pile upon my bed and then a comforter and blankets because the hospital had no spare blankets, they said, and I was so desperately chilled from the cold recovery room.'* (p20)

### **Decision on treatment**

The decision about further treatment was made by Audre Lorde herself. Nobody could make it for her. She had to decide on the type of surgery and adjuvant therapy, as well as balancing her well-being with a holistic health approach that included dietary changes, vitamin therapy and experimental immunotherapy, i.e. German pancreatic enzymes. Audre Lorde gathered a wealth of information before her biopsy, but describes the decision process as almost schizophrenic. At one time she was able to consider this decision from an intellectual point of view, almost personally detached, and at other times she was overwhelmed by the lack of tools she had to make a meaningful decision for herself. A dilemma faced by everyone – each to a degree. It took her a day and a half to come to a decision. She was grateful that she had become accustomed to listening to her own voice and finally decided to have a mastectomy.

*' I felt sometimes utterly calm cool and collected, as if this whole affair was an intellectual problem to be considered and solved: should I have a mastectomy or not? What was the wisest approach to take having a diagnosis of breast cancer and a history of cystic mastitis? Other times, I felt almost overwhelmed by pain and fury, and the inadequacies of my tools to make any meaningful decision, and yet I had to. '*

(p22)

She had chosen her surgeon prior to the biopsy with a view to later treatment: *'I deluged my surgeon with endless questions which he answered in good faith, those that he could'* (p23). Her decision in the end was influenced by the fact that she wanted something already established, not some experimental therapy, as she felt this gave her the best chance to live: *'When it came right down to deciding...I felt inside myself for what I really felt and wanted, and that was to live and to love and to do my work, as hard as I could and for as long as I could.'* (p23)

She decided against chemotherapy and radiotherapy as she considered those options carcinogenic. In her view, a modified radical mastectomy would deal with her problem best. It offered her a degree of control. She chose this option in the hope that the cancer had not spread anywhere else and could be controlled better. Her fears were of pain, and the worry that she might not survive yet another anaesthetic.

*'I was also afraid that I was not really in control, that it might already be too late to halt the spread of cancer, that there was simply too much to do that I might not get done, that the pain would be just too great. Too great for what, I did not know. I was afraid. That I would not survive another anesthesia, that the payment of my breast would not be enough; for what?'* (p24)

In a diary entry she writes:

*'I am going to have the mastectomy, knowing there are the alternatives, some of which sound very possible in the sense of right thinking, but none of which satisfy enough... Since it is my life that I am gambling with, and my life is worth even more than the sensual delights of my breast, I certainly can't take that chance.'* (p25).

## **Mastectomy**

Her mastectomy was undertaken on 22<sup>nd</sup> September 1978. Her memories account briefly for the time before she went to theatre and again her friend Frances brightened the horror of the theatre environment. Her immediate memories afterwards are from the recovery room, screaming and cursing with pain, with little support from the nurses. She was drifting in and out of intense pain between shots and sleep. Twenty-four hours after the operation, the pain had subsided considerably, resulting in euphoria on the second day after her operation. *'The pain was minimal. I was alive. The sun was shining. I remember feeling a little simple but rather relieved it was all over, or so I thought. I stuck a flower in my hair and thought, "This is not as bad as I was afraid of".'* (p27)

The support of her friends helped her through this period and made her feel positive that the ordeal was over. Physical pain still bothered her a lot from the third day onwards and was obviously not well controlled by painkillers:

*'On the morning of the third day, the pain returned home bringing all of its kinfolk. Not that any single one of them was overwhelming, but just that all in concert, or even in small repertory groups, they were excruciating. There were constant ones and intermittent ones. There were short sharp and long dull and various combinations of the same ones. The muscles in my back and right shoulder began to screech as if they'd been pulled apart and now were coming back to life slowly and against their will. My chest wall was beginning to ache and burn and stab by turns. My breast which was no longer there would hurt as if it were being squeezed in a vice. That was perhaps the worst pain of all, because it would come with a full*

*compliment of horror that I was to be forever reminded of my loss by suffering in a part of me which was no longer there.'* (p28)

After two weeks the physical pain receded and Audre Lorde describes it as coming out of a physical and emotional shock period. It was then that the other pain and hurt started and she writes: '*Later after the physical pain receded, it left room for the other. But in my experience, it's not true that first you cry. First you hurt and then you cry*' (p30)

### **Coming to terms with breast cancer: body image and society**

Increasingly she felt herself coming to terms with having breast cancer, with having lost a breast and facing the rest of her life, which had been threatened so severely. She felt it was hard to move through the feelings of shock while still experiencing the after-effects of anaesthesia which prevented her thinking clearly. During this time a woman from *Reach For Recovery* visited. This visit from the charity organisation was a very negative experience. Audre Lorde felt that the only message the woman was trying to input was that she was as good as she was before and could look exactly the same. She was then presented with a lambs-wool prosthesis covered in some pink material. The only thing about which the woman seemed concerned was that Lorde's outer appearance with a prosthesis would be the same. The only useful thing she was given was a set of exercises. Apart from that, she felt she had nothing in common with the woman: '*I wonder if there are any black lesbian feminists in Reach For Recovery?*' (p32). When she was trying the prosthesis on she was horrified, as it did not feel like a breast, did not look like a breast and certainly did not match her dark skin colour.

*'I came round my bed and stood in front of the mirror in my room, and stuffed the thing into the wrinkled folds of the right side of my bra where my right breast should have been. It perched on my chest askew, awkwardly inert and lifeless and having nothing to do with any me I could possibly conceive of. Besides, it was the wrong colour, and looked grotesquely pale through the cloth of my bra. I pulled the thing out of my bra, and my thin pyjamas top settled back against the flattened surface on the right side in front of me....I looked strange and uneven and peculiar to myself, but somehow ever so much more myself, and therefore so much more acceptable than I looked with that thing stuck inside my clothes. '* (p33)

The loss of her breast did not dominate her life; she felt that she wanted to integrate the fact that she had lost her breast in her new sense of self. The prosthesis was definitely not what she wanted; she wanted to come to accept herself as a one-breasted woman and to grow to love her changed body. (p10)

She was allowed to go home and needed no further treatment, as her axillary nodes were not affected. Going home for her was an exciting experience, but also a worrying one. She felt that the whiteness of the hospital had almost offered a kind of protection and insulation from her feelings. Now she was going home she could not carry on without being required to engage more emotionally, whereas in hospital she felt almost detached from her emotions. Many people supported her and loved her, but there were also people who avoided her due to their own pain and fear, or because of the fact that they felt she had become somebody other than the woman she had been.

*' The status of untouchable is a very unreal and lonely one, although it does keep everyone at arm 's length, and protects as it insulates. But you can die of that specialness, of the cold, the isolation. It does not serve living. I began quickly to yearn for the warmth of the fray, to be good as the old even while the slightest touch meanwhile threatened to be unbearable. ' (p37)*

Not wearing a prosthesis was a way of coming to terms with her breast cancer and with accepting herself; for some in the health profession this was viewed as difficult to accept. In Audre Lorde's opinion, the emphasis on physical issues and quick cosmetic reassurance was really the wrong way to deal with herself and her body image. It would prevent her and others from accepting themselves and their bodies in the new shape. It could encourage women to focus on the mastectomy as a cosmetic operation, rather than as the death threat it really was. As a feminist she was very much in favour of women shaping their own destiny and not passively accepting external controls. She got very angry when she was seen at her follow-up and all the stitches were taken out and she was told that she could now wear a proper prosthesis: *' You will feel so much better with it on, ...And besides, we really like you to wear something, at least when you come in. Otherwise it's bad for the morale of the office. ' (p46).*

Lorde was outraged by this admonishment, given in the office of one of the top breast cancer surgeons in New York City:

*' Yet a woman who has one breast and refuses to hide that fact behind a pathetic puff of lambswool which has no relationship or likeness to her own breasts, a woman who is attempting to come to terms with her changed landscape and changed timetable of*

*life and with her own body and pain and beauty and strength, that woman is seen as a threat to the "morale" of a breast surgeon's office!' (p47)*

She linked this threat to the fact that so many women do not come forward early. While early detection and treatment are essential in the management of breast cancer, misconceptions such as treatment of the disease necessitating loss of breast, may prevent women from presenting early enough. She wrote that it was unacceptable that women who had just lost a breast should stick a prosthesis in their bra simply to make other people feel better about it. She was equally opposed to breast reconstruction and all the dangers that might entail.

It was important for her to start embracing her life lovingly again and not to mourn the rest of her life for losing one breast. She felt a need to feel that she could resume a normal life again.

*'It was the urge, the need, to work again, to feel a surge of connection begin with that piece of yourself. To be of use, even symbolically, is a necessity for any new perspective of self, and I thought of that three weeks later, when I knew I needed to go to Houston to give a reading, even though I felt weak and inadequate. ' (p38)*

She started to embrace life and her work as a black feminist writer, which was becoming ever more important to her. In a later publication entitled '*A Burst of Light*', she describes how she continued to live with cancer. She had a period of six years when she was in remission and was then diagnosed with metastases in the liver. '*A Burst of Light*' is the publication that embraces her life even after the diagnosis of liver metastases. She carried on with her work as long as she could adjust her

lifestyle to her disease. She took great care over the process of diagnosis of the liver metastases and eventually refused a liver biopsy because of the fear that it would aggravate the growth of the cancer. Instead she went to an anthroposophy clinic in Switzerland. While she did not agree with the way people were dealing with illness there, she felt it was a more gentle and non-invasive way of treating her cancer. She perceived the anthroposophy clinic as dogmatic and almost too genteel and cultivated: *'The calm directness with which everyone seems to deal with the idea and reality of disease... nobody believes in talking about feelings, even strong expressions of which is considered to be harmful or at least too stressful to be beneficial.'* (p 296).

Her metastases were finally diagnosed on 23<sup>rd</sup> December 1985, and for the first time her narrative addresses loneliness. This might be a result of being away from her circle of supporting friends in New York. People in the Swiss clinic were kind and gentle but did not talk about their feelings. She felt isolated, knowing that she now had a diagnosis, which made it inevitable that she confronted her own death and ideas on the type of palliative care she might want. From then onwards, she confronted the possibility that she could die soon and that she had to live for the moment.

### **Doctor–patient relationship**

Only one episode highlights her relationship with doctors: she refused her liver biopsy and the doctor was unable to understand this.

*'When I told him I was having second thoughts about a liver biopsy, he glanced at my chart. Racism and Sexism joined hands across his table as he saw I taught at a*

*university... "Well, you look like an intelligent girl," he said, staring at my one breast all the time he was speaking, "Not to have this biopsy immediately is like sticking your head in the sand." Then he went on to say that he would not be responsible when I wound up one day screaming in agony in the corner of his office.'* (p 319)

She resented the patronising demeanour of the specialist in liver tumours and was appreciative of the way the clinic in Switzerland dealt with her and other patients.

Her breast surgeon is described as:

*'... a doctor with whom I have always been able to talk frankly, and it was from him that I got my first trustworthy and objective sense of timing. It was from him that I learned that the conventional forms of treatment for liver metastases made little more than one year's difference in the survival rate.'* (p 321)

### **Complementary/alternative medicine**

Increasingly she started to consider alternative medicine. When homeopathic medicine called cancer the 'cold disease', she tried to avoid any sort of coldness and sought sun and warmth, for example taking a hot bath when she was not feeling herself. She designed her own treatment programme, excluding surgical intervention, as she felt that this would have a negative impact on her quality of her life. She opted for alternative, gentler ways of dealing with the metastases. She knew that she couldn't be cured but could improve her quality of life and perhaps lengthen the time she had left. She learned how to ask for help in order to improve her day to day living. She felt that it was important to stop thinking long term and to call in debts.

*'Remember that nice lady down the street whose son you used to help cross at the light and he was always saying "Now if there's ever anything I can do for you, just let me know" Well, her boy's got strong muscles and the lawn needs mowing. '*

(p327-328)

Living with the diagnosis of a terminal illness caused despair and isolation and was described as one of her biggest enemies. She frequently reminded herself that she was not really alone but that it just felt that way. It was now time to interact with people and put solitary ways behind her.

*' I do not think about my death as being imminent, but I live my days against a background noise of mortality and constant uncertainty. Learning not to crumble before these uncertainties fuels my resolve to print myself upon the texture of each day fully rather than forever.'* (p330)

The control of her pain was important and she described pain differently in her palliative phase: *'I have periods of persistent and distracting visceral discomfort that are totally intrusive and energy-consuming. I say this rather than simply use the word pain, because there are too many gradations of effect and response that are not covered by that one word.'* (p330)

She learned self-hypnosis to deal with pain and she addressed her mortality every day. As time went on, she did not shy away from this thought and she felt relieved. Audre Lorde died in 1992.

Audre Lorde (116)



### 3.2.2 Rose Kushner '*Breast Cancer - A Personal History & Investigative Report*' \*

Rose Kushner published this narrative in 1975 in New York. It was written to tell her personal story and describe her journey through the treatment for breast cancer, as well as providing the reader with a guide should they themselves or a close family member or friend encounter breast cancer.

She wanted to show the scientific, medical and socio-economic, as well as the physiological aspects of breast cancer, while setting it into the context of her own experience. This book was not only an expression of herself and her feelings, but aims to be a guide to others to find their ways through the jungle of breast cancer. She enlisted the help of a Professor of Surgery and Physiology from Rosewell Park Memorial Institute in New York. Her story began with the date she found the lump in her breast, on 15 June 1974. *'The date will probably stay with me forever. Like all outstanding anniversaries, the precise time a malignant tumour is found has a way of sticking in one's memory.'* (p3)

#### **Diagnosis**

She found the lump while in the bath shaving under her arm and was afraid. All she could think of was that she might have breast cancer. All the deaths of people she had known had been the result of the disease. *'There was nothing I have ever come across to show me anything but the shadow of imminent death.'* (p 4)

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\* all direct quotes from (117)

She got her partner Harvey to check that there was really a lump and they made an urgent appointment. Her doctor took the lump seriously. Further diagnostic procedures were scheduled during this consultation in an open manner and she was advised to get a mammogram, a procedure that had been newly developed in the hospital. She was told: *'No matter what the pictures say, you've got something in that breast that doesn't belong there. It will have to come out.'* (p7)

A mammogram was done the same day and the results showed that she needed a biopsy. In the discussion about the biopsy, Kushner made it clear to her doctor that surgery was only to be undertaken by a doctor specialising in breast surgery. Her doctor seemed to be amazed at her knowledge and at her request.

*'No, not any general surgeon can do a mastectomy, if I need one. It's got to be an oncologist. How can a person who knows a little bit about cutting everything know as much as someone who does only cancer surgery?'* She clarified this further: *'After all ... if I had a detached retina, you'd send me to an ophthalmologist wouldn't you?'* Her doctor replied: *'Naturally. I don't know a damned thing about detached retinas, except to recognize one when I see it.'* (p8)

### **Decision on treatment**

They debated where she should go, but her doctor seemed to be against referring her to a big teaching hospital, as he believed that she would be treated as a number in a research trial, not as a person. Kushner disagreed and pointed out that there was something called 'informed consent', which would prevent her being enrolled in research against her wishes. She was referred to the National Institutes of Health (NIH). The debate with her doctor left her feeling emotionally distressed. Her

partner was more supportive and understanding, as he was aware that she had a preference for specialists. During the birth of their children she had felt the same need to be looked after by a specialist. They discussed further action and made it dependent on the results of the mammogram. Kushner developed a determination to make her own decisions and to stay in control. She did not want to find herself in a situation where things were happening to her without her full awareness and agreement. *'One thing you can be sure of. Nobody's hacking off my breast while I'm unconscious unless I'm convinced that that's the only thing there is to do.'* (p11)

She used her connections to get an appointment at the National Institutes of Health. She was seen in the breast tumour clinic six days after she found the lump. She felt that taking action and taking control of her own destiny made her feel better: *'With appointments scheduled, a glimmer of plans made, books to read, at least I had my forefinger in my own destiny. I would be no slab of silly putty to be manipulated helplessly by a pack of doctors.'* (p11)

### **Doctor-patient relationship**

Her appointment at NIH did not go well, as a long time was needed to do baseline tests for their research. She wanted clarification of whether or not her tumour was malignant as soon as possible. Eventually she decided to have a biopsy done by the (house)surgeon whom she had known for a long time. She prepared a contract to state that she wanted a biopsy only. She wanted a two-stage procedure and not a mastectomy at the same time, should malignancy be diagnosed. She decided that was the best way for her to deal with everything. Initially her surgeon seemed to support this agreement but in a delayed reaction it became apparent to her that he felt his expertise had been questioned. He told her very bluntly that the biopsy had

shown that it was cancer, leaving her without another opportunity for discussion or support: *'I've got bad news... It's cancer.'* (p24)

She decided after reading all the literature in local and specialist libraries that her choice should be a modified radical mastectomy. She set out to find a centre willing to do this operation. She opted for surgery at Memorial Sloane-Kettering Cancer Center, a private institution. During her consultation at the institution, she felt totally out of control and left the office of the surgeon who had explained what he was going to do when she realised that he had described the Halsted radical mastectomy, which was not what she wanted. She panicked: *'In my panicky state, I assumed it was standard hospital policy to do Halsteds, not a matter of a surgeon's personal preference.'* (p26)

Finally she was referred to the Roswell Park Memorial Institute in Buffalo. This New York State Hospital was one of the oldest cancer hospitals in the world, dating back to 1895. There she met Dr Thomas L Dao, who later became co-editor of her book. He was willing to undertake the simple mastectomy she wanted. Further reassurance was given when she came round from the anaesthetic and was told that he had been able to take everything away and that the cancer had not spread.

### **Mastectomy**

Rose Kushner wrote about her postoperative experience and described the initial burning in her throat and in the area of the incision, which did not last long. The burning in the incision, due to two vacuum drains, caused most irritation. Otherwise she felt numb and worried that she was paralysed. She was given reassurance by her doctor, who said that sensation would gradually return. Sensation returned with pain,

which was something that had not been explained to her. Her pain and discomfort lasted a few months and her own research showed that this was normal.

*'The site immediately around the incision was numb for about five months... My shoulder and arm, however, were exquisitely sensitive if touched. It was not a constantly present pain, but even a light brush with a feather felt like a lighted match. To bump the shoulder or put any pressure on the upper arm was agony.'*  
(p218)

Her experience postoperatively was slightly different from other women as she stayed in hospital until the incision was well healed. Usually women went home one week after the operation with their stitches still in place. Once she got home, she said that exhaustion was her main physical reaction.

*'In the hospital, I had been in great condition in comparison with most of the other patients, and of course I had had nothing much to do but brush my hair... Back home, it was different. Just clearing the breakfast dishes was fatiguing. What had happened to all the vim and vigor I had had in Buffalo?'* (p221-222)

### **Body image**

Rose Kushner did not have a visit from a volunteer from 'Reach to Recovery'.

Normally, every mastectomy patient was presented with a temporary prosthesis kit shortly after surgery, on the second or third postoperative day. The volunteer worker would advise on a set of manual exercises as well as offer moral and psychological support. Kushner was pleased with her long-term silicone gel prosthesis.

*'The silicone-gel prosthesis cost almost a hundred dollars, but mine has been worth every penny the insurance company paid. The latex cover makes it adhere to the skin, so that it does not shift out of position but stays where it belongs. The slick, silky coverings of other prosthesis I tried often moved when I moved; occasionally I would discover the "breast" up near my shoulder or somewhere under my arm, instead of on the left side of my chest.'* (p223)

Kushner did not have radiotherapy, chemotherapy or endocrine therapy. However, her narrative provides copious information on these issues. She offers the reader a wide spectrum of information, written with her own situation in mind, engaging in discussion with relevant people. Topics covered are the discovery of a lump, the diagnostic procedures, staging of the disease and surgical/non-surgical options. The reader is supplied with information about possible complications, and short-term and long-term psychological considerations.

Her opinion on body image is made clear in her comments during a television interview. She was annoyed by the way the interviewer was portraying the heart of the breast cancer problem as a sexual problem: *'The thing you're forgetting is that we're discussing a fatal disease, and the important thing is that the doctor get rid of the cancer, and are you going to live? Unless a woman is unbalanced, the first thing she worries about is her life.'* (p 231)

Rose Kushner used her experience with breast cancer to improve the treatment of women with the same fate. Baron H Lerner devoted a whole chapter to her as one of the main fighters in the 'war on breast cancer' in the USA. She died in 1990.(22)

Rose Kushner (22)



### 3.2.3 Maxie Wander *'Leben wär' eine prima Alternative'*\*

This diary details the breast cancer journey of Maxie Wander, starting with her admission to a hospital in former East Berlin after she discovered a lump in her breast in July 1976. Her husband, Fred Wander, put together a selection of letters and diary notes for publication after her death.

#### **Diagnosis**

Maxie Wander was diagnosed in the former German Democratic Republic (GDR) at the age of 44. Her initial diagnosis was delayed when doctors did not consider her lump to be a serious risk to her health. She was told that surgery would be needed to diagnose the cause of her lump, but half of the surgeons were on holiday, while the other half were totally overworked; she was advised to come back at the beginning of September.

Unsatisfied with this situation, she used one of her contacts who was a young doctor and she arranged referral to the Charité Hospital in East Berlin. Here, too, she was reassured that there was no urgency and she could go on holiday before anything was done. When she was finally diagnosed, the doctor asked why she came to him so late.

Maxie Wander, herself Austrian, chose to live with her husband in the former GDR. She lived in a socialist state where information was not freely available but strictly regulated. Her diary did not reveal any search for information and it appeared that

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\* all direct quotes (translated from German into English) from (118)

Maxie Wander accepted the path suggested by the surgeon. It is unclear if this was due to lack of information or because she did not want to know more. Her biopsy was undertaken with a frozen section (tissue diagnosed during operation), with the possibility of proceeding to a mastectomy in a single-stage procedure if cancer was diagnosed.

She felt threatened by the medical team:

*'At seven, the first ward-round by the house officer. At eight the second one with six male and two female doctors and two nurses. Frightening! They only look at the charts at the end of my bed. Are they not interested in the human being? Do they not want to know what kind of person this is who lies here? Are they only interested in the tumour?'* (p15)

The preparations for her operation took some time and she was allowed to go home over the weekend. She found this period of waiting difficult to deal with: *'It is maddening, this waiting, when will they finally get rid of my cancer?'* (p16)

Fear was an overpowering emotion during this time:

*'To think about the cancer feels as if I am locked into a dark room with a murderer. I don't know whether, where, or how he will attack!'* (p 18)

The pre-operative preparations included taking informed consent, although this was minimal. No explicit time was allocated for these, as they were integrated into the physical preparations: *'It only starts after lunch: shaving under the arms, signing that I am in agreement with all the clinical measurements necessary, nail varnish*

*removed from the feet, hospital gown, no more food and a suppository for the evening. ' (p19)*

### **Mastectomy**

Her first postoperative entry was made two days after the operation. She describes two aspects that highlight her anger about the non-communication between clinicians when she was given wrong advice about taking the oral contraceptive pill:

*'Why don't the doctors get together? Is everyone working for himself or herself here?'* (p21)

Her first memory after the operation was that of a rigor (shivering) and feeling terribly shocked when she realised that her breast had gone. *'...and then the feeling of the tightly bandaged breast: the breast has gone! And I am burning up.'* (p22)

No direct information was given to her, but it was clear that it must have been cancer. When she overheard the clinicians' discussion she realised that they were indicating that not everything was removed by the operation. She was upset that nobody explained the implications of the operative findings to her.

*'Everything the clinicians say over the next few days points to the fact that it is cancer which is clear anyway, but in addition it seems as if they didn't manage to take it all out. I take this from their very few sentences, which I manage to get out of them. I ask and ask, and perhaps they are not used to that. Perhaps other patients are more accepting of their destiny. Why don't they look at me? Why are they not able to explain the situation better to the ill person? I am waiting in vain for some reassurance or comfort.'* (p22)

She was told that she needed radiotherapy, which she understood as a death sentence. She was in pain, and her lungs and her stomach hurt. She feared metastases had developed and was in need of reassurance, which did not come. They did not explain things to her, but kept injecting her with a painkiller she presumed to be morphine.

Her first look at the operation scar was involuntary while the dressing was changed. She was utterly unprepared for this confrontation with her scarred body and describes her feeling during this moment as that of a wounded animal: *'I am perhaps too weak to be shocked. I am a wounded animal, which pretends to be dead in order not to be hurt any more.'* (p26)

She was horrified when she was told that she had to be moved to the cancer ward because she did not want to be confronted with other cancer sufferers: *'No, no, everything but the conversation amongst cancer sufferers!'* (p28) *'All the women look different, grey, miserable and hopeless... I must get home for the weekend, otherwise I will go mad!'* (p39)

When she finally got home she was relieved, even if it was only for a short period before she had to go to another hospital for radiotherapy. She felt intense emotion about life and paid attention to every little detail. This intense feeling dominates the whole narrative. Life is regarded as a precious gift and she wants to enjoy every moment.

*'I want to tell you about all the small things as if they were big sensational matters: to sit at the table, to listen to Mozart with Fred while drinking a cup of coffee, you*

*know? You know all that and you will laugh at me! Real life, says a voice within me, this is now, take it as you find it, even with pain, with fear but at the same time continue all the delight you can possibly imagine!' (p46)*

### **Adjuvant treatment**

The second stage of her treatment started about four to six weeks after the first operation when she was informed that her ovaries must be removed. Doctors told her that this needed to be done but did not give her a chance to discuss the operation and its after-effects. She was expected to comply. Maxie Wander did not question the decision, but wrote about her frustration during this consultation. First, the fact that the clinician said she might not have needed radiotherapy had she been operated on in a specialist cancer clinic. To her, this indicated that some hospitals were working more carefully than others. Second, her confrontation with the clinician who told her that: *'We do all this so that you are able to care for your family!'* A statement she queried in her narrative. *'And for me? It's okay to castrate me and to cripple me, make me an old person just for life at any price?'* (p63)

It took her a long time to recover from the oophorectomy. She felt that her two major operations were undertaken too close together. Her body felt weakened at a time when she wanted to have all her strength to fight the breast cancer: *'On the one hand I need all my strength to deal with this disease and on the other hand they destroy my immune system.'* (p75)

## **Body image**

Maxie Wander thought that she had suddenly grown old, ugly and unattractive.

*' Other women get older slowly and hardly notice it. I have grown old in the autumn, they have cut my body to bits, and no man will be interested in it. I will never again be able to undress myself unconsciously on the beach. My body, which I really loved, has been thrown out on a rubbish tip. I can hardly believe it, it is too dreadful.'* (p78)

There was no evidence of a support network. The prosthesis was mentioned once when she was discharged from hospital: *'Oh, and the prosthesis, she tells me in passing, you will only get after your radiotherapy has finished. For the time being I am supposed to stuff my bra!'* (p45)

She wrote about her exhaustion:

*'... I feel exhausted like an old woman, unable to make big decisions. ...obviously we can't expect better, but we don't want to become arrogant and remain curious about the wonderful little things, which are the really big things! The trees, which are getting green again and which grow, and the clouds and the music and our children...'* (p220)

She reflected on life and death and there were moments when fear and panic overwhelmed her thinking. She did not know where hope would come from. Often she found it in her work and amongst the things which gave her joy. Sometimes the thought of death strengthened her because it made her live more intensely, thankful

that she was aware that she might die soon. She did not take life for granted any more. (p221)

She felt that her time in the hospital was dominated by a feeling of tension. Back home, she felt more relaxed and had more time to enjoy her life again: *'I only now realise how tense I was during the hospital period and afterwards when I was always together with other people who brought so much unrest and problems! I hardly got to sleep. Now I am able to listen to music and I am happy.'* (p222)

In June 1977 the first signs of further problems appeared. She complained of stomach pain and felt psychologically worn down by it: *'And I have stomach ache, which makes me bitter and seems to take away the last bit of my sense of humour.'* (p229)

Her narrative is unclear about the treatment for these complaints. She seemed to be treated for a benign stomach complaint, but her doctors spoke of a swollen liver and queried possible liver metastases. For that she seemed to go to the clinic every ten days to be infused by something and she wrote that she felt terrible afterwards, suggesting she may have received chemotherapy treatment: *'And once every ten days I go to the clinic and let myself be put onto an IV drip, for the liver. Afterwards I feel dreadful, but that poisonous stuff does go and then I feel better.'* (p241)

She does not write directly about this as chemotherapy. It is unclear if she was ever told that she had liver metastases. The last weeks of her life were spent in the knowledge that the illness brought her closer to many people, although it adversely

affected her sex life: *'Sex is not playing a big role in my life at 44 anymore (with only one breast) one no longer thinks about lovers.'* (p269)

In one of her last letters she analysed the relationship between patient and doctor more sympathetically. She acknowledged that doctors might need a distance from their patient, as otherwise they might not be able to deal with the pressure of each day. However, she still felt that it was important to treat the whole human being: *'They cannot heal just body parts without thinking about the whole human being. That's absurd.'* (p272) She died: 1977.

Her narrative allows the reader an insight into breast cancer diagnosis and treatment. It provides snapshots showing the relationship between her and her doctors, her fellow patients and friends. At times deep emotion is put into words and at other times she holds back, especially when helplessness and fear take over.

**Maxie Wander (118)**



### 3.2.4 Barbara Rosenblum and Sandra Butler '*Cancer in two voices*'\*

Barbara Rosenblum was diagnosed with advanced breast cancer in February 1985.

She and her partner, Sandra Butler, decided to write a joint narrative in order to share their experience with others and to tell their story about life and death. This narrative sees the illness from the point of view of both the cancer victim and her closest partner.

*'It was then that we chose to write this book as a map of our experiences in the hope that it would be of use to those of you now reading it. We wanted to tell you our story. Or at least some of our story. The story about struggle and courage, even more than the part about sickness and death. A story about loss and the gifts it brings. We wanted to tell our story, finally, because this writing made us visible to ourselves as we were living it.'* (p6)

#### **Diagnosis**

At the time of diagnosis, in February 1985, Barbara expressed her feelings of shock and horror when she was told that she was suffering from advanced breast cancer. Her breast lump had been examined more than a year previously and dismissed as fibrocystic disease. It had progressed to an advanced stage and was seriously threatening her chance of survival. The misdiagnosis made her angry, jeopardising any kind of trust with the medical team. Her tumour had grown in the year since misdiagnosis from 2 cm to 6 cm, ruling out the possibility of lumpectomy and radiation therapy.

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\* all direct quotes from (119)

*'I shut my eyes and saw absolute black, no lines of red or purple, pure black. My agitation lifted me off the table and I started walking around the examining room in small steps, working off the tension. I thought I might put my fist through the wall. And then, when I opened my eyes, I couldn't see too well. Or hear too well either.'*  
(p10)

Her partner, Sandy, reacted to this terror with numbness and helplessness, feeling she faced a terrible unknown: *'I want so desperately to engage with Barbara, with this disease, in a loving and useful way. Yet in my racing to strategize and to plan - I lose all feeling. I cannot yet know what this will mean and only hear the terror in her voice.'* (p11)

### **Friends and family**

From the moment of her diagnosis Barbara decided to engage all her friends in the healing and treatment process. She invited them into her house and gave them short clinical outlines, sometimes almost hiding behind the clinical details in order not to have to address her personal fears.

She communicated with friends in letters to inform them about what was planned and how they could help. She wrote about her treatment plan, saying that she had advanced breast cancer, which required treatment for about 18 months. She explained that advanced breast cancer meant that her lymphatic system was involved. She would be having chemotherapy for three months before a mastectomy of her right breast. This would be followed by three additional months of chemotherapy. Afterwards, radiation of the breast area was needed to make sure it was free of any

cancer cells. After that she would be on a different kind of chemotherapy, which would be less aggressive than the one used in the first six months, for a further year.

*'I have finally chosen an oncologist, a tough-minded woman, and developed a treatment plan... Chemotherapy first. Then surgery. Then more chemotherapy. Then radiation. Then more chemotherapy. It is a very aggressive treatment with devastating side effects: loss of hair, vomiting, prematurely induced menopause, fatigue; but it seems the only chance of controlling this virulent force that has invaded my body.'* (p23)

Sandy and Barbara agreed with their friends to use visualisation exercises to support Barbara during her treatment. Friends came and stayed during the time of chemotherapy and were able to offer constructive support according to instructions from Barbara on how to help her through this time.

Barbara's side effects were extreme, with non-stop vomiting for two days and the loss of seven pounds in weight, leaving her, and Sandra, exhausted.

*'Whew! The worst of the chemo reaction is over. Non stop vomiting for two days. I've lost seven pounds. It was intense and in moments grim. My throat went into spasm from all that vomiting. Just swallowing hurt. And now I have mouth sores and feel scared about radiation. How much of a decrease in energy will there be? How much pain?'* (p14)

Barbara became aware that her life expectancy was shortened to possibly five to eight years as the cancer had invaded her lymphatic system. She experienced an

intense search for meaning in her life. Many of the things that had been important to her over the years in her previous work as a sociologist were suddenly perceived as 'bullshit'. She wanted to enrich her life with the things she had always wanted to do.

*'Time is incredibly important, and, every month, I do something I always wanted to do but, somehow, never found the time... Because I am so aware of time, I want to live richly and fully, and do a great many things during the next years of my life. People, closeness, laughter, good times, trips, connectedness with friends and nature, music and poetry. Right now, these are important.'* (p18)

Sandy found this difficult to comprehend. *'She will never get well. Barbara is going to die. It is now only a matter of years. I repeat this new reality over and over, much as I did the original diagnosis. Barbara has cancer. She has had cancer. Her cancer is advanced and will be terminal.'* (p26)

### **Complementary/alternative medicine**

This was important. Barbara used forms of alternative medicine such as special diets for cancer, relaxation and visualisation exercises, as well as other forms of healing.

### **Doctor-patient relationship**

Barbara researched her treatment and taped consultations with doctors in case she could not remember them at a later stage. Due to her initial misdiagnosis she was extremely anxious and cautious. She was particularly troubled by the recommendations given by different specialists. She developed her treatment plan with an oncologist and finally felt that she was in good hands, regaining trust in the medical establishment.

*'tough, gentle, sensitive, coolly professional woman, a few years younger than me. She will be my lifeline. She will become the centre of my life. I will visit her for a year and a half for my treatments. I will fall in love with her, hold onto her every word, her every hope for me. I will turn to her for optimism, realism, help, understanding, drugs. She is my doctor, my hope, my survival.'* (p24)

### **Chemotherapy**

After surgery, Barbara's energy levels fell drastically, due to her post-surgical recovery as well as further chemotherapy. She felt unable to concentrate and could not remember things well. She experienced a certain distortion of time due to the different release time of the chemotherapy drugs. One drug was released on the fifth day after the infusion and the second on the fourteenth day, while the others worked in small cycles. She felt terrible during day one and two and then, during day three and four, was less fatigued. On day five other drugs kicked in and she developed mouth sores and fatigue.

*'I have to tolerate horrible side effects from the drugs, the inside of my mouth becomes inflamed and sore, and then the symptoms lift a bit. No sooner do I have a day of relief then day fourteen comes and the third drug peaks, bringing new symptoms with it. This cycle is repeated every twenty-one days, and days nineteen, twenty and twenty one are the best - after the peak affects have passed - when I'm recovered the most.'* (p27)

Although her chemotherapy made her feel awful, she kept trying to see it as something that would keep her cancer at bay: *'Two more times on chemotherapy,*

*then off. I feel protected until October.* (p76) Sandy felt that Barbara was being drained of her joy and laughter in all this discomfort and physical pain: *Barbara seems to be wearing down emotionally. She is eroding.* (p79) Unfortunately the end of chemotherapy did not bring the hoped-for relief due to anxiety attacks; she thought she was falling apart and a 'chemo junkie'.

*I'm gripped and consumed by the fear. The fear. The fear of more cancer. The fear of going off chemotherapy. The fear of recurrence. The fear of not living because I'm afraid of dying... It's fear. It's the fear of death, pure and simple. The fear of no time. Of claustrophobia. Of shrinking, shortened time.* (p80)

### **Radiotherapy**

When she started her radiotherapy Barbara described the procedure as torture; the side effects were as unpleasant as those of the chemotherapy. *The side effects of radiation are extremely unpleasant, enervating, creeping in slowly and catching me unaware. I'm exhausted, but it's different from the exhaustion of chemotherapy. A different depletion, different sense of lassitude.* (p41)

### **Body image**

Her body image before and after mastectomy changed drastically. In a questionnaire before the mastectomy she was satisfied with her body, but after the mastectomy she hated it: *...this time I hated my body: my waist, thighs, hips. I hated my hairlessness. The loss of my breast made the earlier pain, humiliation, and the embarrassment of losing my hair almost unbearable.* (p31) This negative feeling intensified when she gained weight through the treatment, her skin became flaky, her body oedematous and her sex drive non-existent.

She endured more treatment, including chemo-embolisation when liver metastases were found. Sandy found this extremely distressing. During this hospital admission she shared every minute with her suffering partner.

*'The liver infusion was a nightmare. This was the first time Barbara has been in such pain. I lay beside her at night, poised on my cot, peering through the bars of her hospital bed, watching her sleep, being sure she received her pain medication on time, holding her hand.'* (p100-101)

### **Palliative care**

Shortly after the liver embolisation, lung metastases developed. This meant more intense chemotherapy in order to stay alive longer. Sandy and Barbara were aware that Barbara had not much longer to live and proceeded to make a will. The lawsuit and the payment that was made to Barbara after her misdiagnosis complicated things. Dealing with the money was causing problems, as it was perceived as blood money, and they could not decide what to do with it. They talked about Barbara's death and prepared the will and funeral. While attending a workshop on dying, Barbara asked Sandy if she had come to terms with her death and, although startled by the question, she said that she had. Barbara then said that she had come to terms with it, too, and decided to leave there and then: *'Let's go then. We have no more work to do here... Let's live the life we have.'* (p107) They managed to create times of intense joy and relaxation away from Barbara's continuous battle against cancer, times when they travelled and were not ruled by hospital appointments. *'Life as usual...I don't want to be a cancer patient twenty-four hours a day.'* (p 125)

Towards the end of the narrative, the issue of pain control became more urgent; both Barbara and Sandy were afraid of uncontrollable pain. Finally, no further chemotherapy was possible, as it was too toxic for Barbara's body to tolerate. This was the point when Barbara decided she could not endure any further treatment and moved into the palliative care phase. She deteriorated quickly.

*' I try to imagine a series of pictures of me taken at 9 A.M. Three months ago they would have shown a bright, spunky woman walking her dog or eating a big breakfast of ham and eggs, complete with cups of steaming coffee made from first-class beans... three weeks later the 9 A.M. pictures would be different. Breakfast is a small bowl of porridge and I may be sitting at the table in my bathrobe rather than in my daily clothing. There would be no more pictures of me walking the pooch... Another three weeks pass. The 9 A.M. images are different yet again. I sit at the table in my bathrobe, staring at the glass of orange juice and the anti-nausea pill. The next image shows me struggling to get it down. By now I hardly walk around the apartment. Even that is too tiring... Three weeks later I'm sleeping at 9 A.M. If the film were colour, it would show a yellow tone to my skin and eyes. Liver malfunction manifests itself as jaundice. In one picture my left eyelid is lifted slightly, a sign that I understand that I am being photographed, but that I am too weak to speak or interact or perhaps even to care. ' (p169)*

Barbara died at home with her partner present. Sandy then published the narrative. It is the story of two women who battled to the last against breast cancer, one as a sufferer not surrendering any ounce of her love of life, and the other supporting her, even during the toughest parts of her treatment.

### 3.2.5 Angelika Mechtel *'Jeden Tag will ich leben'*\*

*'This book aims to: comfort, to encourage, to provoke the will to stand up against authority and rigid treatment of the disease.'* (Introduction)

Angelika Mechtel used this narrative as self-observation and as a psychological outlet to deal with her experience of breast cancer. It was easier for her to do this using a different name. She calls herself Margot to create a third person's distance, while using her own diary entries.

#### **Diagnosis**

She found the lump in her left breast in September 1987. Her immediate feelings were of fear and terror, as cancer was well known in the family: *'Her feelings are equal to panic.'* (p 8)

She decided to take a previously planned trip to Rio. She remembered that she always felt she would sell everything and go on a round-the-world trip should she ever be diagnosed with cancer. Now this had become reality and it was not so easy as a diagnosis had not yet been made.

Mechtler developed an intense need for information to safeguard herself. She did not want to become a victim of the disease or be patronised by doctors.

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\* all direct quotes (translated from German into English) from (120)

At every stage she delayed any action suggested by her clinician to allow herself to form her own opinion and make her own decisions: *'She asks as a child but she must ask if she doesn't want to surrender totally.'* (p11)

She did not agree to the one-stage procedure which included a sample from the tumour being analysed (frozen section) while she was still in theatre. A lumpectomy or mastectomy would be performed under the same anaesthetic should the frozen section be malignant. *'For the first time Margot comprehends that she is sitting opposite male clinicians who are hindered by all their maleness when they have to deal with the fears of the female patient.'* (p14)

She describes a lack of information. She would have appreciated information about different types of operation for breast cancer and possible complication rates for each one. No one informed her of the possible risks of lymphoedema. Adjuvant treatment with radiotherapy and chemotherapy was not discussed and she was unsure about the possible side effects. Long term she was looking for reassurance about local recurrence rates and the development of metastases. She had an urgent need to inform herself properly before making a decision about treatment and the alternatives: *'In a desperate hope she starts taking Vitamin A, Vitamin E and Vitamin C as well as stinging nettle extract, and other herbs.'* (p17)

She sought a second opinion from a doctor who was working in homoeopathic medicine. He referred her to a hospital that incorporated modern medicine and holistic treatment, where the biopsy would be taken. She identified with this way of approaching life as she had been educated at a Waldorf school, one that encouraged a more holistic way of learning. She was taken into hospital in October 1987 and her

admission was dominated by panic. She was desperate to find her own way, to make her own decisions and take control: *'I only know one thing: I want to decide for myself: I want to steer: I don't want to be at the receiving end of a decision, I don't want to be herded in any way, I don't want to become a victim longer than necessary.'* (p29)

She decided against the mastectomy and had a lumpectomy. Due to misinformation and misconceptions, she did not understand the importance of removing the axillary nodes, and refused. Her operation went well and she healed quickly.

### **Body image**

About her own body she wrote when everything was beginning to heal that she was quite pleased with the appearance: *'Both breasts don't look destroyed. The body is beautiful. My body is beautiful. I am healthy. The nastiness has been cut out.'* (p39)

Every bit of her energy was concentrated on daily life. When the operation was over she was in control of her own healing process. To help her cope, she used a previous experience as a child when she had 60% burns and only a 40% chance of living and had made herself get better by constant positive affirmations.

Angelika Mechtel then had a second operation to sample the axillary nodes.

Restlessness, fear and doubt dominated her wait for her results: *'As soon as I turn off the light: restlessness. Fear. Worries. Doubts.'* (p50) She was determined that this would not control her or eat away at her. She wanted to fight: *'I am not really afraid of dying, I am afraid of the suffering.'* (p59)

Frequent holidays maintained her quality of life.; she looked forward to them during her treatment: *'I want to live to the full.'* (p43) *'In four weeks I will be in the Caribbean.'* (p46)

### **Radiotherapy**

She then needed radiotherapy treatment and gave a detailed account of it after it started in December. She described the feeling of having arrived in some sort of underworld. The treatment area was an unattractive part of the hospital and many of the people waiting there looked tired and withdrawn, resigned to their destiny. It symbolised her fears of the demon cancer: *'...she can't get rid of the thought that she has arrived in an underworld. No Orpheus will come and save her.'* (p80)

Staff working in the department appeared to be working under extreme time pressure and everything seemed to be dominated by routine sentences that lacked any sort of real friendliness – 'work done on a conveyer belt'. She was scheduled for six weeks of treatment with weekends as rest periods. However, this phase took much longer than she expected. During the first few weeks she was well and experienced few side effects.

Once there was a technical problem with the machine, which left her feeling helpless. She felt that she was surrendering all control to modern technology. A piece of lead flew off the machine and in her isolation she was terrified: *'I was shocked. I needed time to realise what happened. I mustn't move. Helplessness. Don't move I told myself just don't move otherwise these rays will hit the wrong place.'* (p100)

## **Financial pressure**

After the operation she suffered from exhaustion and pain and was unable to write. As a freelance writer, this caused her financial problems and she had no insurance to cover the initial few weeks of her illness. She spent her savings and agreed an overdraft facility with her bank. During radiotherapy she was able to work for only a few hours between treatments and the financial pressures increased: *'If I account for the exhaustion and tiredness which I have to deal with after every treatment I am only left with a very few hours in which I can do something different than dealing with my cancer.'* (p93)

She was approached by her doctor to discuss the possibility of anti-oestrogen therapy and oophorectomy. Initially it was portrayed to her as absolutely necessary to prevent metastases, but when she refused and insisted on more information, it became clear that there was a lack of hard evidence for the surgery. She became annoyed with the way the doctor addressed her, not, she thought, as an adult but as if she was a handicapped child when he tried to explain the treatment to her: *'As if they would deal with mentally handicapped people!'* (p109)

She was angry with her doctors because they did not give proper answers to proper questions and left her alone with the responsibility of life or death decisions: *'I am furious and hurt. Hurt because when I ask a precise question I do not get a precise answer, no honest and objective information is given to me. I am furious because they treat me as if I am not all there.'* (p125)

After her six-month routine check-up she decided to close this chapter of her life, putting away everything to do with her illness. Although returning to normal life

was difficult, she slowly started to think about the future, which she had not allowed herself to do before. At the time of the publication of her book, she had been recurrence-free for four years and seven months and felt that she had learned to deal with it. The fear and the threat remained, but were less intense.

### 3.2.6 Joyce Wadler *'My Breast'* \*

In 1992 Joyce Wadler published her narrative in the New York Magazine. Because of the tremendous response of the readers, she wrote a full-length version entitled *'My Breast'*. This narrative became an instant international best seller.

#### **Diagnosis**

Joyce Wadler discovered her lump one morning while showering.

*'Then, as I'm showering, I feel it: a large, egg-shaped swelling on the upper, inner part of my left breast... this lump seems so big, and I don't remember it being there yesterday. I decide I should probably get it checked out, but I am not very concerned. What I have heard about breast cancer is that except for finding a lump, it is asymptomatic – you don't have pain.'* (p13)

Her initial reaction was to ignore the lump, but she became more concerned as the day went on. Her initial appointment was with a staff surgeon at her place of work who decided to refer her to a specialist, which concerned her. It brought back memories of her father, who had died of cancer the year before. Suddenly her life seemed threatened: *'I want to **live**. The things I haven't done flash before me...'* (p15)

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\* all direct quotes from (121)

Her appointment was with Dr Luke, whom she knew and with whom she seemed to have a good relationship. She felt relieved when he told her there was probably nothing to worry about. Her anxiety increased, however, when the doctor was unable to draw any liquid from what he thought was a cyst. The uncertainty of her diagnosis left her fearful and worried: *'I am not a hypochondriac. I lean toward the other extreme, a person who associates sickness with weakness and therefore denies being sick.'* (p18)

When she got her results a few days later, she was told that it was not typical of cancer and was prescribed antibiotics. Eleven days later the antibiotics did not seem to have worked and she was advised by Dr Luke to have a biopsy and to have the lump removed. Dr Luke performed the operation and came to tell her that it was malignant 20 minutes after the lump was removed. Joyce Wadler was shocked; the diagnosis was totally unexpected.

*'I am having trouble following. Thoughts are going through my head faster than I was aware thoughts could travel: this can't be real. Is he telling me I'm going to die? Should I ask for a rabbi? No, wait, I'm not a religious Jew, I'm more like an ethnic Jew, that would be hypocritical, but maybe rabbis in hospitals are more like therapists. Why is he telling me this stuff here, where I'm alone? Wasn't that the point of bringing Herb? I interrupt him.'* (p35)

### **Decision on treatment**

Joyce Wadler engaged in research to become better informed and realised that, regardless of varying specialist opinions, she would be the one deciding on her treatment. The choice she had to make was to have either a lumpectomy and

radiotherapy, or a mastectomy and breast reconstruction. She consulted plastic surgeons, oncologists and surgeons and decided to have a lumpectomy and radiotherapy. She sought a second opinion from the specialist cancer centre Sloane Kettering, and opted to have her lumpectomy and axillary node sampling done there.

### **Fear of anaesthesia**

Whilst her biopsy had been undertaken under local anaesthesia, the lymph node sampling and lumpectomy had to be performed under a general anaesthetic. Joyce Wadler was worried about having a general anaesthetic and needed to address these worries before her operation: *'I have another terror besides death – general anaesthesia. I am afraid that even if I survive, my brain will not.'* (p37)

### **Body image**

Before the biopsy she marked carefully where she wanted the incision.

*'Then I take off the dress and turn down the top of the bra and trace the edge with a ball point pen. As I do, I start to cry. I don't have a perfect body by model standards; my breasts are different from what they were in my twenties; I did, when I watched the plastic surgeon, have a fantasy of a lift. But they are my breasts; it is my body – I like it very much. Now I am making a mark that says, Cut me.'* (p29)

These concerns about her body image played an important role when she considered a mastectomy and reconstruction, but in the end she opted to keep her own breast while ensuring safe treatment of her breast cancer.

*'I won't have to run around nippleless or with a football on my chest. I could also end up with a very pretty pair of breasts. I do like my body, basically; there are times I look at myself naked and think I'm gorgeous, but as I've gotten older, or have seen skinny women with high little breasts at the gym, I have sometimes felt bad, looking at my sag, and wondered what it would be like to have a lift.'* (p59)

At the end of her treatment she was pleased with the scar that was left after the operation: *'As for the mark on my left breast, I am happy to have it. It is the battle scar over my heart; and if no one but my doctor and the girls at the gym have seen it lately, I am certain, believing as I do in musical comedies, that somebody will soon.'* (p166)

### **Dealing with cancer**

Joyce Wadler decided to deal with her cancer with a positive attitude. She felt as if under attack from invading missiles and worried about her own negativity, and was in need of support from friends and loved ones. She wanted to consider herself as having had cancer rather than having cancer. The cancer had been cut out:

*'Then I talk tactics with Herb. The position I am taking, I say, is not that I have cancer, but that I had a cancer and they cut it out of me.'* (p43)

### **Contact with cancer patients**

She was worried about meeting other people with cancer and found a visit from a volunteer from the charity organisation SHARE, upsetting because the woman told her own story.

*'The Volunteer, who is my age and single, talks to me as if we are friends. Lymph-node removal is serious surgery, she says, I will be able to type and use my arm, but most people don't have full range of motion for a few weeks... the more this woman talks, the more upset I become.'* (p78–80)

Another time she thought about talking to other women who had breast cancer but decided that she would feel awkward: *'I could talk to them, but I'm not sure that would make me feel better: they both had tumours the size of peas. It's scaring me to be the girl with the biggest one on the block.'* (p72)

Her partner was not helpful or supportive during her breast cancer treatment and the relationship ended. She had good support from a friend called 'Herb', who accompanied her to all the appointments.

### **Lumpectomy**

Joyce Walder's surgical treatment was undertaken in Sloane Kettering Cancer Institute. She opted for a female surgeon because this doctor was straight with her and offered the kind of surgery she wanted, lumpectomy and radiotherapy. She also felt that better back-up might be available in the specialist centre. The operation went well and she managed to deal with her anxiety about the anaesthetic. She recovered well from the operation, but there was some pain once she came round.

*'There's a slight burning, pulling pain near my left armpit when I try to move, and I feel encumbered by tubing: on my right a pouch of a dextrose-and-saline solution is hanging from a metal pole, feeding a clear solution through a needle-thin IV into a vein on the top of my right hand; coming off my left side, about four inches under my*

*armpit, there's a peculiarly long robe of plastic tubing attached to a plastic pouch. I am so woozy with morphine I cannot raise my head...'* (p119-120)

She recovered quickly and daily stretching classes ensured that her arm regained normal movement. All her lymph nodes were clear and she did not need chemotherapy.

### **Radiotherapy**

One month after surgery Joyce Wadler started radiotherapy for six weeks, five times a day. She did not have any great worries about her treatment: *'A few days later, I come back to Sloan to begin the radiation. I have no concerns about the process...'* (p140) During her first session she described her feelings as a little apprehensive, as she did not know anything about radiation. She received the treatment calmly and had few side effects.

*'I'm a little apprehensive, too. I don't know the first thing about radiation; all I know is that somebody is going to aim a beam at my chest and kill a bunch of cells – my cells. I find myself feeling bad for them... A whirring sound goes on. I concentrate, trying to feel. Giving it full attention, I can sense the smallest bit of warmth on my breast, like a ray of sunshine coming through a window. The whirring stops, the arm of the radiation machine rotates forty-five degrees, and I am nuked again. A minute later, the doors open, and Herb and the technician are back.'* (p143)

Her breast became slightly inflamed and felt heavy and swollen, similar to the way it felt before a period. The skin did not peel. On occasions she was tired and

exhausted. There was relief when the treatment was over, without any further side effects.

### **Chemotherapy**

The shock came a year later when Joyce Wadler was told that she probably should have had chemotherapy. There was a possibility that her breast cancer had been misdiagnosed. This left her angry and her life seemed threatened yet again. She was given chemotherapy with CMF. Joyce Wadler felt positive about her appointment in the chemotherapy department, which was well prepared and administered. Side effects were minimal and well controlled with drugs. She changed her antihistamine once to avoid anxiety, a side effect of the anti-sickness drug, not chemotherapy. She suffered hot flushes in the middle of the night and her periods stopped, but she was reassured that they would probably return to normal after the chemotherapy finished. Other side effects that she was warned about did not occur, including hair loss, sores and infection. She was not fatigued, apart from three days following treatment, and able to work normally.

*'I am surprised and delighted: chemotherapy is a piece of cake.'* (p161)

*'Except for three days following treatment, I am not tired. I put in a normal workday, I take dancing lessons. I go to the gym three times a week, as I always have. I get winded more easily than in the past, but my body gets stronger – probably because, in order to prove to myself I am not a sick person, I increase my weights.'* (p164)

## **Doctor–patient relationship**

Joyce Wadler's doctor–patient relationship with Dr Luke initially was one of trust and friendship, although it was revised slightly later in her treatment. *'I trust Dr. Luke and I know he's good – a journalist friend was a patient and says his reputation is excellent; he's known among doctors who treat Presidents.'* (p21) After having a second opinion at the cancer centre she felt slightly different.

*'I'm also not happy with Luke when I get a copy of the aspiration lab report. The results are a lot more ominous than Luke told me in our phone conversation... It is possible Luke's paternalism extends beyond an arm thrown warmly around one's shoulder. If so, or if he's not going to give me all the facts, he is not the doctor for me.'* (p85-86)

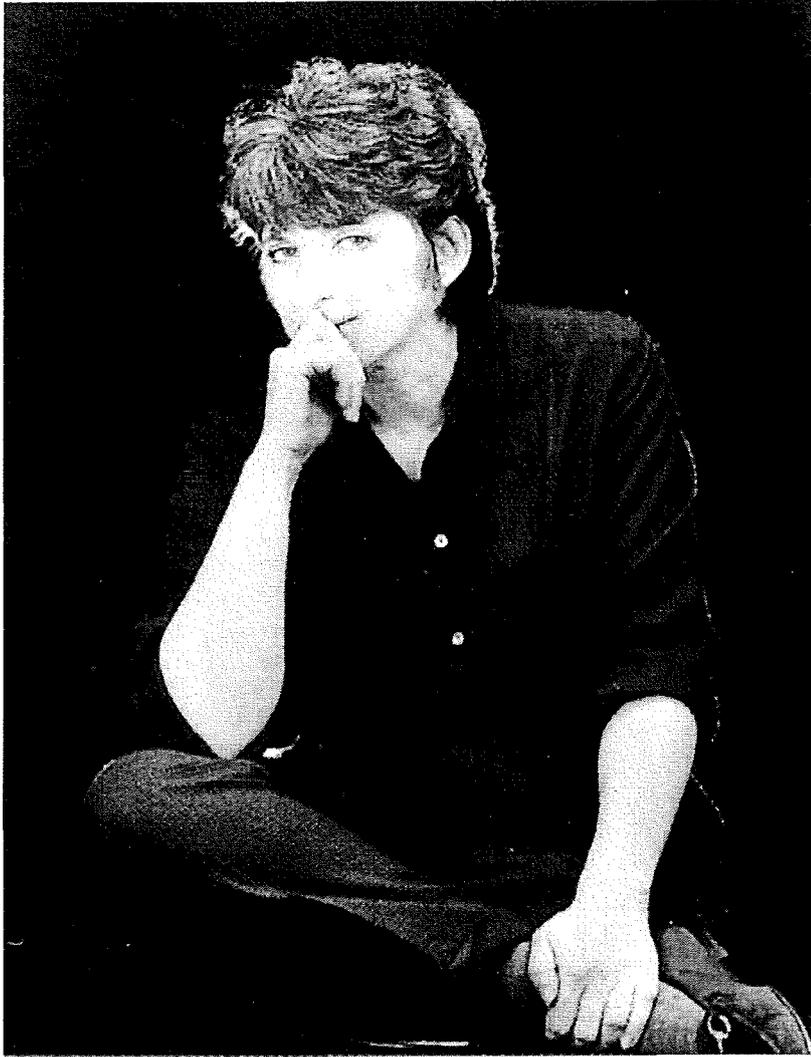
Other relationships with doctors included her plastic surgeon and the surgeon at Sloane Kettering. About the plastic surgeon she wrote, *'I like Dr. Veteran, too. He's not slick. There's an air about him that suggests he has had personal experience with serious illness.'* (p59)

Dr Jeane Petrek, the breast surgeon at Sloane Kettering, was described as a doctor after her own heart: *'I like her the minute I see her. She's a great-looking redhead who wears a Mickey Mouse watch with her white doctor's coat and has a smart, hyper, full disclosure style.'* (p102)

Joyce Wadler managed to get through her breast cancer treatment by remaining in high spirits and supported well by close friends. A review described her book as

written with unflinching honesty and humour, giving a detailed and powerful, fiercely personal, picture of the process of dealing with this terrifying disease.

Joyce Wadler (121)



### 3.2.7 Elisa Segrave *'The diary of a breast'* \*

Elisa Segrave discovered a small lump in her breast in September 1991. Her diary records her treatment for breast cancer as an NHS patient over nine months until May 1992. Her first reaction when she found the lump was to ignore it: *'My first instinct was to pretend it wasn't there. I tried to forget about it.'* (p1)

#### **Diagnosis**

At that time she was worried about her mother, who had had a fall and broken her hip. There were concerns about her mother's possible alcoholism. Her son had difficulties dealing with the divorce she was seeking from her husband and was being treated by a child psychologist. She only saw a doctor when urged to do so by a friend.

*'The fact that I might have breast cancer did not hit me at once, since I am sick with worry about my mother... Later I realized that if I do have breast cancer, I am being invaded from within as well. I still have not been to the doctor... Now my mother was dragging me back into the world of chaos I remembered from my childhood. Miranda [a friend] told me to go to see the doctor at once about the lump.'* (p2-3)

Unfortunately her usual doctor was on holiday and she saw a young locum. He thought that the lump was probably benign, but sent her for an appointment at the breast clinic of St Charles Hospital. She was told she would have to wait at least two weeks for an appointment and decided to seek a private consultation.

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\* all direct quotes from (122)

Elisa Segrave had a private mammogram and ultrasound immediately. The mammogram showed a suspicious area and she was referred to Charing Cross Hospital, London for a surgical appointment, where she was given another appointment for the lump to be taken out. Biopsy confirmed that the lump was malignant, and she underwent axillary node clearance, which determined the need for chemotherapy and radiotherapy treatment as some of her lymph nodes were involved.

### **Doctor–patient relationship**

The first doctor–patient relationship for Elisa Segrave was that with the locum GP. It was a brief encounter and no indication was given by the GP that the lump might be sinister. During her visit to the private hospital she described a distinct difference of the locality, but not the doctor.

*'Rather than a frightening receptionist like Mrs H there was a polite New Zealand girl behind a computer...The hushed atmosphere in the exclusive waiting-room of the X-ray department was also unlike the local surgery. Instead of making me feel more secure, this made me feel isolated.'* (p5)

Her next encounter was at Charing Cross Hospital; when she realised that her appointment was actually in the cancer clinic, she was shocked.

*'Gradually I became aware that I was in a cancer clinic... Most of the people waiting didn't look particularly ill, until a very young woman arrived with a young man. This woman looked as if she was going to die in the next few weeks, if not days.'*

*Her face was very pinched and so sallow it was almost green. I hoped the man was her boyfriend, sticking by her til the last. ' (p7)*

She thought this consultation was efficient, but not personal. An appointment was made for the biopsy, which unfortunately, coincided with her son's birthday: *'The off-putting thing was that there was no attempt to make any of us feel that we were anything other than cattle. ' (p7-8)*

Next time she met the surgeon she was given the result of the biopsy and was in a state of shock about the malignant diagnosis. She appreciated the surgeon's direct way of telling her that she had cancer, but found it difficult to concentrate on the explanation.

*' He looks at me directly and tells me that the lump was cancerous. He draws a diagram and tries to explain what it means, what kind of lump it is and what the next stage will be. I pretend to concentrate, but I don't. I am shocked. I'm grateful, however, for the straight forward way he has broken the news to me.' (p20)*

Her next encounter with the medical profession was when she had her axillary nodes cleared. She wanted to talk in private to one of the doctors she could relate to well, Dr Isaacs, but found it was difficult to do so. She specifically disliked a 'red-faced Scotsman': *'Dr Isaacs seemed to find me amusing. There were several other doctors with him. One, an uncouth and red-faced Scotsman built like a rigger-player, I did not like. I thought he was uncomfortable with women. Will I ever be able to talk to Dr Isaacs on my own?' (p31)*

## **Operation**

Both operations, the lumpectomy and the axillary node clearance, went well, but left her feeling helpless and abandoned: *'Later I slept a great deal. I woke up in the ward to find there was a drip in my arm. I was attached to a large stand. I felt completely helpless ...for the first time in my life I was admitting that I felt completely abandoned.'* (p26)

## **Friends and family**

Friends supported her during the treatment, especially one called Nick, whom she admired for his coping mechanisms after being diagnosed with Hodgkin's disease, who worked as a solicitor during most of his illness, except when he was an in-patient.

*'I admire this. He says the great thing about continuing to work was that it meant he had other things to think about, rather than just the disease. He did not become "solely a patient, someone who is operated on and does nothing." The worst part of being a patient - worse even than the pain and tiredness - is the "sense of the loss of power".'* (p13)

## **Contact with cancer patients**

Elisa struggled to keep her power as a patient but kept on working and living a sort of normal life during her treatment. She found her times in hospital particularly difficult because she did not like the contact with ill people, which she stressed repeatedly.

*'Again I cannot ignore the fact that I am in a room with people with cancer, and that I may have cancer myself. This is very frightening.... I remember that the word "cancer" was always spoken in a low voice by the adults. ' (p19) 'I'm afraid of meeting terminally ill people. I don't want to see what might happen to me in the end. '(p51)*

*'The most off-putting thing of all is seeing the other patients on drips; it makes me want to vomit. At least I don't have to be on a drip; my chemotherapy drugs are administered by injection. It isn't the idea of the needle that revolts me, but the idea of poison going into my body, and the association of this with cancer. When I see the other patients lying there, I don't want to talk to them. Like an animal with another animal who's sick, I shy away. I hate looking at their bald heads, will I also go bald? '*

*(p67)*

*'But when I see this very young bald woman with her baby I feel sicker than ever. I don't want to talk to these other people having chemotherapy...I don't want to be associated with very ill people. He looks doomed. I want to survive. ' (p155)*

### **Struggling with responsibilities**

Elisa Segrave struggled to fit her treatment around her commitments as a mother and felt guilty for not being able to be the perfect mum, as she missed crucial moments in her children's lives. She had hoped to be out of hospital after her axillary node clearance in time to spend half-term with her children but due to excessive lymph drainage she had to stay in hospital. Her ex-husband looked after the children. It

was not easy to come to terms with this: *'In the afternoon my ex-husband brings the children in to see me. My daughter's very excited about half-term, which starts today. It looks as though I won't be out of hospital in time as the lymphatic area under my arm has still not drained enough.'* (p37)

During this time when her ex-husband was looking after her children, she had a phone call from her son: *'I rang the house in Sussex with my phonecard and my son told me he had been locked in a shed in the garden for two hours. No one came to find him. Although he often exaggerates, I am now consumed with anxiety.'* (p39)

### **Dealing with cancer**

The wait before getting the results of her axillary node involvement was difficult. She had thought that she would stay in hospital until she was given the results but was told that she should go home and come back for them, which meant leaving the safety zone and confronting the fact that she had cancer. Every now and again panic set in about her situation and she worried about her diagnosis, the treatment and possible death.

*'A few days ago I wanted to leave the hospital, but now I'm being told I can I don't want to. I've quickly become used to being treated like a child and having everything done for me, to the regular meals, the safe atmosphere of the ward, the friendliness of the other women, my friends coming to see me. I suddenly don't want to go.'* (p41)

*'Tomorrow I'll know the results of my operation, whether or not my lymph glands are infected and whether or not I'll have to have chemotherapy. I can't concentrate*

*on my writing, except my diary, which I write every few days, sometimes every day now, since I've been ill, in longhand. I've been doing this since I was eighteen.* ' (p54)

### **Complementary/alternative medicine**

Elisa Segrave did not find alternative therapies helpful. She was given the address of the Bristol Cancer Health Centre several times by different people, but did not visit. A cook who tried to prepare healthy food for her was not able to encourage her to eat more healthily. Often she felt almost bombarded with advice to relax, but found that difficult, too. She addressed her religion again in the face of possible death and went to church.

*'Emily brings a book on the Bristol Programme. This is a holistic centre in Bristol for people with cancer, which encourages them to eat more healthy food and do meditation and relaxation techniques. It stresses the relationship between the mind and the body... I flip through the book on the Bristol Programme. Is my only hope of survival to live on pulses and bean sprouts for the rest of my short life?'* (p29)

*'I said I'd never wanted to go to the Centre as I hadn't wanted to be among terminally ill people. I found the idea of this frightening and I didn't want to realize how I might end up.'* (p204)

*'I have decided to do without coffee for the next few months because I have cancer. This is very depressing. There is something ghastly and dead-end about a determinedly healthy diet, particularly when one's ill.'* (p32)

*'I hate Yoga. The only time I did it everyone else seemed to be able to bend their bodies into contortions that I couldn't possibly do.'* (p50)

*'Teatime. I now find the smell of Paquita's [her Shiatsu teacher who offered to cook healthy for Elisa] cooking absolutely nauseating, as I associate it with chemotherapy and being ill. I can't eat the bean-curd stew. She has brought me some fresh ginger root from the health-food shop and advised me to make ginger tea. The idea of this revolts me. Also I hate the puritanical overtones of health food.'* (p223)

### **Adjuvant treatment**

After the axillary node sampling, Elisa was told that she needed chemotherapy and radiotherapy. She had two doses of chemotherapy, then six weeks of radiotherapy followed by another five more months of chemotherapy twice a month. She was treated with CMF. Radiotherapy was administered according to a time-table. She found it reassuring to have a plan to deal with her breast cancer.

### **Chemotherapy**

The most difficult aspect of the oncology department for Elisa was the contact with other patients: *'Normally I'm very friendly. But now it's as though by not talking to these other cancer patients I am telling myself I am not as ill as they are.'* (p67)

She waited a long time for her chemotherapy injection and stayed overnight for observation. Her side effects set in on the second day, with hot flushes and an allergic reaction.

*'I have been having outbreaks of sweat since I came home yesterday. I have been told to drink as much water as possible.'* (p77-78)

*'I woke up a few times in the night. Each time my sheets were soaked and I had to change them. I rang up Liz Whipp, my doctor friend, and she said to experience these hot flushes after chemotherapy was normal.'* (p80)

Exhaustion caused her distress as she felt she was losing control over her life.

*'I felt weak and unreal after the drugs I had had two days before.'* (p89-90)

*'I am not in control in my own house. Also, I feel extremely ill. I am in a panicky state and I keep feeling hot and cold.'* (p91)

*'I realize that I am overcome with exhaustion. I am so tired I nearly start to cry.'*  
(p92)

Her nausea was treated with drugs and she did not lose her hair. When she was told to think of chemotherapy as an ally, she was not able to. *'I can't think of it as other than traumatic and frightening.'* (p179)

### **Radiotherapy**

Her experience in the radiotherapy department was different: *'I feel none of the apprehension I had in the chemotherapy ward...because of the absence of pain and the fact that there are no obvious after-effects, the dangers involved in the high doses of radiation are not quiet real.'* (p93-94)

She developed a sore throat but was told that this was not a side effect but flu. She minded not being able to wash the area and developed a sore nipple; itching and exhaustion were her main problems.

*'I am in a very weak state today and sometimes can hardly stand up. ' (p97)*

*'I am more tired than I have ever been in my life. Even now I am still not allowed to wash my right breast or under my right arm...My nipple is still raw ... Also I itch all the time.'* (p131)

During her treatment Elisa Segrave was looking after her children with the help of a nanny. Friends helped her to deal with her daily responsibilities. After her treatment she was apprehensive about check-ups and shocked by a fellow patient who developed a metastases.

Her story was critiqued as containing a mixture of truth and hilarity, privilege and deprivation, pleasure and pain, therefore reflecting real life – and her experience as an NHS patient in the 1990s.

Elisa Segrave (122)



## DISCUSSION

This thesis describes the development of breast cancer treatment during the 19<sup>th</sup> and 20<sup>th</sup> centuries. It highlights major developments in surgery and links these with the narratives of patients or their carers to give their views of the history of breast cancer treatment.

Lorenz Heister initiated an easy to follow surgical technique for the amputation of a breast. Surgeons in Europe and the United States used his technique, with minor alterations, until the end of the 19<sup>th</sup> century. Heister included information from a patient in his case report. The communication between patient and surgeon provided a useful history of the development of the breast lump and added information on home remedies and treatments experienced while consulting empirics. The decision to operate was a joint one between patient and surgeon, and Heister made sure that surgery was really necessary, because of all the risks it carried. In modern terms, one could argue that he sought informed consent.

Heister wrote instructively about the operation itself, but did not include any comments about his patient. His report provided a detailed technical description, which was easy to follow by other surgeons attempting mastectomy. The amputation of a breast, or indeed any organ, was certainly not commonplace at the time. It was undertaken only as a last resort when the life of a patient was threatened. These operations were associated with high mortality and morbidity rates due to a lack of bleeding control and sepsis, as well as the horrors of extreme pain for the patient. Surgeons operated under tight time constraints. Heister stated that the amputation of

the breast should only take one minute. This meant, of course, that there was no attention to detail when removing a tumour.

The view of the patient was given in three selected narratives. For this study they provided the essential link between the scientific and clinical developments and the patients' perception of their treatment. The views of patients recorded in journals, diaries, letters and other narratives form an essential source of information for the analysis and assessment of breast cancer treatment. This study aimed to fill a gap in the historical analysis of breast cancer treatment through the identification and analysis of narratives written by women with breast cancer or their relatives. These narratives are set into the context of the science of their day.

The 19<sup>th</sup> century was represented by the narrative of Fanny Burney, an English novelist who wrote about her mastectomy in 1811. Fanny Burney survived her ordeal and her narrative provided a rich source of information about the treatment of patients before the introduction of anaesthesia and infection control. The narrative of P H Gosse allowed an insight into the feelings of the patient, his wife Emily Gosse. Emily was desperate to find an alternative to the cruel option of mastectomy after she was told that she was suffering from breast cancer in 1856. She opted for treatment with caustic paste, a supposedly new and effective treatment provided by an American surgeon. Unfortunately, this treatment was much more painful than she had understood and she suffered months of excruciating pain before she died.

The third narrative is that of Zélie Martin, who died from breast cancer in 1877. She lived in France and the narrative was found in her regular letters to a distant relative. Zélie discovered a lump in her breast and accepted advice given by her brother to use

home remedies, rather than seeking a surgical opinion. When the disease progressed she accepted the decision by her doctor that there was nothing to be done and died of advanced breast cancer a short while later.

Roy Porter suggested that each patient's experience should be explored in the context of their standard of living and their belief systems. This thesis explores experiences of living and dying and offers patients' views on the remedies offered. Special care has been taken to accept the individuality of each woman's suffering. Certain aspects, such as their social and financial standing, the importance of family and friends and their religious beliefs, Protestant, Brethren or Catholic, influenced the individual perception of their illness and treatment. They had an impact on their coping mechanisms, how they dealt with the diagnosis and treatment of breast cancer, and influenced the decisions each woman made with regard to her treatment.

Fanny Burney did not draw strength from her religious belief, but it played an important role in the shaping of Emily Gosse's response to her breast cancer. The Gosses felt that they had found a treatment in line with their beliefs and were able to fully support it, whereas mastectomy would have violated every aspect of their lives.

The Catholic faith of Zelig Martin influenced her life and death from breast cancer. She believed that her suffering would be rewarded by God after her death. Her narrative allows an insight into the views of a patient who did not receive any treatment for breast cancer.

## **Diagnosis**

All three women initially believed their breast problems were benign and attempted to treat them with home remedies. They did not seek medical attention immediately. It was only when the breast became increasingly painful that they discussed this with their partners and friends and were urged – in two cases - to seek medical advice. Fanny Burney was not given her diagnosis during the consultation, but the physician talked to her husband about the seriousness of her condition. Emily Gosse was told very bluntly that she was suffering from breast cancer. Zelig Martin was told by her pharmacist brother not to seek medical advice and he attempted to treat her with scented oils. Fanny Burney and Emily Gosse sought a second opinion, which was customary at that time. In both cases the diagnosis was confirmed.

Once it became apparent that surgery or aggressive treatment was necessary, the two women were horrified. Fanny Burney realised that the mastectomy was a last resort to save her life, but Emily Gosse was unable to accept the horrors of the surgery, even though her life was at risk. She opted for a new kind of treatment advocated by an American surgeon who treated her with caustic paste. She submitted herself to this treatment in the full belief that it would be less painful and less mutilating than a mastectomy and offered an 80% chance of dealing with the tumour successfully.

## **Treatment**

Fanny Burney opted to have the mastectomy and faced the horrendous pain with incredible courage. She was lucky to survive such a major operation and the tumour had obviously been removed completely. Her narrative provides specific details of her experiences and the pain she suffered, but she was still able to convey sympathy

for her surgeon, Larrey, who she thought suffered almost as much as she did. Emily Gosse chose to be treated alternatively and faced her ordeal with equal courage.

While Burney illustrates a combative approach to her disease and was carried through her treatment by her strong will to live, Emily Gosse was strengthened by her religious belief. She chose her treatment convinced that it was what God wanted her to have and that He would provide the necessary help and support, a belief linked to the theory of 'Natural Theology'.

Zelie Martin had no active treatment and treated herself conservatively. She suffered from her progressive breast cancer, which was ulcerating and extremely painful. She found strength in her role as a mother and wife up to the point when the disease became debilitating; she too was strengthened by her Catholic faith. Overall she had a fatalistic approach to her illness.

### **Doctor-patient relationship**

The doctor-patient relationship between Fanny Burney, Dubois and Larrey was characterised by the hesitation of her physician and surgeon to consider the mastectomy. Only as a last resort, when all conservative treatment was exhausted did they proceed to this decision, in which Fanny Burney was involved and to which she gave her consent. The consenting process did not offer her any information about the treatment and left her in the dark about any preparations necessary. In Emily Gosse's case, she was not willing to accept the opinion of James Paget, who advised her to have surgery. She chose to believe Dr Fell, who promised an 80% success rate without much pain.

Not much was said when the treatment failed, only that she went back home and was relieved to be there, and that she and her husband decided to opt for a totally different course of treatment using homoeopathic remedies.

### **Pain**

All three women suffered excruciating pain due to the treatment they chose, Burney from her mastectomy, Emily Gosse from her treatment with caustic paste, and Zelig Martin from an ulcerating breast tumour. There was no effective pain control available.

### **Family and friends**

All three women were supported during the time of their treatment by their family and friends. Fanny Burney's husband was involved at the point of diagnosis, but then she chose to exclude him from the surgery in order to save him the worry. She wanted to see this through by herself.

Emily Gosse was supported by her husband and they made joint decisions about the course of her treatment. He wrote this narrative and their experience caused him to question his whole belief system, resulting in him renouncing his Brethren belief.

Zelig Martin attempted in every way to keep her disease to herself and not to trouble her husband, family or friends. It was hard for her to accept help once she became too ill to do things for herself.

## **Improved diagnosis and treatment options**

Major scientific advances altered the treatment of breast cancer during the second half of the 19<sup>th</sup> century. These included measures to improve the survival rate after surgery, with the introduction of anaesthesia and infection control, and also the long-term survival of a woman with cellular pathology and the development of x-rays. Anaesthesia enabled surgeons to operate with more attention to detail, and infection control reduced the morbidity and mortality by more than 10%. Surgeons developed new surgical techniques for the treatment of breast cancer, introduced by William Halsted. Radical mastectomy became the standard operation for breast cancer until the second half of the 20<sup>th</sup> century. Geoffrey Keynes was one of the first to speak out for less radical surgery after his initial trials with radiotherapy at St Bartholomew's Hospital. This opened a debate amongst surgeons as to the best treatment that was only answered by randomised controlled trials. These trials established that there was no difference in survival or recurrence rates between lumpectomy and radiotherapy or mastectomy in selected patients.

The doctor-patient relationship changed during this time. The patient became a less important source for the clinician of information about the history of their illness. Improved diagnostic and treatment methods meant that clinicians were able to treat patients, and they became less likely to engage with patients about their treatment. Historians talk about the time of 'the disappearance of the patient'. The patient became less powerful and, according to Foucault, was more passive and a fabrication of the 'medical gaze'. Ackerknecht wrote about the involvement of the patient in 1967, but argued that there was a delayed reaction, and it took ten years for this to sink in.

Patient narratives of this period were difficult to find, reflecting the increased influence of technology making it difficult for patients to be involved in their diagnosis and treatment. Patients were treated under anaesthesia and surgeons did not talk to them during treatment. The diagnostic procedures were difficult to understand for the average patient, particularly x-ray and cellular pathology. Most patients were unable to engage in conversation about these things and accepted the increased influence of their highly trained doctors. Patients did not have sufficient medical knowledge and stopped questioning their doctors, but consequently felt excluded and in need of a different kind of support.

A need was therefore created for information and support. During this time the first cancer charities, CRMF and Breast Cancer Care, were founded, addressing the needs of patients for information, financial and psychological support. These charities remain essential for the support of patients today and have increasing political influence in the shaping of cancer services.

The first half of the 20<sup>th</sup> century saw the development of adjuvant therapies for breast cancer, starting with radiotherapy, then chemotherapy and endocrine therapy, and yet patients also increasingly sought out complementary and alternative ways of treatment independently.

The 20<sup>th</sup> century narratives were chosen with the aim of covering views of patients in the United States and Europe. They included women who survived their breast cancer treatment, and those who needed palliative care and died. Seven narratives were chosen, three from the 1970s, two from the 1980s and two from the 1990s.

Audre Lorde had a radical mastectomy for breast cancer and later died of metastases. Rose Kushner had a biopsy and modified radical mastectomy but no further treatment as there was no lymph node involvement. Maxie Wander had a biopsy and frozen section and then a mastectomy with subsequent radiotherapy, and probably chemotherapy for metastases. Barbara Rosenblum suffered from advanced breast cancer and underwent chemotherapy before a mastectomy, followed by further chemotherapy, radiotherapy and another year of chemotherapy. She also developed metastases and died. Angelika Mechtel opted for a two-stage procedure: a lumpectomy and a second operation for axillary node clearance and radiotherapy. Joyce Wadler had a lumpectomy and radiotherapy, with delayed chemotherapy for a possible missed diagnosis. Elisa Segrave had a biopsy and lumpectomy with axillary node clearance, chemotherapy and radiotherapy.

Narratives from the 20<sup>th</sup> century demonstrate the complexity of modern breast cancer treatment but also that there was a choice of surgical treatment and different combinations of adjuvant therapy. Once it had been established that lumpectomy and radiotherapy was as safe as a mastectomy, there was a theoretical choice for some women. The choice of treatment remained heavily influenced by the individual surgeon's preference, and women were not always given an option. It was only when women increased their power as patients during the feminist revolution of 1970 that their voices began to be heard and surgeons began to adapt their practice.

Since the 1970s there has been an emphasis on campaigns to increase women's awareness about breast lumps and the necessity of seeking urgent medical advice.

## **Radiotherapy**

It was a new concept that the decision between mastectomy and conservative surgery with radiotherapy should be made by the treating clinician and the patient together. Whilst the clinician focused on the clinical aspects of making such a decision with regard to the grading of the tumour and the involvement of axillary nodes, the patient focused on practical and emotional issues. Was she able to undergo radiotherapy for six weeks, attending the radiotherapy department five days a week? Cosmetic and body image implications of radical surgery versus lumpectomy and radiotherapy were considered.

Patients' reactions to radiotherapy varied widely and depended upon their thoughts about radioactive material, their ability to confront a life-threatening diagnosis and the possibility of losing a breast. They were also influenced by the support network women could establish, and the availability of close relatives and friends. Negative experiences often resulted from the apparent impersonality and arbitrariness of the treatment, the potential dangers of radiation, the appearance of the equipment, and the novelty of the experience. Positive remarks suggested that radiotherapy was fairly straightforward and that the patient felt well and had few distressing side effects. Radiotherapy offered patients the possibility of preserving part of the breast.

In their narratives, women often describe the practical problems of attending the radiotherapy department every day. Elisa Segrave describes her experience with radiotherapy in detail and the reader is offered an insight into her feelings and perceptions. On her first appointment for radiotherapy she writes about her first impressions of the department, the decor and the way the waiting area was designed. She had been given a leaflet entitled 'Radiotherapy, your questions answered'. This included advice on washing the treated area, what might happen to the area with regards to colour, texture change and perspiration. On her second appointment it became clear that she had made her arrangements well. She took a taxi to the hospital and had arranged for friends to help with her domestic duties. The main side

effect of her treatment was extreme fatigue. Barbara Rosenblum had more severe side effects, while Joyce Wadler did not have too many worries about the treatment and experienced few side effects.

Similar side effects and feelings were described in a paper published in *'Patient Care'* in 1982, which examined patients' views on breast cancer treatment.(123) The most common difficulty women experienced during radiotherapy was travelling to the radiotherapy department. One woman said that she was fortunate to have a supportive family who came to stay with her. She was driven to the radiotherapy centre every day while her mother stayed at home and looked after the children. She believed she would have needed a mastectomy if her parents had not been able to support her, as she could not have coped with the logistics of travelling for her radiation treatment.

The body marking before radiotherapy was often perceived as impersonal. Elisa Segrave did not find the radiotherapy department or machinery threatening and, in the absence of pain, she did not understand the dangers of high doses of radiation. Another patient described the marking procedure as a very strange experience. She wrote: *'they draw on you with a magic marker and then they put this machine on you, that has millions of volts. Up to that time I wouldn't even allow X-rays of my teeth because I didn't want to have the extra radiation. I'm that kind of person'* (123, p122)

Another patient wanted to be sure that the clinicians and radiographers knew exactly what they were doing and she didn't feel encouraged by the fact that she had a different therapist each time. She did later say that this was her first emotion, but that she then found the therapists to be well trained and to know what they were doing.

During radiotherapy, patients' opinions varied. Some felt that they needed more preparation and that explanation should accompany the treatment. Most patients were told initially what to expect, but felt that they would have benefited from somebody talking to them during the treatment itself. Other women described feelings of isolation while lying in the radiotherapy room.

Extensive research has established that conservative surgery and radiotherapy is a safe treatment for breast cancer, offering the same control over local recurrence as a mastectomy in selected women. Research today focuses on improving/maintaining quality of life for patients undergoing radiation therapy, and three main tools have been used to investigate this. These assess how a woman functions in normal everyday activities. One method of assessment is the Sickness Impact Profile (SIP). Emotional stress can be measured by the Profile of Mood States (POMS), measuring the moods of tension-anxiety, anger-hostility, vigour-activity, fatigue-inertia, depression-dejection and confusion-bewilderment. The last assessment of symptoms, using the Symptom Distress Scale, specifically examines symptoms related to breast cancer treatment on a five-point scale. A study by J E Graydon reported that following 4 -12 weeks of radiation therapy, women who had breast-conserving surgery for breast cancer were not adversely affected by their treatment.(124) They did not experience many changes in their usual activities, were not distressed emotionally and suffered very few symptoms. Most experienced fatigue and those who had most fatigue had the most symptoms and the poorest level of function. Sleep and rest were most affected by the radiation therapy. Insomnia had the highest score on the Symptom Distress Scale.

Breast-conserving surgery and adjuvant radiotherapy is today the treatment of choice, with similar success in the local control of breast cancer. Patients' narratives indicated that the perception of radiotherapy treatment was individual. A woman and the treating clinician have to decide together what is best: from the clinical point of view whether surgery is possible and safe, and from the patient's point of view

whether radiotherapy is an option. Some women might feel that they would prefer a mastectomy offering the same local control over the breast cancer as lumpectomy and radiotherapy. Women might find it difficult to travel every day for six weeks to the radiotherapy department, and to cope with the additional fatigue. Breast-conserving surgery might not be an important issue for them personally. If a woman decides to opt for breast-conserving surgery with radiotherapy, all practical aspects and side effects should be discussed and support during treatment must be secured.

### **Chemotherapy**

Chemotherapy treatment was also perceived in different ways. Some women felt that it was 'a piece of cake' and others suffered severely from side effects. Side effects were usually less severe with endocrine therapy.

Three narratives provided details about chemotherapy. Barbara Rosenblum received aggressive chemotherapy treatment and suffered severe side effects. Despite this, she saw chemotherapy as a lifeline as it kept her tumour at bay. At one point when chemotherapy finished she described herself as a chemotherapy junkie. Elisa Segrave felt that the most difficult issue during chemotherapy was the contact and confrontation with other people at various stages of their cancer treatment which she found extremely upsetting. Joyce Wadler had a positive approach to chemotherapy, despite her shock at having to have delayed chemotherapy due to a possible misdiagnosis.

### **Comparing narratives from the 19<sup>th</sup> and 20<sup>th</sup> centuries**

Narratives from the 19<sup>th</sup> and 20<sup>th</sup> centuries narratives were used to analyse changes in the women's perception of treatment linked with clinical progress spanning 150 years of clinical development. Joyce Wadler provided a representative sample, offering an insight into her treatment in the late 20<sup>th</sup> century. Her narrative incorporated the major developments which represented the progress in breast cancer treatment. It was compared to the 19<sup>th</sup> century narratives from Fanny Burney.

The narratives of women writing in the 20<sup>th</sup> century about their experience of breast cancer identified two major areas which were essential to the way they bore their treatment. First, they felt that they had to deal with the fact that they had been given a malignant diagnosis, which threatened their life. Second, they were faced with treatment options threatening the integrity of their body image and identity as a woman.(125) Narratives in the 19<sup>th</sup> century were concerned mainly with survival and pain in the face of high mortality/morbidity and no pain control.

### **Doctor-patient relationship**

The analysis of the narratives identified common themes written about by women a century apart. One of the most important themes was that of the doctor-patient relationship. In the 19<sup>th</sup> century, women delayed and avoided seeking medical advice. Only when extreme discomfort made a consultation unavoidable, and encouraged by family and friends, did they seek medical help.

During their first appointment the clinician took a detailed medical history. Fanny Burney was not told about her diagnosis, and the relevant information was given to her husband. Emily Gosse was told in a cold matter-of-fact tone about her cancer.

During the time of traditional surgery, women described their treatment as involving horrendous suffering. A mastectomy was performed without anaesthesia, a prospect many women were not able to face. In the search for alternative treatment, they suffered from attempts to treat the tumour with caustic ointments. Doctors were not able to offer much reassurance with regard to the treatment of breast cancer. The only accepted treatment was mastectomy, which was associated with high mortality and morbidity rates.

Women's prospects during the later period changed with better diagnostic and treatment facilities. The surgeon was now regarded as a professional of high social ranking. Diagnosis and treatment were more accurate. With the introduction of anaesthesia, operations were performed with more attention to detail and speed was less important. Surgeons were able to offer their patients a higher success rate and to consider the consequences of their treatment. For the first time, surgeons acknowledged the disfiguration of a woman's body after a radical mastectomy. It was still of importance to the surgeon and patient alike that the treatment resulted in long-term recurrence-free survival. Women's main fear concerned survival after they were diagnosed with cancer. However, for the first time some women were able to choose between two treatments, which had been assessed in trials and found to be equally successful: a mastectomy or a lumpectomy accompanied by radiation therapy.

The doctor-patient relationship deteriorated from the first half of the 20<sup>th</sup> century, but by the 1990s became patient-orientated once more. Since 1970 patient narratives have reflected the fact that women became involved in the selection of their treatment. Modern narratives identify the choice of treatment as essential to a

successful outcome. This has been supported by studies assessing the psychological implications of breast cancer. As the treatment for breast cancer became more successful, the focus of the doctor- patient relationship was directed towards achieving good results. Treatment became the most important issue, and the doctor ceased to attend to the whole patient. Whenever treatment was impersonal and only concerned with scientific detail, women criticised this in their narratives. If, however, it was delivered in a supportive and individual way, women felt well treated and cared for. This was achieved by a holistic team approach, usually including oncologist, the surgical team and a pathologist.

From a woman's perspective, the doctor-patient relationship was centred on three commonly identified themes: the fear and anxiety on discovering a lump in her breast and being given the diagnosis of cancer, her perception of the treatment for breast cancer, and worries about body image.

### **Fear and anxiety on discovering a lump**

Fanny Burney discovered her breast lump in 1810. She did not, however, seek a consultation with a clinician until the spring of 1811, when her breast had become increasingly painful and the movement in her right arm restricted. The decision to amputate the breast was not taken lightly and she was frightened. Her fear and anxiety increased with the intrusion of the whole entourage of doctors.

A century and a half later, Joyce Wadler discovered a painful lump in her breast while showering one morning. She decided to get it checked without delay but was not really concerned about it being breast cancer as she was under the impression that a cancerous lump in the breast was not painful. Wadler had a first consultation

with a staff doctor at her place of work. He arranged for her to be seen at the Guttman Breast Diagnosis Institute in Manhattan where Wadler was known as a patient and had regular mammograms. With this referral, fear set in. During her wait in the doctor's office she realised that fear was present in the faces of the other women waiting for their consultations. Wadler decided to undertake her own research and this increased her anxiety. Her medical reference books undermined her belief that a cancerous lump was not painful. At her next appointment it was decided that the lump must be removed under local anaesthetic. Wadler experienced great relief at that moment. Her next worry was about her body image. She was concerned about the scar on her breast, until her surgeon reassured her that he would discuss the site of the incision with her.

As surgery was performed under local anaesthetic, Wadler saw her tumour before it was sent to the laboratory for analysis. Twenty minutes later, she was told by her surgeon that the tumour was malignant, a medullary carcinoma.

Wadler was confronted with the fact that she had to make a decision with regard to her treatment. The choice was between lumpectomy and radiation, or mastectomy and reconstruction. Some lymph nodes were removed before a final staging of her tumour was possible. At this time the real terror of the diagnosis dawned on her. She had seen her father die of cancer and was frightened that the same might happen to her. In addition, she was petrified of general anaesthesia.

## **Perception of the treatment**

Fanny Burney consulted the physician Monsieur Dubois and had a second opinion from Larrey. She was aware of her life-threatening diagnosis but there was no pathological confirmation. She gave formal signed permission for a mastectomy but no further information was offered to her. She was given a vague idea from a friend as to what preparation she should make.

During her surgery, Burney thought her clinicians were threatening and intrusive. They did not offer her any reassurance and she had to comply with the physician's orders. She was asked to lie on the bed in the middle of the room and her face was covered without any explanation. Through the transparent cloth she saw her surgeon draw a line with his finger from the top to the bottom of her breast, then make a cross, and then a circle. Only at that moment did it become clear to her that her whole breast was to be taken off. This was not what she had expected and she was horrified. The pain during the operation was excruciating. After the operation, which took place in her own house, she was put to bed. It was an ordeal she would never forget.

One hundred and fifty years later, Joyce Wadler was faced with deciding between a lumpectomy and radiation therapy and a mastectomy and reconstruction. It was possible for her to have a general anaesthetic in order to avoid the horrifying prospect of surgery while conscious. However, in her case, this was the root of her problem. She was horrified by the thought of something going wrong during the anaesthetic and this fear added to her anxiety.

The decision about lumpectomy and radiotherapy or mastectomy and reconstruction was difficult for her to make. Dr Luke gave her information about both treatment options. Statistically there was no difference in the cure rate, but he advised her to have a mastectomy. More information about the reconstruction was given to her by a plastic surgeon. She had a second opinion from a breast surgeon at another institute, where she was given exactly the opposite advice: she was apparently the perfect candidate for a lumpectomy. Eventually, three weeks after her diagnosis, she decided to have a lumpectomy and axillary clearance at the cancer institute, performed by a female surgeon.

After the operation, she was pain free, but unable to think about anything apart from her anxiety about the result of the lymph node sampling. The consultant oncologist explained her results and further treatment. Twelve nodes had been removed and all were negative, and therefore there was no need for chemotherapy.

Joyce Wadler's radiation therapy was started one month after surgery. She was not worried about this part of her treatment. During her first treatment with radiation she felt as if she was getting ready for a space launch. After six weeks, her treatment was officially completed. However, almost one year later during her check-up appointment, her initial diagnosis was questioned. Somehow, not all the slides had been sent from one centre to the other. There were some doubts as to whether her cancer was medullary rather than ductal. She was devastated by this late change in her diagnosis.

This meant that she had to have a course of chemotherapy with CMF, administered once every three weeks over six months. Wadler was able to see the necessity for

chemotherapy from a practical point of view, but the treatment itself frightened her initially as she was worried about losing control over her mind. She had few side effects from the chemotherapy, mostly night sweats. She did not lose her hair, nor did she develop sores or infections, and she was able to work normally with the exception of the three days after her treatment.

### **Information and support**

Another theme that was identified by patient narratives was that of information and support. During the 19<sup>th</sup> century there was little support available for a woman who had a mastectomy. Fanny Burney and Emily Gosse had been able to secure support from servants and paid nurses but poor women of that era would not have been able to arrange individual care and support. They would have been treated in hospital, with a decreased chance of survival due to the higher risk of infection.

Fanny Burney had to rely on information from a friend who had some experience in caring for the ill. No other support system was in place and this caused additional anxiety.

The influence of the media with regard to the availability of information was evident in patient narratives of the 20<sup>th</sup> century. The media added additional anxiety and often confusion to their decision making about different forms of treatment. Today, women often feel overwhelmed by the extensive mass media coverage. In the 19<sup>th</sup> century, surgeons presumed that their patients had no prior knowledge apart from hearsay from family and friends. Some 150 years later, it was impossible to predict the level of knowledge of a woman attending her first appointment after finding a

lump in her breast. She might come with no prior knowledge or could have informed herself in detail about breast cancer treatment.

Support for Fanny Burney came from family and friends; however, her narrative gives an insight into the loneliness of her situation. The clinicians did not inform her of the intended treatment and she had no preparation for her ordeal. She was not aware what was about to happen to her until she was already on the bed and realised to her horror that her whole breast was to be taken off rather than just the troublesome lump as she expected.

The support she had organised for herself, in the form of a maid and two nurses, was sent away and she had to plead that at least one of her nurses be allowed to stay by her bedside. She had already arranged for a nurse to look after her in her own home after the operation and for straw to be spread outside her front door to minimise the risk of infection and the pounding noise of horses out on the street.

Joyce Wadler benefited from 150 years of progress in the treatment of breast cancer. Her diagnosis was taken in stages with the involvement of clinicians of various specialties: the surgeon, plastic surgeon, oncologist and pathologist. Information was available to her from all these sources and she embarked on her own research in order to be able to make treatment decisions. Nothing happened without her consent and prior agreement. She had the support of her best friend, Herb, during the time of diagnosis, the initial biopsy and the lumpectomy. He was with her during radiotherapy and chemotherapy. In addition she had a volunteer from the cancer support group to explain things to her and to visit her. Her physical discomfort was minimised by the advancements in treatment.

Burney's fear and anxiety must be analysed in the context of her situation. She was an English woman living in France, having lived there for eight years without any of her family nearby. She was told that she had to have a mastectomy and could only go by hearsay as to what to expect. No information was given to her before the operation. The delay in the arrival of the surgeon increased her anxiety, which was compounded when a whole entourage arrived, which she had not expected. This was at a time when any visitors had to be announced and formalities and etiquette were important in social structure. It was perceived as gross misconduct if a woman received seven or more men in her house unannounced, without any male escort. Little effort was made to reassure Burney, who was about to have a mastectomy and felt herself in need to be saved from her fatal diagnosis of breast cancer and the associated risks of the operation.

Wadler's narrative incorporated the progress that had been made in the diagnosis and treatment of breast cancer. However, during the time of her diagnosis she found herself on 'a rollercoaster of emotions': fear of breast cancer and the death sentence a malignant diagnosis carried, the reassurance of the doctors around her that there was no indication of malignancy when she discovered her lump, misunderstanding led her to believe it was not malignant. Her first consultation underlined the seriousness of her condition and she started to feel worried. At the specialist institute, this anxiety increased when the needle biopsy raised concern with her surgeon. The biopsy gave a conclusive malignant diagnosis, increasing her anxiety to terror about what was going to happen to her.

She was involved in the decision-making at each step of her treatment and her narrative is characterised by the positive way she was able to cope with all that was happening to her. She felt in control of her treatment right up to the moment when her diagnosis was changed and she realised that a mistake had occurred with the analysis of some pathological slides. It was only then that she began to feel angry and out of control.

Modern surgery offered Joyce Wadler safe treatment choices and minimised the physical discomfort. Information was made freely available to her and she had a good support network.

## CONCLUSION

Twentieth-century narratives provide evidence of more accurate diagnostic procedures, and a wider choice of treatment for breast cancer. Women are aware about the importance of early diagnosis for a better survival. Treatment is available under anaesthesia and intra-operative control of pain is possible. There is a better chance of survival due to a clean hospital environment, more accurate operating techniques and adjuvant therapy. A comprehensive support network is also often available.

However, the fear experienced by women when they find a lump in their breast is still present. For the 19<sup>th</sup> century patient it was the fear of pain and postoperative death. For the 20<sup>th</sup> century patient there is less fear of pain at the time of operation, but still worry and fears about the side effects of adjuvant therapy, together with similar fears concerning survival and body image.

Patients in the 19<sup>th</sup> century were given little information, which added to their anxiety; similar anxiety today can be the result of information overload and conflicting evidence. The choice of treatment was just as difficult for patients in the 19<sup>th</sup> century as it is today. Fanny Burney chose a mastectomy, while Emily Gosse opted for alternative treatment. Both chose what they felt offered them the best chance of survival. Treatment today is more complex and there is a benefit of evidence-based medicine, which statistically evaluates the success of a treatment. The decision, however, is not always easy and causes the same worries. For about 100 years women were not given a choice, despite the different treatment options available. Treatment today offers a higher success rate, and early detection ensures

lower local recurrence rates and fewer distant metastases. Over the years various emphasis has been placed on the voice of the patient. Lorenz Heister was reliant upon information from the patient and he incorporated the words of his patient in his case report. However, the patient was not given a voice in his description of the operation, nor were the feelings of the woman who had a mastectomy described. It was almost as if he wanted to distance himself from the emotional side in order to be able to carry out the operation, a concept not so very different from today. Surgeons had different coping mechanisms when dealing with women with breast cancer. At the end of the 19<sup>th</sup> century, surgeons dealt with patients by applying newly gained knowledge to offer the best possible treatment, but either shied away from the emotional and psychological needs of patients or considered them irrelevant. Halsted concerned himself in great detail with the best and most accurate way of operating on a woman with breast cancer, ensuring good locoregional control. But he had less concern about the consequences of the operation.

Geoffrey Keynes was a pioneer in rediscovering a concern for the feelings of the patient. He thought the radical mastectomy described by Halsted was mutilating and, in the face of new x-ray technology and radium implants, unnecessary. The debate continued in medical circles but almost disappeared from the scene during World Wars I and II, when surgeons were occupied with a totally different horror.

There is still a gap in the record of patients' views during this time. Porter and Fissell offer the concept of the 'disappearing patient' because patients were excluded from science as their narrative had little to add to diagnosis and treatment. Scientific procedures were considered more accurate and 'objective' than the subjective narrative of a patient.

Support networks and cancer charities were established during the second half of the 20<sup>th</sup> century to provide information, practical and emotional support. Charities were established in Europe and the US to improve the support available to patients at a time when cancer treatment was gaining in complexity, with various operating techniques to choose from, and a variety of adjuvant therapies available.

Patient consent and choice of treatment are becoming an ever-more complex process and go far beyond the uninformed consent given by Burney and Gosse. For patients today, the complexity of information available can be helpful and threatening at the same time. On the one hand, information allows patients to make informed choices about their treatment, but on the other hand, some will feel overwhelmed by the mass of information and find it difficult to decide for themselves. Studies indicate that women deal with a treatment better if it was chosen by them with the support of their surgeon, regardless of the treatment success.

Narratives indicate that women want to identify with their treatment and must be happy with the practical arrangements. Gosse was unable to agree to a mastectomy and Angelika Mechtel needed to stay in control. Barbara Rosenblum needed to be treated with every available treatment, while others chose to accept that they were suffering from advanced breast cancer with metastases and opted for a gentler, often homoeopathic approach, as in the case of Audre Lorde.

This thesis began by explaining the need for a new NHS plan aiming for a more patient-centred way of delivering treatment. Narratives indicate that in the 19<sup>th</sup> century there was a patient-centred approach due to the necessity of gaining

information from the patient. Unfortunately, a differential diagnosis was not possible and treatment was frequently unsuccessful or suffused with great risks. Modern diagnosis and treatment have their roots in the developments of the late 19<sup>th</sup> and early 20<sup>th</sup> centuries, which unfortunately excluded the patient's view. Today we are on the road to combining both, and the newly developing discipline of 'narrative medicine' will offer the best possible analysis of a treatment as it is patient centred, using the patient's own resources of understanding, fighting and healing as well as offering the most up-to-date modern technology.

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