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BEING THERE FOR WOMEN: the work of breast care nurses

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Thesis submitted in part fulfilment of the award of Doctor of Philosophy

University of Huddersfield

April 2001

ABSTRACT

Breast cancer is a major health challenge. It is also is a high profile disease with extraordinary media attention that places an immense burden on women, families, children and health resources. Over the last two decades the way in which women experience breast cancer has undergone significant changes. The implementation of the National Health Service Breast Screening Programme, development of specialist multidisciplinary teams, and greater involvement of women in decision making surrounding treatment choice are just some of these changes. A discrete clinical nurse specialism has developed to provide support and information to women undergoing treatment and care for breast cancer.

This multi-method two staged study explored the work of breast care nurses supporting women with breast cancer. The particular focus was on the body image and sexuality dimensions of the breast cancer experience. Firstly, a postal survey using modified versions of the Sex Knowledge and Attitude Test (Lief and Reed 1972) and the Williams-Wilson Sexuality Survey instrument (Wilson and Williams 1989) was undertaken and completed by breast care nurses (n=100) across England. Secondly, adopting an interpretative perspective, breast care nurses (n=29), recruited via the earlier survey participated in focused conversational interviews. In addition a secondary analysis of two focus group interviews with women breast cancer patients (n=14), and a further two individual interviews with lesbian women were undertaken. The audio taped data was analysed using a thematic approach assisted by ATLAS.ti 4.1 qualitative software (Muhur 1996).

Three major themes: the delivery of breast cancer care, knowing women, and the territory of breast care nursing were developed. The theme of knowing women was connected with three sub themes titled: authenticity and domesticity, moral journeys, and the (in)visibility of lesbian women. The thematic analysis presents a critical account of contemporary breast care nursing in the endeavour of "being there for women".

Acknowledgements

This thesis is dedicated to my family, especially my daughters Elizabeth and Imogen who have grown up with this project, my sister Susan for her enthusiasm and my husband, Edward for always being there.

I would also like to thank my supervisors: Professor Martin Johnson, for all his hard work, pithy criticism, and encouragement; Dr Dallas Cliff for his support and Dr Vivien Burr for her assistance in the early stages of the project.

I would also like to thank colleagues at the Universities of Huddersfield and Leeds for their patience. Ruth Moore for her assistance with the focus group interviews and Dr Lesley Lockyer for listening.

Finally I would like to thank the women: those who have breast cancer, those who had breast cancer, and those that help women with breast cancer, without their stories this research would not have been undertaken.

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CHAPTER 1

INTRODUCTION

Introduction

During the period 1985 to 1988 I worked as a ward sister and subsequently as clinical nurse specialist at the Royal Marsden Hospital and developed an interest in sexuality and body image problems experienced by cancer patients undergoing treatment for pelvic tumours. Many of these patients underwent surgery and had stomas formed as part of that treatment. As a result of that interest I undertook a small qualitative study (Topping 1987) as part of an undergraduate degree course and acquired some clinical experience in counselling clients who were experiencing difficulties such as impotence, erectile difficulties, and pain on sexual intercourse along with body image concerns associated with treatment for cancer. Those experiences were made easier by the willingness of the men and women I encountered to trust me with these concerns and recognise that I was willing, albeit inexpertly, to listen to disclosures about the personal and private aspects of their lives. For the most part that work involved listening and talking and was sometimes instructional. Although I hope my work helped in some ways to ameliorate their concerns, I have no evidence that my interactions were beneficial to those patients. Nevertheless I can assume that I had some effect as patients often appeared to seek me out and, and/or presented cues in interaction which provided me with an access point to their concerns. These interactions presented challenges as they exposed my lack of expertise and forced me to seek sources of knowledge and the expertise of others. This enabled me to understand subsequent interactions better and provide information and education where appropriate. Much of that activity was 'working in the dark' (Melia 1987), nevertheless I gained a range of experiences which could then be used to question my extant knowledge and open up other aspects that required exploration if I was to understand my patients' reality better. I learnt on the job and had minimal preparation for those aspects of the work.

At that time I had the privilege to work alongside a very experienced and expert nurse, a pioneer breast care nurse specialist, who became a source of support during that period. She in conjunction with colleagues, in the then School of Nursing, were

developing what became the first English National Board A11 Advanced Course in Breast Care Nursing (ENB A11) and invited me to contribute by teaching the sexuality and body image session on that programme. That opportunity brought with it the challenge of an unknown territory of breast cancer and became the starting point for this thesis.

In 1990, the then West Yorkshire College of Health Studies approached me to participate in the development of the ENB A11 Advanced Course in Breast Care Nursing, and following validation I had the opportunity to teach on the programme. This course has since been re-validated conjointly by the English National Board (ENB) and the University of Huddersfield and forms part of the Diploma in Breast Care Nursing offered by the School of Human and Health Sciences, University of Huddersfield. Through those experiences, and particularly my exposure to breast care nurses, my interest in sexuality and body image concerns of women associated with breast cancer have been sustained. They have become more focused upon the complexity of practitioner-patient interaction and the construction of meanings engendered by and within interaction for both the client and practitioner. My personal interest ultimately resulted in the research proposal that is laid out for account in this thesis.

That background does impute a very personal justification based on a particular some might say somewhat peculiar, interest. Whereas the ‘core business’ for all involved in cancer care is rightly cure and/or effective palliation not what could be perceived as a ‘minor’ consequence of that endeavour. I would however counter that argument whilst in no way attempting to minimise the importance of research and development or clinical practice to bring to fruition to the larger project.

My position is as follows: there is considerable evidence to indicate that breast cancer brings with it a burden that is largely hidden from the gaze of health care professionals as it is experienced and lived in women’s real world lives. An aspect of that burden is the impact and meaning of cancer and/or disfigurement resulting

from treatment upon sexuality, self concept and body image which affects some women to the extent that they can no longer enjoy their lives as previously. Breast care nurses have been employed, and breast care nursing has developed in part, as a response to the recognition that some of the impact of breast cancer and its treatment can be helped by intervention. I argue, and have presented in later sections of this thesis, some of the weaknesses in the evidence used to justify the breast care nurse specialist role. Nevertheless a weak evidential base is not a sound premise for suggesting the work of breast care nurses is not effective. The basis for this work is therefore twofold: one, given the needs, concerns, problems, associated with breast cancer for some women; and two, granted the aim of breast care nursing is to provide support, it appeared cogent to further examine that activity. Moreover, the little work that has to date explored breast care nursing has not fully explored the meanings and interpretations given to interactions by the parties concerned. It therefore seemed timely to undertake that examination of the experience of breast care nursing from the viewpoints of both patients and breast care nurses. These underlying assumptions will be developed in subsequent chapters.

The focus on sexuality and body image issues was chosen to frame not to curtail examination of the work that breast care nurses undertake with women. No attempt is made to strip sexuality and body image concerns or issues from the context in which they are lived. To do so would distance them from the way(s) in which they are lived, and the way(s) in which they are told by women in their encounters with breast care nurses or breast care nurses give account of women's concerns. Nevertheless I adopted to base knowledge of interaction solely upon accounts contained within interviews with breast care nurses and women who have had breast cancer. No fieldwork using participant observation was undertaken. That decision was not taken lightly. I now offer a justification for that decision prior to laying before the reader the body of my research endeavour.

Firstly, I have a minor level of notoriety in the field of breast care nursing despite not having held a position as a breast care nurse. I have, as mentioned previously

had involvement with two of the educational programmes and undertaken sessions as a visiting speaker on another. I have presented papers at cancer nursing and breast care nursing conferences on the subject of sexuality and body image concerns and contributed to the only United Kingdom textbook on breast care nursing (Denton 1996) on that subject. Those activities gave me a status almost of being both an 'insider' and 'outsider'. I knew something of the culture of breast care nursing but am distanced from it: I have some knowledge but no credible practice.

Nevertheless, there was a perception, however unfounded, that I have expert knowledge. This became apparent when seeking informants from the community of breast care nurses as a number remarked "Why talk to me? You know the issues?". I then presented a case indicating that I believed the individual breast care nurse had acquired understanding(s) through her contact with women which when analysed systematically could contribute to understanding of the meaning of the breast cancer experience. Once access had been negotiated, during the actual interviews my status as 'expert' was often referred to during the course of the event and sometimes openly challenged. On one occasion my response was demanded to a question confirming whether in my opinion the breast care nurse had acted appropriately. A large part of the preamble to beginning interviews was spent allaying concerns that I would be overly critical and interestingly I felt a need to minimise my personal knowledge.

Secondly, when I was practising as a clinical nurse specialist I was occasionally accompanied by other nurses in order for them to learn through "sitting by Nellie". I know that my interaction with patients was influenced by the presence of another whether that was another nurse or the patient's partner or family. Intimate issues and exploration of feelings at any level other than the superficial were avoided when another nurse was present, except on those occasions when to avoid an explicit cue from a patient would have been detrimental to subsequent interactions. Often those interactions were sanitised and it appeared to me as if two of the participants (the patient and myself) in the interaction had independently determined to maintain

discussions at the level of practical concerns. I therefore recognised that this might have influenced the value of any fieldwork undertaken observing interaction between breast care nurses and women.

Thirdly, I believe that interactions in these areas are fraught with sensitivities. To place additional burden upon interaction by seeking informed consent from all participants could well have been too demanding. Moreover in providing information about the purpose of my role I would have been bound to disclose the focus of the research and in so doing perhaps precipitated non-disclosure of concerns or initiated disclosures, which were difficult to 'control'. I use the analogy of undressing to more effectively describe my concerns. Interactions in this area often demand the patient metaphorically undresses through disclosure and the skill of the nurse is to assist that individual in getting dressed again with some semblance of order so that they are comfortable enough to go out in the real world. My presence could have one, produced a rather hurried undressing and redressing in the absence of order; or two, prevented undressing all together. Both scenarios produce an unsatisfactory outcome that might influence the quality of the ongoing breast care nurse – patient relationship.

Mindful of these issues, and in recognition that all views are partial and that it is the aggregation of knowledge which has the potential to bring understanding to the complexities of health care, I now present my contribution to understanding the work of breast care nurses.

The organisation of the thesis

Chapter two provides an overview of the demography of breast cancer, the management of primary breast cancer as delivered in the United Kingdom National Health Service, and the challenges of the disease for women and the small number of men (less than one per cent) who develop the disease. The policy context for the delivery of cancer and breast care services is discussed and the location of breast

care nursing within that. Also some attention is given to the development of breast care nursing as a discrete specialism within the range of nurse specialist roles which have proliferated over recent decades.

Chapter three presents the research process used to undertake the work. The chapter charts the evolving nature of the research journey and offers justification for deviations from the original research design in response to emergent findings. In keeping with the qualitative perspective adopted for the major part of the study I have sought to respond to the challenges that emerged through the collection and analysis of data. This chapter adopts a reflexive style in keeping with a tradition demanding explicit transparency in the research act enabling the reader to scrutinise and judge the rigour of that process.

Chapter four presents a short overview of the sex knowledge and attitude literature which functions to contextualise the remainder of the chapter. The results from a postal survey administered to breast care nurses using two modified instruments: the Sex Knowledge and Attitudes Test [SKAT] (Lief and Reed 1972) and the Williams-Wilson Sex Survey [WWSS] (Wilson and Williams 1988) and in addition demographic information. The demographic data is presented first followed sequentially by the sex knowledge (SKAT), attitudes to sexuality (SKAT and WWSS), and practice behaviour (WWSS) data. This is followed by a discussion and summarising conclusion.

In chapters five, six, and seven the narrative data from interviews undertaken with a volunteer sample of breast care nurses (n=29), secondary analysis of two focus group interviews (n=14) and two lesbian women informants (n=2) are presented. In chapter five the experience of cancer care delivery is set out. The journey from the initial phase of diagnosis and treatment, the more protracted period of adjuvant treatment, and transition to becoming a woman who has had breast cancer is charted. In chapter six the theme of knowing as partially explanatory to the work of breast care nurses associated with sexuality and body image is explored in terms of

awareness contexts, moral journeys and (in)visibility. The data related to the range and scope of the territory of breast nursing is examined using the metaphor of colonisation in chapter seven.

Chapter eight provides a summary of the research endeavour, and offers an account of the work of breast care nurses in their agency of “being there for women”. The implications of the work for nurse education and further research are presented.

CHAPTER 2

BACKGROUND

Introduction

Breast cancer is a common disease affecting one in twelve women in the United Kingdom, 34,600 new cases are diagnosed and 21,000 women die annually (Cancer Research Campaign 1999). Those striking statistics reflect the challenge to health care providers and moreover the burden of the disease on the UK population. It is a disease that remains largely unknown despite its high profile within the field of oncology and media attention. In the government policy document “Our Healthier Nation” (Department of Health 1997a) breast cancer was highlighted as a particular target for attention. Regular government investment in England and Wales has been directed at improving screening for early detection, the further development of specialist care in all National Health Service (NHS) Trusts, and in commitment to research into best treatment. The recent NHS Cancer Plan provides an even more detailed plan demonstrating government commitment to cancer “one of the central priorities of the NHS” (Department of Health 2000b:3). In the United Kingdom survival rates from breast cancer, irrespective of the introduction of a national breast screening cancer programme, remain lower than those reported in the majority of countries elsewhere in the European Union and North America although incidence rates are lower. This chapter will examine the problem of breast cancer, the recent developments in cancer care services in the United Kingdom, in order to contextualise this study within the broader context of health care delivery, policy and politics.

Demography of the disease

Breast Cancer is a disease that has been reported in ancient Egyptian and Greek historical documents (Denton 1996; Dixon and Sainsbury 1993). In de Moulin (de Moulin 1989) the historical medical management of breast cancer is well documented and the traditions of surgical (local control) and medical (systemic) treatment for the disease, rather lyrically described as the influence of Galen the physician, is charted. Accounts from textbooks of surgical techniques practised in

mediaeval times also show surgical management of breast cancer which were undertaken without anaesthesia or proper understanding of asepsis (Siraisi 1990).

Breast cancer was, until very recently, the commonest form of cancer in women in the United Kingdom and accounts for one in four female cancers. Men can, although rarely, develop breast cancer and account for less than one percent of breast cancer incidence. The worldwide breast cancer incidence is rising but rates vary from country to country. The world average cases for 100,000 of the population are 65 with the rate in England and Wales at 68.8 per 100,000, Scotland 72.7 per 100,000 (Scottish Executive 1998). Much of the rise in incidence has been accounted for by “increased diagnostic activity, and will accelerate with the introduction of screening” (Quinn and Allen 1995: 2).

The incidence of breast cancer is in general higher in first world countries, with women in Europe and North America being at higher risk than those in less affluent countries. Rates amongst women migrating from low-risk to high-risk countries show similar levels by second and third generations. This gives some credence to the assertion that environmental or social factors in affluent hosts countries may be influential, but what the exact influencing factor or combination of factors remains as yet unknown (House of Commons Health Committee 1995). One of the problems associated with using country by country comparisons is the unreliability of national cancer statistics produced by variations in the methods used to collect and record data. Although the United Kingdom (England and Wales, Scotland and Northern Ireland) does not have a particularly high incidence in comparison to the United States of America (USA), Netherlands, and Canada the incidence of the disease is rising (see table 2.1). Recent rises in incidence have been attributed to the introduction of the National Breast Cancer Screening Programme identifying cancers earlier therefore increasing the incidence rate. This screening induced artefact should level, allowing the true picture of incidence trends to emerge. A problem emphasised by the recent rise in incidence is (over) specificity of mammography for detecting early or pre-malignant pathology, ductal carcinoma in

situ (DCIS), which may not develop into invasive breast cancer. Across England and Wales there are regional variations in incidence rates although these rates are 'crude', not standardised, for the population/age structure (House of Commons Health Committee 1995). This differentiated picture may be a reflection of regional population changes due to employment patterns and socio-economic factors rather than any clustering of cases due to localised environmental risk.

Table 2.1: International comparison of breast cancer incidence (1988-1992) per 100,000 population

Country	US (White)	Netherlands	US (Black)	France	Scotland	England & Wales
Rate	90.7	79.6	79.3	78.8	72.7	68.8

Source: Scottish Executive (1998)

Risk of developing breast cancer increases with age with a one in ten (1:10) risk for women living to the age of 85 years. The disease is rare under the age of twenty-five. From the age of thirty five there is a rapid increase in incidence with peak age of diagnosis at sixty years. Early menarche and late menopause appear to be risk factors. Other risk factors that have been postulated include high fat diet, smoking, the organochlorine pesticide Lindane (The All-Party Parliamentary Group on Breast Cancer 1998), high alcohol intake, hormone replacement therapy (HRT) and the contraceptive pill (Breast Cancer Care 2000). The research evidence on the effects of high fat diet are predicated on the geographic distribution and cultural dietary habits i.e. Finland and United Kingdom with high levels of saturated fats (dairy products) in the diet. The United Kingdom has worse survival statistics than elsewhere in Europe and these have only recently improved. Age standardised five year survival rates vary with stage of disease at initial presentation (Quinn and Allen 1995). For women diagnosed in the period 1985 to 1989, the five-year survival was 65% in Scotland and 67% in England and Wales. A number of reasons have been offered for the poor United Kingdom survival rates including a more virulent form of the disease, low level of resourcing, inadequate provision of specialist breast cancer services and less aggressive treatment protocols particularly with newer, and

more expensive, chemotherapeutic agents such as Taxol (House of Commons Health Committee 1995).

Table 2.2: Comparison of five year survival rates for breast cancer

Country	England & Wales	Switzerland	Denmark	Finland	France	Germany	Italy	USA
Rate	68%	75.7%	68.1%	73.1%	71.4%	68.4%	70.8%	84%

(Black 1997)

The influence of familial history as a risk factor is well reported since the discoveries of BRCA1 (Miki, et al. 1994) and BRCA2 (Wooster, et al. 1994). Although family history is an important risk factor only about 5% to 10% of cases can be attributable to an inherited predisposition (Hallowell 1999; Hallowell 2000). It is argued that a ‘geneticisation’ of cancer has occurred resulting in an over emphasis on the genetic risk of breast cancer (BASO 1998) irrespective of those who carry mutation having a breast cancer risk which may be as high as 85% (Easton, et al. 1995; Tonin, et al. 1995). A recent study (Henderson and Kitzinger 1999) examining media coverage of breast cancer genetics argues that presentational style, particularly the use of highly personalised “human interest” stories, increases public perception of genetic influences but fails to inform at an individual level about potential risk. Their review of articles from eight tabloid and broadsheet newspapers for the period 1995 to 1997 produced 708 articles of which 152 focussed on risk and 51 had genetics as the main topic: a ratio of one to three (1:3). This finding is particularly striking when other risk factors possibly more amenable to behaviour modification, such as diet, use of the contraceptive pill, HRT, and smoking, receive far less coverage.

The most recent guidelines produced by the British Association of Surgical Oncology (BASO) present guidance for the management of women who enquire about familial breast cancer and they open with “Many women enquiring about a family history of breast cancer will not have a significant history” (BASO 1998: 2). These unsolicited inquiries made by women may in fact be reflection of volume and

accuracy of genetic information provided by the media (Henderson and Kitzinger 1999). BASO adopt a simple categorisation system to describe women according to high, medium, and low risk but warn that the assumption that breast gene mutation identification and subsequent screening surveillance has yet to be established as effective in reducing mortality among the high risk group (Neugut and Jacobson 1995). Genetic testing is currently a technologically difficult procedure and this may restrict its use to those at high risk. Women can be identified as 'high risk' from plotting their family history and be offered cancer risk management; this involves annually screening (mammography and clinical examination) or prophylactic bilateral mastectomy. Mammography carries health risk as there are iatrogenic implications from radiological examination. The calculated risk from screening mammography is that for every two million women screened under age of fifty years one new cancer per ten years will be caused (Blamey, et al. 1994). As a screening instrument it has reduced sensitivity with younger women due to the density of breast tissue. In practice this produces high levels of false positives, thereby incurring unnecessary interventions (surgery, diagnostic tests) and anxiety. Cancers that subsequently occur between tests, known as interval cancers, may fail to be diagnosed. Women may have a false optimism about the test and dependency on medical surveillance rather than adopting personal self-management through breast awareness (Hallowell 1999).

Detection and surveillance: screening and self examination

Breast Cancer poses a major threat to women, has a high media profile, and carries a large social and economic burden (Alderson, et al. 1993; Thompson 1998). Against that background it would seem a reasonable assumption that women would take responsibility for their own health. This assumption of responsibility is the basis of many health promotion campaigns. That is, given the correct information individuals will take a rational course of action and comply with prescribed health behaviours. These behaviours may be healthy living i.e. life style, or as in the case of breast cancer, undertaking self surveillance through self examination, exploring and

establishing genetic risk, and/or participation in screening programmes. It is well recognised that health behaviour is far more complex than a simple input-output model and influences such as personal beliefs, understandings of causation of disease, the possible benefit(s) proactive action will bring to the individual's actions, and personal assessment of risk. This latter point is particularly pertinent in breast cancer where success in surveillance, or participation, actually results in the negative reward of finding the disease.

The current expert advice in the United Kingdom suggests that all women should be 'breast aware' (primary prevention) and those asymptomatic, low risk women, aged fifty to sixty four should participate in three yearly breast screening by mammography (secondary prevention) offered by the National Health Service National Breast Screening Programme (NHSBSP). At age sixty-five and over women are encouraged to have three yearly mammography but are not invited unless they request to participate. Routine invitations for screening are to be extended however risk versus benefit beyond the age of seventy has yet to be established (Department of Health 2000b).

Breast awareness

In 1991, the then Chief Medical Officer, Sir Donald Acheson announced that the Government's Advisory Committee on Breast Screening "took the view that there is no convincing evidence that the ritual of monthly breast self-examination (BSE) reduces death from cancer" (Clayson 1992: 442). This announcement was despite the evidence that 90-98% of breast cancers are found by women themselves (Senie, et al. 1981; Nettles-Carlson and Smith 1988; Agars and McMurray 1993). It is widely recognised that where diagnosis is dependent on finding a palpable lesion it is more than likely that the cancer is fairly well advanced, the disease may well be disseminated thus making prognosis poorer. Previously, breast self examination (BSE) had been advocated as the primary health promoting behaviour for women. Evidence does suggest that some women found the procedure difficult to perform

and many held beliefs that it was not necessary in the absence of a family history of the disease (Lierman, et al. 1991).

Since 1991 “Breast Awareness” has been advocated in the United Kingdom rather than the ‘ritualised’ practice of breast self examination. A closer examination of the health promotion literature would suggest that this is merely a rebranding of breast self examination rather than total dismissal. Nevertheless, the potential message received by women from the Chief Medical Officer’s statement was that self surveillance was less dependable than the National Health Service Breast Screening Programme. The statement may have been part of a strategy to bolster compliance, particularly in the light of the national investment in the scheme and some vocal, but nevertheless minority criticism of efficacy (Bindless 1995). Breast awareness invites women to become familiar with the shape, texture, sensations and changes through the menstrual cycle so that women will identify any unusual changes and report them. The five point code titled ‘Be Breast Aware’ (Cancer Research Campaign 1999) is currently the advice being advocated. Thompson (Thompson 1998) suggests that breast awareness carries a much subtler message than the widespread teaching and practice of breast self examination. Breast self examination involves the palpation of the breast either in linear fashion (vertical strip method¹) or concentric circular or radial spokes using light finger palpation over the surface of the breast. A recent review of fifty-seven studies (Clarke and Savage 1999) examining breast self examination training suggested that education increased frequency of use, and proficiency in the technique. There was no evidence that health care professionals were superior at training women over trained lay educators. Attendance at one or more consolidating sessions after initial training was found to improve compliance and proficiency. Women older than sixty appear to have greater difficulty identifying lumps and required longer to perform the technique.

¹ May be most effective search technique although evidence equivocal (Clarke & Savage, 1999)

The National Health Service Breast Screening Programme (NHSBSP)

In the United Kingdom the real emphasis on early detection of breast cancer has since the implementation of the Forrest Report (Forrest 1986) been the NHS national breast screening programme. Some argue this was initiated with undue haste for political rather than health gain immediately prior to 1987 general election (Baum 1988; Hann 1996). The working group chaired by Professor Sir Patrick Forrest was charged with examining the best available information, principally from outside the United Kingdom, to inform any changes in UK policy regarding mammography screening of symptomless women. A secondary purpose of the committee was to examine the cost benefits of breast screening and produce a plan for developing the infrastructure to support mass breast screening. The evidence was scrutinised against criteria first formulated by Wilson and Jungner (1968) [see table 2.3] but the Expert Group recognised that a number of the criteria would not be met by a national breast screening programme. It has been argued that the National Breast Screening Programme has in effect become the means to verify those principles, i.e. the natural history of the disease (Foster 1995).

The commitment to the NHSBSP has continued and has recently attracted further government support and remains a cornerstone of the cancer policy despite recognition that “services have not always been of a consistently high standard” (Department of Health 1997b: 10). The current government position is that breast cancer along with cervical screening “continues to bring real benefits to women, despite local problems in the provision of such services that came to light” (Department of Health 1998a: 161)

Table 2.3 Principles of screening

1.* ²	The condition to be screened should be pose a health problem
2.	The natural history of the disease should be understood
3.	There should be a recognisable early stage
4.*	There should be a treatment benefit from early intervention
5.*	Availability of a suitable test
6.*	The test should be acceptable to the target population
7.	There should be adequate support services to underpin diagnosis and treatment
8.	For diseases with an insidious onset the screen intervals between screening events should be determined by the natural history of the disease
9.	The risk of physical or psychological harm should be less than the benefits
10.	The cost of screening should be balanced against the benefits it provides

(Wilson and Jungner 1968; Forrest 1986)

The research evidence on which the Forrest recommendations and ultimately the NHSBSP were based were derived from a number of studies: the Health Insurance Plan (HIP) study conducted in the USA (Shapiro 1977), the Two Counties study (Tabar, et al. 1985) undertaken in Sweden and the Nijmegen and Utrecht studies (Verbreck, et al. 1984). Since its introduction there has been considerable controversy about the benefits of national breast cancer screening with experts repositioning themselves on either side of the debate. The different viewpoints are polarised and broadly represented by the positions that mammography is “the best screening tool available for detecting breast cancer and is the screening method shown to be of value in randomised trials”(Blamey, et al. 1994:1076)) to “since the benefit achieved is marginal, the harm caused substantial, and the costs incurred enormous, we suggest that public funding for breast cancer screening in any age group is not justifiable” (Wright and Barber Mueller 1995: 29).

Breast Cancer Screening is based on the use of mammography which is either a single x-ray of the breasts using medio-lateral view or a double x-ray of both the

² Those marked with an asterisk (*) had been established at the time of Forrest (1986). The other principles have not been fully established or remain equivocal.

medio-lateral and cranio-caudal view. In the United Kingdom all women aged between fifty and sixty-four years are normally invited by letter, with an accompanying letter from their general practitioner, to attend a breast screening centre. Information relating to attendance is normally held on a woman's medical record. Failure to attend usually results in a further invitation and appointment and sometimes a personal visit from a member of the primary health care team e.g. health visitor or practice nurse. The NHSBSP, at inception, used single view x-ray views, which were a less expensive and less reliable approach but since 1995 has adopted the double x-ray approach. This was largely in response to the increase in interval³ breast cancer cases being reported and concerns about the quality control mechanisms in the NHSBSP (House of Commons Health Committee 1995). The x-rays are interpreted by a radiologist with the purpose of detecting tissue abnormalities possibly indicative of malignancy known as test positive. Those women who "test positive" are then recalled for further investigations to determine the nature of the abnormality. For mammography to be an effective screening tool it needs to be capable of detecting abnormality suggestive of breast cancer (high sensitivity) yet produce few false negative results. It must also be able to eliminate women from further investigations who do not have suspicious pathology (high specificity) thereby eliminating high numbers of false positive test results. For example for women aged fifty to sixty-four in 1992-3 1,165,726 women attended, 63,076 were recalled, 9,129 received biopsies and 6,597 (true positives) were diagnosed as having breast cancer (House of Commons Health Committee 1995). In effect 56,479 were erroneously recalled for further investigations of which a large proportion will have resulted from over cautious or inaccurate reporting. Currently standards of mammography are monitored as part of the quality assurance programme (QAP) of NHSBSP. Nevertheless a number of studies have reported the psychological distress (anxiety, cancer phobia and poor quality of life) associated with 'false positive' events in screening (Ellman, et al. 1989; Lowe et al. 1999). It is outwith the scope of this chapter to debate the rights and wrongs, benefits and

³ Interval refers to cancers identified, usually by the woman herself, in the period between screening points.

disbenefits of the NHSBSP and excellent accounts are offered from a variety of perspectives (Skrabanek 1988; Batt, 1994; Bindless 1995; Hann 1996)

A sceptic may conclude that the UK national approach to breast cancer surveillance is cautious and more concerned with monitoring the disease in order to provide greater understanding of the natural course of the disease from ductal carcinoma in situ (DCIS) to death. The surveillance approach of the NHSNBSP also provides a forum for quality enhancement through providing training opportunities for clinicians thereby reducing false positive and negative results. It assists in establishing whether treatment in the form of prophylactic bilateral mastectomy is better than annual surveillance mammography for those who carry the BRCA1 and/or BRCA2 gene(s) and assists in monitoring the natural course of the disease from DCIS onwards in a National Health Service committed by government to a quality and evidence based agenda (NHS Executive 1996; Department of Health 1998b; Department of Health 2000b) and is in fact research under the guise of surveillance. Breast care nurses via the Breast Care Nursing Society of the Royal College of Nursing have been advocates for the introduction of screening and continue to support the NHSBSCP.

Breast cancer – the natural history of the disease

Breast cancer starts in the milk-producing cells in the breast (terminal duct lobular unit). Traditionally the different histological typology of breast cancers has been described as ductal or lobular suggesting that their origins are in slightly different anatomical areas of the terminal duct lobular unit. Eighty five per cent (85%) of breast cancers are invasive carcinoma of no special type (invasive ductal carcinoma). Carcinomas restricted within the terminal duct lobular unit and adjacent ducts are known as carcinoma in situ and can be ductal (DCIS) or lobular (LCIS). Once the cancer invades into surrounding tissues, beyond the basement membranes, it is referred to as invasive. Breast cancer can spread to local lymph nodes and from there be disseminated (metastasised) to more distant sites usually the bones, liver and

brain. It is a disease that can extend locally and fungating lesions of the chest wall are not unusual as primary presentation or as a sequel to local excision of tumour. It has been suggested that the natural history of breast cancer remains difficult to map due to the long tradition of treatment, particularly since the development and widespread use of anaesthetics (Baum 1988). Retrospective analyses of historical records, however imperfect tend to show a ten per cent (10%) survival after ten years of presentation with a lump with no treatment. Extrapolating that information to estimate impact of non-treatment is problematic even in the pre anaesthesia era as selection bias in the form of some women choosing not to present whereas others, often with severe rapid onset symptoms, presented themselves.

The histological picture at a cellular level is important in informing treatment decisions. For example invasive ductal carcinomas which on histological examination have extensive intraduct components (EIC) require wider resection, as this presentation tends to be multifocal. Tumours of specific histological typology (lobular, tubular, cribriform, medullary, mucinous, microinvasive, papillary) tend to have a better prognosis. Following removal tumours are graded I to III according to the Bloom and Richardson system where a numerical scoring system is applied to components of the specimen (tubular differentiation, nuclear pleomorphism and volume of mitotic figures present) to produce a score based upon degree of differentiation (Dixon and Sainsbury 1993). Tumour grade can be a useful predictor of prognosis as can nodal status. Nodes are normally dissected and removed and pathological examination undertaken following initial diagnostic surgical intervention, the general rule being the greater number of nodes involved the poorer the prognosis. Other prognostic indicators such as biochemical levels of 'biological markers' will be determined to provide the multidisciplinary team with a full clinical picture on which to decide best treatment options. Oestrogen receptor (ER) is one such factor that is present in sixty per cent (60%) of tumours although it is not as sensitive an indicator as nodal status. Currently prognosis is estimated based on weighing all factors: tumour size, histological type, nodal status and biological markers together.

Breast cancer – the management of women

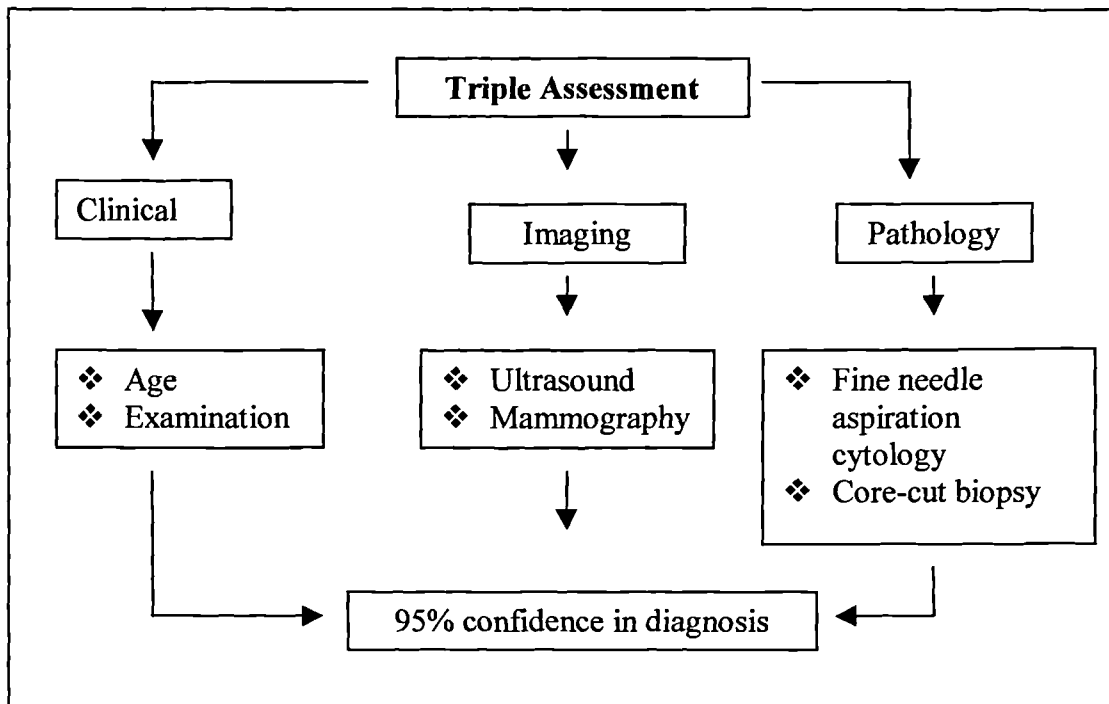
The majority of women enter the health care system by approaching their general practitioner with a symptom most often a small lump. A smaller proportion of women emerge from asymptomatic screening (either NHSNBS or private/occupational schemes⁴) and an even smaller group of women who are monitored as being at risk (i.e. those women who identify themselves as having a genetic risk). Following examination, assuming the general practitioner considers the symptom to be sinister and worthy of further investigation; the women are normally referred to their local designated breast clinic. This referral process is increasingly rapid and a referral letter is often sent by facsimile to the receiving breast unit. The referral is normally scrutinised by a specialist breast surgical consultant in the first instance and prioritised according to the description of signs, symptoms, and communication of urgency offered by the originating doctor. The outcome of that vetting process will result in an out patient appointment. The current expected NHS standard is that eighty per cent (80%) of women who subsequently are diagnosed with breast cancer should be seen within two weeks of referral.

At the out patient department women may experience one of two systems. One is described as ‘one stop’ clinic where ‘triple assessment’: mammography using two views and/or ultrasound, fine needle aspiration (FNAC) and/or core biopsy, and clinical examination, are undertaken and when the results are collated the preliminary diagnosis is communicated to the woman (see figure 2.1). This usually occurs at the end of the day of attendance hence the term ‘one stop’. Some breast units cannot offer rapid processing of specimens or mammography reporting, as speed is dependent on the ‘slowest’ reporting clinician (usually pathology/radiography). In this instance the tests may be undertaken on one day, or over a period of a week, and the outcome of the investigations with the diagnosis is provided at the next available appointment. Once the diagnosis of breast cancer is

⁴ For example Marks and Spencer plc have offered breast screening for staff for a number of years

relayed to the woman normally initial surgical intervention is planned and a date for admission is arranged. Good practice currently advocates this surgery should be within three weeks of the decision to operate (BASO 1998).

Figure 2.1: Triple Assessment



(Baum 1998)

Most women presenting with a breast symptom suggestive of malignancy will have surgery to fully establish a diagnosis, particularly where triple assessment has been inconclusive, or to initiate therapy. Further information, both verbally and in written format, will be given either on the day of diagnosis or subsequently prior to admission for surgery. It is usually a breast care nurse who provides this information. Should the women be offered a choice of surgical techniques and/or treatment options the decision making process may involve re-visiting the outpatient department to see the lead clinician (usually surgeon) and/or to discuss options with a breast care nurse. Many breast care nurses routinely arrange to meet with a woman prior to admission either in a timed appointment at the woman's home or in hospital. The purpose of this consultation is to ensure that the woman

understands the nature of her disease, proposed treatment and where clinically appropriate is involved in deciding treatment choice (Royal College of Nursing 1994).

Information, decision making and the breast care nurse

There has been something of a sea change in terms of the volume of information and willingness of health care professionals to engage women as participants in decision making in breast cancer. A major influence was the volume of research evidence which led to the issuing of a consensus statement at the National Institute of Health Development Conference in the United States in 1990 (Fallowfield, et al. 1994a). This statement confirmed that breast conservation treatment, excision of primary tumour plus radiotherapy, was as effective for stage I and II breast cancer as mastectomy and lymph node clearance and had the added advantage of preserving the integrity of the breast. It is worthy of note that the evidence underpinning the declaration had been accumulating throughout the preceding two decades and had been adopted, or at least offered by surgeons in some hospitals in the United Kingdom during the 1980's (Wilson, et al. 1988). As Fallowfield and colleagues noted in 1994, assuming the availability of radiotherapy is assured, then conservative treatment would become the preferred option or at least one option from which women could choose (Fallowfield, et al. 1994a). Treatment options have also brought with them the potential for patient involvement in decision making.

During the 1980s and early 1990s a number of studies had been undertaken to ascertain the psychological burden of involvement in decision making (Ashcroft, et al. 1985; Wilson, et al. 1988; Cotton, et al. 1991; Fallowfield, et al. 1994a; Fallowfield, et al. 1994b) and to establish whether assumptions about the "putative benefits of offering choice" (Fallowfield, et al. 1990: 202) were not assumed without the production of evidence. The overall consensus of the work was not clear cut. It suggested that not all women wished to make the final decision concerning treatment choice. There was no conclusive evidence that choice alone produced psychological

benefit. However, the view adopted was that women wanted information about the costs, benefits, and implications of treatments and wished to be supported in decision making. More recent work in this area has examined amount, approaches to, and recall of, information given to women about their diagnosis (Hughes 1993; Beaver et al. 1996; Luker, et al. 2000).

Once breast cancer has been diagnosed the actual severity of the disease is estimated, known as staging, using a classification system called Tumour size-Node-Metastasis (TNM) often reported in conjunction with a International Union Against Cancer (UICC) classification based on a scale of grades from I to IV.

Primary surgery for operable breast cancer

In recent history there is a divide in terms of primary surgical intervention and what is classed as ‘early’ i.e. stage I or II, and ‘advanced’ disease i.e. stages III and IV. Like much of the language of cancer meaning of terms has changed with the fuller understanding of the history of the disease or is context specific. For example: ‘early’ in relation to natural history of the disease would be ‘asymptomatic’ whereas ‘early’ in relation to treatment means stages I and II.

The most usual first line treatment until relatively recently (1980s) was mastectomy with lymph node clearance. This has been the dominant treatment for over one hundred years since Charles Moore formulated the general principles and William Halstead in America developed the Halstead radical mastectomy (Yalom 1998) the objective being the clearance of cancer cells from the breast and regional lymph nodes. Baum (1988) reviewing Halstead’s contribution during the period 1889-1931 showed a six percent peri-operative mortality rate, incidence of local recurrence at thirty percent, with a twelve percent ten-year survival rate. He suggests that Halstead’s approach was improved local control “without influencing long term survival” (Baum 1988: 5). The period from 1930 onwards showed some improvement in breast cancer survival to which a number of factors are thought to

have contributed including better health education, women feeling able to present earlier, improvements in anaesthesia, and a more accurate system for estimating disease progression. This last factor facilitated more accurate selection for radical surgery resulting in a better ten year survival, of around fifty per cent (50%) for women. Until the 1980s, the modified radical mastectomy was the most commonly used surgical technique in the United Kingdom. This involved removal of the breast with some overlying skin (including the nipple), dividing the pectoralis minor muscle, and clearance of the axilla of all nodes. From this description the level of disfigurement and long term implications for the development of lymphoedema of the limb emphasises the devastating impact this must have had on women irrespective of its efficacy in effecting a cure.

In the 1970s and 1980s a series of clinical trials in the United Kingdom, North America and Europe provided evidence that mastectomy was not always necessary to achieve local control of disease. This growing body of evidence was possibly one of the most significant in terms of clinical care. In a review of the evidence (nine randomised controlled trials with 5000 participants in total) no difference in mortality was found between those undergoing mastectomy compared with those undergoing breast conservation with radiotherapy (Fallowfield, et al. 1990; Cancer Guidance sub-group of the Clinical Outcomes Group 1997).

The 'correct' management for DCIS is as yet unknown but the consensus among surgeons is that the area of malignancy needs to be removed although what constitutes clear margins is less clear⁵ (Dixon and Sainsbury 1993). If the affected area is large or multifocal then normally mastectomy is indicated otherwise lumpectomy is currently viewed as adequate. Axillary sampling is encouraged although axillary clearance⁶ is not usually considered necessary despite considerable

⁵ BASO (1998) guidelines suggest a 95% rate of non-recurrence at 5 years constitutes adequate clearance

⁶ Removal of all lymph nodes on affected side. Total lymphadenectomy is associated with lymphoedema

debate about what constitutes adequate volume of sampling⁷ and similarly defining axillary clearance. More recently evidence suggests that mastectomy is more effective than conservation with radiotherapy for women with DCIS for controlling local recurrence. A recent meta-analysis (Boyages, et al. 1999) sought to explore whether those women most likely to experience local recurrence could be predicted thereby avoiding mastectomy. The authors recognised current limitation of evidence to inform prediction. The major issue was the difficulties associated with comparing studies because of varying interpretations of extent of surgery, definition of clear margins, and differences in radiotherapy protocols.

As a diagnosis of DCIS carries a nine times increased statistical risk of developing invasive breast cancer within fifteen years, establishing best practice in terms of follow up treatment is recognisably important. The current advice is that: “a few years of tamoxifen therapy has been shown to prolong survival and disease free interval in all categories of early breast cancer except for young oestrogen-receptor negative women”(Cancer Guidance sub-group of the Clinical Outcomes Group 1997: 52). Conservation surgery i.e. removal of cancer tissue and a surrounding margin of unaffected tissue followed by radiotherapy is now known to be as effective as mastectomy for women with invasive breast cancer. That is, those with a single lesion measuring four centimetres or less, no evidence of local advancement, nodal involvement or metastases. Some surgeons undertake quadrantectomy, where an entire quadrant of breast tissue is removed. For some women the location of the lesion makes conservation surgery far from ideal as attempts to undertake minimal surgery may produce a less than pleasing cosmetic result. These women, particularly those with a centrally located lesion, may be encouraged to undergo mastectomy. Those undergoing mastectomy may be offered simultaneous reconstruction if that service is available.

Approximately five percent of women who require a mastectomy for primary treatment will undergo breast reconstruction. The current professional opinion is that

⁷ The BASO guidelines suggest a minimum of four lymph nodes as adequate for axillary sampling.

immediate rather than delayed reconstruction is preferable in terms of reduction in psychological distress however ensuring that is an option for women in current practice is more problematic (Schain, et al. 1984; Stevens, et al. 1984; Schain, et al. 1985; Baum 1998). The aims of reconstruction are to restore contour, symmetry, and “produce a pleasing nipple-areola complex” (Baum 1998: 49). The options are available in terms of surgical technique: silicone gel implants, tissue expanders with prostheses, and myocutaneous flaps using the latissimus dorsi or transverse rectus abdominus myocutaneous (TRAM) muscles.

Silicone gel implants involve surgically placing the implant high on the chest wall. This settles over ensuing months as skin and surrounding tissues stretch to accommodate the device. Over recent years silicone gel implants have received considerable media and legal attention (Zimmerman 1998). Tissue expansion involves the surgical placement of an inflatable bag that is gradually inflated with saline until one and a half times larger than the opposite breast. The bag is subsequently removed and replaced⁸ with a gel prosthesis when the tissue has expanded. Myocutaneous flap reconstruction involves use of a flap of skin and muscle to recreate a breast shape on the chest wall. In addition a nipple can be reconstructed using tissue removed from the opposite breast or from thigh or labia.

The management of the axilla in the treatment of primary breast cancer remains controversial although with earlier diagnosis resulting from breast screening it may become an issue of less significance. One of the problems with lymph node surgery is the difficulty in preventing disruption to lymphatic drainage ultimately leading to the development of chronic lymphoedema, associated discomfort, and disfigurement. Other problems include anaesthesia and paraesthesia of the axilla and medial aspects of the arm (West and Brown 1996; Baum 1998). Sentinel node biopsy is a recently advocated approach that reduces the morbidity associated with axillary dissection. Here, due to the predictable spread of breast cancer along

⁸ A recent development is a silicone prosthesis containing a tissue expander, which is filled via a subcutaneous valve. The valve is removed under local anaesthetic when appropriate volume reached.

lymphatics in the axilla, the lowest (sentinel) node is identified and removed as the probability is that it will be the primary site for infiltration: although there is a three percent risk of cancer skipping the sentinel node. Identification and subsequent surgery to isolate the sentinel node still carries surgical morbidity. The use of radioactive isotopes has been shown as effective in directing surgeons to sentinel nodes and thereby establishing level of spread and informing decision making relating to extent of axillary dissection (Veronesi, et al. 1997).

Radiotherapy is given to all women undergoing conservative surgery. It is also used to treat women with high risk of local recurrence. Treatment usually occurs over a six week period involving three to five doses of radiotherapy per week. Treatment can induce side-effects such as skin reactions, nausea and vomiting and pneumonitis. In addition in the long term it can produce deformity and discolouration of the treated breast which can, understandably, be disturbing to some women.

Systematic or adjuvant therapy

The purpose of systemic therapies is to prevent or delay the development of distant metastatic spread. As some breast cancers are influenced by hormones, especially oestrogen, cancer cells are sampled to see whether hormone receptors are present. If the cells contain either oestrogen, or progesterone receptors or both they are termed 'receptor-positive'. Women whose cancer is 'receptor-positive' can often respond well to hormone manipulation and in general have a better prognosis (Buckman 2000). A crude rule of thumb is that chemotherapy is used on pre-menopausal women whereas hormone manipulation is used on post-menopausal women. Ovarian ablation by surgery or radiotherapy has been shown to improve survival by fourteen percent in women less than fifty years (Early Breast Cancer Trialists Collaborative Group 1996). Nevertheless for younger women the consequence will be infertility and early menopause. Tamoxifen (non-steroidal anti-oestrogen) has become the most significant treatment for reducing mortality (Rea, et al. 1998). Treatment with the drug for two to five years reduces risk of death and in the over fifty year age

group has particular benefit. There is still uncertainty about duration of maintenance on Tamoxifen and this is currently being investigated in two large international multicentre trials (Rea, et al. 1998). Other advantages include reduction in incidence of cancer in the opposite breast, and maintenance of bone mineral density and possible protection against coronary heart disease (Baum 1998; Rea, et al. 1998). Tamoxifen is not without side effects that can have an impact on a woman's quality of life. Menopausal symptoms such as hot flushes, vaginal dryness, vaginal discharge and weight gain are commonly reported and frequently described in medical texts and self help guides as mild (Baum 1988; Baum, et al. 1994; Buckman 2000). Other risks although rare include developing a deep vein thrombosis, cataracts and endometrial cancer (Buckman 2000).

Cytotoxic chemotherapy is used extensively and is particularly effective in premenopausal women with lymph node involvement. Two combination chemotherapeutic regimes are commonly used. These are:

- Cyclophosphamide, Methotrexate and Fluorouracil (5-FU) every 21-28 days for six months.
- Doxorubicin and Cyclophosphamide (with or without 5-FU) every 21 days for 3 months. Epirubicin is sometimes substituted for Doxorubicin.

Chemotherapy is not without side effects. Mucositis (Kowanko, et al. 1998) hair loss (Williams, et al. 1999), nausea and vomiting and fatigue (Richardson 1995), are frequently experienced. Complete hair loss is rare except with Doxorubicin (Giaccone, et al. 1988).

The impact of treatment for primary breast cancer

This overview of current treatment does not fully communicate the experience and demands of diagnosis and cancer management, whether ultimately curative or palliative, on women. In addition to the side effects discussed in relation to specific treatment modalities, there are a number that relate to specific difficulties that some

women experience associated with sexual functioning, body image disturbance, anxiety and depression.

Research examining the cost of breast cancer and impact upon sexuality and body image in terms of its effects on women's lives has been ongoing since Bard and Sutherland (1955). The research since that period has tended to adopt a reductionist⁹ approach to psychological and sexual problems by focusing upon depression and anxiety, marital adjustment, sexual functioning, and body image disturbance. This trend may reflect the availability and development of instrumentation for measurement of these domains. Although far from certain that the instruments provide an accurate picture of the total or even partial meaning of the experience, the use of rating scales and pre-existing instruments have dominated psycho-oncological research. This tradition has continued and the trend of incorporating quality of life scales which include elements to measure these domains has become the norm in clinical trials examining the efficacy of treatment modalities in cancer (Sprangers, et al. 1996; Webb and Koch 1997; Costain Schou and Hewison 1999). Maguire and Selby (1989) in a review of this type of approach were critical of the quality, or more particularly the accuracy, of quality of life instruments used in clinical trials. They advocated greater energy be spent on increasing the sensitivity of quality of life tools rather than revisiting the complexity of the subject. This approach has culminated in the development and widespread use in the UK and Europe of the EORTC Quality of Life scale in cancer research.

Other writers have criticised the measurement approach particularly in relation to breast cancer (Rosser 1981; Bransfield 1982/3; Cannon 1988; Batt 1994). The main argument focuses on the over reliance on a positivist approach which fails, through the project of reduction, to recognise the complex interplay of human experience and an individual's response and mirrors the medical model of pathologising those elements most conducive to treatment (Alderson, et al. 1993). More recently

⁹ The term reductionist is used as a description of the positivist position of reducing the vocabulary of theory to the vocabulary of observable statements which are measurable (Schwandt 1997)

criticisms have questioned the assumption that sexuality and body image concerns of women are greater than the threat to life posed by cancer. It has been more widely recognised that the heteropaternalistic orientation of previous research failed to recognise that not all women are heterosexual, in monogamous relationships, or sexually active (Batt 1994; Wilkinson 1995; Webb and Koch 1997). This tradition of measurement with slightly different emphasis (namely shift towards quality of life and involvement in decision making) has persisted despite these censures (Fallowfield, et al. 1990; Massie and Holland 1991; Wainstock 1991; Stefanek 1993) and frequent iteration of the need for complementary research approaches to cast light on the experience and meaning of cancer (Wilkinson and Kitzinger 1993; Costain Schou and Hewison 1999).

Despite limitations the current opinion in terms of the impact of breast cancer on sexuality and body image disturbance and subsequent adaptation and psychological morbidity is the following: Mastectomy as a treatment option carries the likelihood of psychological implications and /or sexual problems for a proportion of women. There is thought to be greater risk of problems developing for those women who value highly an intact body image (Morris 1977; Fallowfield, et al. 1990). Conservation (local excision of tumour with or without lymph node clearance or sampling) treatment without choice carries a similar risk of development of psychological morbidity, depression, anxiety and sexual difficulties however this is less likely to be associated with body image disturbance (Ashcroft, et al. 1985).

Patient choice, based on an understanding of the options and supported decision making may reduce psychological morbidity and sexual problems (Ashcroft, et al. 1985; Cotton, et al. 1991; Fallowfield, et al. 1994a; Luker, et al. 1996). Women who undergo adjuvant chemotherapy appear to experience high levels of sexual disinterest (Maguire, et al. 1980b). This probably has more to do with fatigue (Richardson 1995) and may have been lessened by better chemotherapy management (Topping 1996).

Early breast reconstruction¹⁰ (for those women considered suitable candidates) may reduce psychological impact, particularly associated with concerns about loss of body image integrity and adverse effects on sexual functioning brought about by mastectomy (Stevens, et al. 1984; Schain, et al. 1984; Schain, et al. 1985). Breast conservation compared with immediate or delayed reconstruction produces better levels of satisfaction in terms of body image (Mock 1993). Although the overall quality of studies are poor due to small, self selected study populations making firm recommendations elusive (Cancer Guidance sub-group of the Clinical Outcomes Group 1997)

From the summary what is evident is that much of the work examining the psycho sexual aspects of response to treatment is becoming dated with little research activity in these areas since 1990. What remains unknown is whether the work holds up to scrutiny with the passage of time and improvements in the management of breast cancer treatment. These findings may well not remain valid for all women because factors such as ethnic background, culture, class, relationships, prior sexual behaviour and sexual preferences appear absent from much of the research. A further consideration is the recent doubt cast that sexuality and body image is a problem. Luker et al. (1996) found that women ranked sexuality, at point of diagnosis and thirteen months following diagnosis, as a relatively minor consideration in decision making and information needs. This does not necessarily mean that sexuality and body image problems do not emerge during or following treatment when women are regaining some sense of 'normality' but they are not reportedly central to decision making. An alternative reading may be the hidden impact of professional support. Since the time when much of the UK original work was undertaken there has been a significant change in the professional care and support offered to women undergoing treatment for breast cancer. So a further consideration is that the professional support offered by breast cancer nurses may have an impact upon sexuality and body image disturbance; or that this support (by women for women) diffuses concerns that

¹⁰These are both US studies and early, often immediate, reconstruction is encouraged and normal practice.

women may have in this area. A consequence is that the women no longer bring sexuality and body image concerns to the attention of medicine and therefore it falls outside the medical 'gaze' and it is absent from the discourse within client-doctor consultation. A second effect is that if it is no longer a medical problem then there is no imperative to examine it further through research other than as a subset of quality of life.

In the UK over the last 15 years there has been a large increase in the number of clinical nurse specialists (breast care nurses) employed to support individuals, predominantly women, through the experience of breast cancer. Estimates in excess of 250 - 400 nurses¹¹ are currently employed in supportive roles (Stewart 2000). Arguably in the UK professional psychosocial support in cancer care has increasingly become the domain of nursing (plus other non medical professionals such as clinical psychologists, non statutory agencies, and self help groups). More pertinently in the case of breast cancer it has become the work of specialist breast care nurses. Therefore it seems unjustified simply to accept that the problem has diminished or disappeared but to examine breast care nurse - client interaction to identify the nature and scope of that support, if it exists, and its efficacy. What may no longer be evident in research activity or part of the labour of medicine may remain problematic and a significant aspect of the work of breast care nurses. There is some evidence that suggests that these issues are sometimes perceived as emotional territory by doctors and it is the domain of breast care nurses to relieve the emotionality of the doctor-client encounter by removing the woman or taking steps to reduce expression of emotion (Alderson, et al. 1993). This probability holds some currency as the standards of care developed by the RCN Breast Care Society (Royal College of Nursing 1994) include psychological support and body image disturbance and the recently published textbook for breast care nursing (Denton 1996) has chapters covering aspects of psychological and sexuality dimensions with strategies for working with women experiencing difficulties in these areas. However it may be that

¹¹ It is very difficult to gain an accurate picture as there appears to be variation in roles and responsibilities and no central registry

breast care nurses have constructed their own understanding of the experience from their work with women. In this thesis I believe I will shed considerable further light on this.

The influence of cancer policy

A number of policy documents have been instrumental in providing the necessary impetus to the improvement of breast cancer services in the United Kingdom. These are the Forrest Report (Forrest 1986), the Calman-Hine Report (Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales 1994; Department of Health 1995), and Improving Outcomes in Breast Cancer (Cancer Guidance sub-group of the clinical Outcomes Group 1997). The Forrest Report advocated the establishment of the NHSBSP whereas Calman-Hine proposed a national structure for service delivery for cancer patients in general of which screening programmes form a part.

The Expert Advisory Group were given the task of producing an “outline for the direction in which cancer services in England and Wales should be developed” (1994: 4) and produced a consultation document (Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales 1994). The subsequent report (Department of Health 1995) was based on the evidence collected through the consultation exercise and analysis of documents. The context of the report was the immense cost exerted by the nation’s cancer burden in terms of death and disability, as well as an estimated six percent of the NHS budget. The Health of the Nation (Department of Health 1992) set out cancer targets but it was considered doubtful whether these were attainable without a reconfigured infrastructure. Also the increased awareness, and media coverage of the considerable national variation in cancer incidence, availability and consistency in services and treatment(s), reported consumer dissatisfaction with provision, and the “political profile of cancer” (Thames Cancer Registry 1994:1) made action necessary. The consultation report (Expert Advisory Group on Cancer to the Chief Medical Officers of England and

Wales 1994) also recognised that equity of access to cancer services was to be an underpinning principle of any restructuring process. At that time there was an increased awareness of the “substantial inequity in cancer survival, which may be partly due to inequity of access to treatment” (Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales 1994:1).

The Calman-Hine report proposed three levels of care. The first level, primary care was described as “the focus of care” (Department of Health 1995:7) and particularly important for ensuring appropriate referral to Units and Centres, and follow up to “ensure the best outcomes” (Department of Health 1995:7). The second level, designated cancer units within district general hospitals with facilities and expertise to manage patients with common cancers. The third level, designated cancer centres to provide expertise in all cancers including common cancers for the local population and by referral from cancer units for less common cancers. Cancer centres would provide specialist diagnostic and therapeutic services including radiotherapy. Cancer registries were also to have an important surveillance role “through their ongoing registration of a comprehensive data set on all patients” (p8) in order to “monitor and audit service performance’ (Department of Health 1995:8). Cancer registries therefore ‘ provide unbiased, population based estimates of survival.....and examine variation in cancer services and alleged clusters of cancer” (Quinn and Allen 1995: 1393).

Cancer units would form part of an integrated part of hospital provision in order that the full range of services could be provided i.e. diagnostic support from pathology. It was envisaged in the report that specialists (most often surgical specialists) in specific common cancers (breast, colorectal, lung, genito-urinary etc.) would lead teams which would be multidisciplinary in make up. It was viewed that this was not: “likely to change in the foreseeable future” (Department of Health 1995: 9). The report stressed that surgical sub-specialisation “in a particular anatomical area” (Department of Health 1995: 10) was essential and volume of work would need to be sufficient to justify seeking unit status for a particular cancer. The report did not

at that time indicate what constituted appropriate volume. The more recent BASO (1998) guidelines estimated a district general hospital serving 300,000 population¹² would generate between 180 to 250 new cancers per annum and require input from two consultant surgeons. Calman-Hine also proposed a system whereby cancer units and centres underwent an accreditation process to be granted unit status for specific common cancers and centre status. This process was to be repeated regularly (three yearly) to assess ongoing development of service provision. The cancer unit would have a lead clinician to “organise and co-ordinate the whole range of services provided within the Cancer Unit” (Department of Health 1995:10).

Non-surgical oncological (either physician or radiotherapist) input was also proposed as an essential element of service provision. They should, according to the report, practise within a Cancer Centre as well as the Cancer Unit. The report recognised that sub specialisation within medical oncology might in practice mean different individuals providing different parts of the medical oncology contribution to Cancer Units. The report also stressed that wards and outpatient clinics catering for cancer patients should be planned and led by oncology trained nurses and that nursing staff should have access to appropriate specialist nurses. These could be nurses with site specific expertise as in breast care nurses, have specialist skills often associated with cancer treatment as in chemotherapy administration, or expertise associated with specific patient problems for example lymphoedema specialists.

Implementation of the Calman-Hine recommendations has been ongoing since 1995 and the review processes through accreditation of units and centres and evaluations have created momentum and scrutiny. More recently a deluge of policy, guidelines, and standards have been published which inform and guide a national cancer strategy (NHS Executive 2000a; NHS Executive 2000b; NHS Executive 2000d; Department of Health 1997d; Cancer Guidance sub-group of the Clinical Outcomes Group 1997; Department of Health 2000a; Department of Health 2000b). An

¹² This estimate would include consultant contributions to a breast screening unit. Whereas some designated cancer units only have one designated breast surgeon.

interesting feature of all recent documents designed to guide practitioners is that the medical role is clearly defined with performance indicators whereas that of other health workers including nurses is often implicit and far less clearly delineated.

Nurse specialism and the breast care nurse

The increasing specialisation of health care professionals in cancer care has also been apparent in terms of proliferation of nursing roles. The first breast care nurse specialist posts emerged in the 1970s (Tait 1996). These nurses were predominantly based in hospital settings and their main activity related to care and support of women around diagnosis and initial treatment for primary breast cancer. Unlike many other nursing roles breast care nurses have been subjected to research to examine their efficacy in assessing women for psychological morbidity (Maguire, et al. 1980a; Maguire, et al. 1982), their role in information giving (Suominen 1993) and more recently efficacy in comparison with providers of psychological support (McArdle, et al. 1996), and nurse-led follow up of women following primary treatment for breast cancer (Garvican, et al. 1998). This concentration of scrutiny on two aspects of the role – information and psychological support - has been suggested as unduly narrow and partly responsible for fragmentation producing poor role definition (Poole 1996).

Breast care nurses are one of the few clinical nurse specialists who can lay claim to having a research base for their practice (Maguire, et al. 1980a; Watson, et al. 1988). Moreover Tait (1994/5) found that her respondents were familiar with that evidence, although she made no claims that this meant breast care nurses were effective consumers or users of research evidence. Maguire (1980a) in a randomised study where women who had undergone mastectomy either received counselling from specially trained nurses (n=75) or experienced ‘normal’ care (n=77) found a reduction in psychological morbidity in the counselled group. Although as pointed out by Watson et al (1988) the reduction in psychiatric morbidity was achieved

following referral to psychiatrist not as a result of therapeutic intervention by the breast care nurses.

Whereas Watson et al's own study of forty women who had undergone mastectomy randomised to breast care nurse intervention versus 'normal' care found the group counselled by a nurse specialist were significantly less depressed at three months (Watson, et al. 1988). There were however no significant differences between the two groups at twelve months following surgery. They concluded that the intervention may well have an effect in terms of early resolution of mood state and adjustment. The authors suggested that counselling beyond the initial post-operative period was important and this "seemed crucial in establishing a trusting and knowledgeable relationship between the counsellor and her client and provided the foundation for their continuing relationship" (Watson, et al. 1988: 29). Average counselling interventions undertaken by the breast care nurse in that study were ten to eleven, with a range of between two to sixteen interventions, occurring throughout the year following surgery.

More recently McArdle et al (1996) compared two hundred and seventy two women who consecutively presented for treatment for primary breast cancer. The women were randomised to receive counselling from a trained nurse or support offered by a voluntary organisation. The researchers deemed that eliciting informed consent would introduce bias thereby invalidating findings and therefore did not seek permission from participants of the study. The nurse counsellor also collected and collated the data from patients at four assessment points (one, three, six and twelve months following surgery). The nurse offered pre operative counselling including information about impending surgery and subsequent further treatment. She offered a joint interview with the woman's husband and relatives. The nurse saw patients at subsequent outpatient clinic appointments and was available for telephone consultation. The group receiving support from the voluntary organisation received an introductory leaflet, were approached by a counsellor following discharge from hospital. Women received either or all of the following based on counsellor

assessment: telephone or postal contact, one to one counselling sessions, or group meetings. A significant reduction in psychological morbidity in the breast care nurse group was reported, and only two women were considered to need referral to a clinical psychologist by the nurse. No information was given about referrals in the voluntary support group.

These three studies despite obvious methodological weaknesses in terms of sampling, bias, and in the last study ethical concerns, do present some evidence in support of the efficacy of breast care nurses to provide psychological assessment and support. The most extensive work to date exploring the range of breast care nurses work was undertaken by Tait (1996). This study attempted to draw together a personal autobiographical account from one of the pioneer UK breast care nurses and a large mixed method study, involving semi structured interviews (n=108), documentary analysis of records, psychometric testing and estimation of job satisfaction. She described her typical participants as:

“The ‘typical’ breast care nurse was hospital based, but also worked in the community, was employed at an H grade, has been in post 4 years, had 5 O’levels, 1 A’level, lived with a partner, had 2 children, drove seven miles to work and was aged 43 years”

(Tait 1994/5: 4).

The consensus of the participants in her study was that the nurse-patient relationship was central to the role moreover filling “existing gaps in the support available to patients” (p4). She intimated that the breast care nurses espoused the use of a holistic supportive model to underpin care. This involved “valuing patients, connecting with them, ‘doing’ for them and finding meaning with them” and she claimed there was “strong identification with being women helping other women” (p5).

Her other findings presented a picture of well-meaning women under pressure with limited resources and little financial or management support. However, many of the nurses themselves appeared to show little commitment to increasing their knowledge base or undertaking education or training in cancer or breast cancer. More usually

her participants indicated that they wished to advance their communication or counselling skills in preference to enhancing knowledge of the disease. Perhaps it is best to locate Tait's (1996) work in its historical context, although reported immediately before the Calman-Hine Report (Department of Health 1995), much of the field work was undertaken during the early 1990s, a period characterised with free market economics and stringent control on service development. These factors could have been influential in determining the rather limited aspirations of many of the participants described by Tait. Nevertheless it does provide a very valuable benchmark to contrast more recent profiles of breast care nurses. However another area worthy of some consideration in the trends associated with evolving nursing roles in the UK.

Much of the UK literature concerning clinical nurse specialists frequently commences with a North American definition and at some point in the commentary discusses the shortcomings of the home grown variant of the role. This creates a false impression of inferiority as the educational preparation of nurses both at pre qualifying and post qualifying levels between the US and UK are very different as is the length of history of the discipline within the higher education sector. Moreover it assumes award titles i.e. bachelor, masters and doctorate constitute a standardised kite mark of commensurate level and content of study and programme duration irrespective of where the education was undertaken. The range of academic level, curriculum content and expectations in terms of capability of 'product' is considerable just across those courses that carry the English National Board for Nursing, Midwifery and Health Visiting (ENB) branding (Langton, et al. 1999). As Stewart (2000) points out the ENB A11 Specialist Breast Care¹³ course is currently offered at both undergraduate intermediate (level 2) and advanced (level 3) as well as masters level albeit often as a part of broader education package. This range does however present difficulties when attempting to establish a baseline of knowledge and competence underpinning a specialism.

¹³ Considered the minimum standard of education for breast care nurses (Royal College of Nursing 1994)

Castledine (1995) characterises this as a narrowing of clinical focus balanced with gain of an in depth knowledge and skill of the specialism. Most accounts of traits of clinical nurse specialist postholders suggest that they are both highly skilled and knowledgeable. Yet the level of educational preparation to underpin that knowledge, or nature or length, of clinical experience necessary to acquire skills to undertake the specialist role remains unspecified (Bamford and Gibson 1999) and ambiguous (Bousfield 1997). This has become even more clouded with the confusion associated with nurse specialism, advanced practice, and more recently the development of the consultant nurse. The policy direction outlined in "Making a Difference" (Department of Health 1999) proposes a new framework for nursing ranging from health care support workers to consultant practitioners. The latter are expected to combine "leadership, consultancy, educational, research and service development functions" (Department of Health 2000a:11). All these functions have been attributed to nurse specialism in earlier literature (Storr 1988; Sparacino 1992; Miller 1995).

Most recently Stewart (2000) presents the following list as components of the breast care nurses role: education, advocacy, psychological support, research and professional autonomy. This she suggests should be underpinned by graduate level education and preferably breast care nurses should be "working towards a masters degree" (Stewart 2000: 61). This linkage of nurse specialism with graduate level education has been affirmed in the recently published cancer nursing strategy (Department of Health 2000a) for registered nurses who need to develop specialist skills or have a cancer specialist qualification. Moreover the notion of "teams led or supported by senior registered practitioners" (p10) has appeared and these individuals "would be working towards or have achieved specialist qualifications at masters level" (p11). These nurses would be recognised as functioning at a higher level of practice (United Kingdom Central Council for Nursing Midwifery and Health Visiting 1999). In effect a career structure is emerging which locates nurse specialists within a range in contrast with the previously quite narrow definition.

This may well reflect the demands of health care delivery and the professional and academic changes occurring in post registration education. Nevertheless it does present a problem in terms of the public, and in respect of this study the woman with breast cancer, namely that a title may reflect different levels of expertise, academic achievement, and knowledge. Therefore the level of support or rather expertise to underpin support may be variable. This of course is based on an assumption that continuing professional education does make a difference which has not as yet been sufficiently demonstrated in the field of cancer care (Langton, et al. 1999) but work is in progress to explore this assumption (Watson, Porock et al. in progress).

Conclusion

In this section I wish to draw together the background information presented into some cohesive context on which the subsequent chapters rest. Breast cancer is without doubt a major health problem and the impact of the disease upon women can exert an immense burden both in the diagnostic and treatment phases and subsequently for those women in whom disease recurs. It has been argued, through the analysis of policy, that cancer services in the UK have historically been poorly organised. Patchy availability of specialist expertise, some quality assurance difficulties associated with the NHSBSP, and low levels of resourcing, have resulted in a less than optimal level of service delivery. The result has been demonstrated as poor performance of the UK, in statistical terms, in comparison to other countries in Europe and North America. Various policy changes starting with the implementation of the Forrest report (Forrest 1986), followed by Calman-Hine (Department of Health 1995) and most recently the modernising agenda outlined in The NHS Cancer Plan (Department of Health 2000b) have already been shown to be having an impact. Nevertheless the statistical profile of breast cancer, incidence, five year survival and mortality, fails to fully recognise the human cost, the burden, this disease places on the nation (Alderson, et al. 1993). The actual experience of diagnosis and cancer management, whether ultimately curative or palliative, are recognisably demanding for women. Some of these demands include difficulties

associated with altered sexual functioning, body image disturbance, anxiety and depression. These side effects of treatment can be for some women demoralising and at worst the cause of severe mental ill health.

The breast care nurse has developed as a specialist role to provide support for women through the experience of breast cancer. There remains debate concerning the nature of nurse specialist practice in general and disparity across the UK in terms of educational preparation to provide the knowledge and skills of practitioners. Nevertheless there does appear to be a consensus that supports the role of the breast care nurse and further role development of specialist nurses in cancer care (Department of Health 2000a).

The efficacy of the role of the breast care nurse has been in part supported, albeit by weak research evidence. This criticism highlights the need for further work in order to examine the work of breast care nursing both in terms of efficacy and also to elucidate the nurse–patient relationship within the context of breast cancer. The remainder of this thesis is an attempt to contribute to the understanding of work undertaken by breast care nurses with women who have, and who have had, breast cancer.

CHAPTER 3

METHODS

Introduction

This chapter will provide an overview of the research design from original conception to completion. This description will locate the work in terms of its theoretical antecedents and the decision making process inherent in undertaking a research project over a protracted period of time. Some attempt will be made to weave the account with theoretical discussion relating to methodological concerns that informed the development and delivery of the project. Ethical issues will be considered within the context of the issues raised by specific aspects of research process not in a separate section within this chapter.

Denzin at the beginning of “The Research Act” (Denzin 1989: 1) proposes that; “The sociological enterprise rests on three interrelated activities: theory, research and substantive interest”. He then proceeds to present a convincing argument outlining why dividing these activities without due concern to their integral nature. That is theory cannot be divided from its means of production namely research, research is best seen within the theoretical presumptions underscoring the process, and “substantive interest” is sparse if not rooted in theoretical discipline and robust research activity. This thesis is my attempt to deliver on that challenging enterprise although it makes minimal claims to being part of the ‘sociological enterprise’. I intend to present the work in a way which demonstrates my manoeuvres through the proving ground of the postgraduate endeavour and more importantly offer a contribution to understanding the complexities of the breast cancer experience.

The research perspective

The starting point for this research project was in retrospect an ill defined but instinctive feminist position based upon a number of assumptions. Firstly, management and care delivered to women with breast cancer is primarily a medically driven, and therefore patriarchal activity, with little concern given to the

individual women's agenda, emphasising traditional male-female dualism (Batt 1994).

Secondly, medical intervention explicitly objectifies the individual which separates the person from body. This mind-body dualism (Costain Schou and Hewison 1999) enables the physical aspects of the disease and its management to be compartmentalised; moreover, it encourages the psychosocial burden to be conceptualised as 'behaviour' and therefore stripped of its social, political and institutional contexts. This was exhibited in the uncritical allegiance to radical surgical removal of the breast and lymph nodes which until relatively recently was considered best practice despite mounting evidence to the contrary (Baum 1988; Yalom 1998). Moreover that evidence had been ignored and suppressed by those, such as surgeons, with a vested interest in maintaining their territory (Fox 1992; Batt 1994).

Thirdly, that women had been oppressed through the continued use of inappropriate medical treatment and had little knowledge or voice to change practice due to the gendered differential in power throughout society but explicit in the patient-doctor consultation (Oakley 1980; Foster 1995). This is evidenced in the psycho-oncological preoccupation with fitness of women to participate in decision making (Ashcroft, et al. 1985; Morris and Royale 1987; Morris and Royle 1988; Cotton, Lockyer et al. 1991; Fallowfield, et al. 1994a; Beaver, et al. 1996).

Fourthly, not only were/are patients oppressed but so were/are nurses within the health care system and both were/are thwarted from achieving their own projects by both medical practice, and increasingly in the case of nursing, managerialism. Moreover the breast care nurse's axiom is to ameliorate the onslaught of medical intervention by humanising (Howard and Strauss 1975) the patient's experience and this could only be partially achieved in a hierarchical relationship rather than in partnership with the medical team.

This emerged from a partial understanding of the context of breast cancer care, evolved from my socialisation as a nurse, education, and reading. Although I accept that all understandings are partial this one could be criticised for being highly selective, rather unfocussed, and a relatively guileless position. It did however locate the work within a feminist paradigm but failed to offer a solution to what has been one of many problem(s) to beset this work namely what was/is my theoretical framework for the study (epistemology)? What was my interpretative basis (methodology)? What sort of research was I doing (method)? I therefore intend to set out where this project has come to rest in terms of location within theory, within methodology, and the research activities undertaken.

This particular difficulty with location and definition is not unique to this project and is a criticism frequently levelled at qualitative nursing research. Perhaps manifest in the long raging and polarised debate associated with qualitative versus quantitative research in nursing (Corner 1991), criticisms of method slurring (Baker, et al. 1992; Crotty 1997), and criticisms of naive realism (Porter 1993) have driven the numerous attempts to theorise the nature and unique contribution of nursing (Taylor 1993) for example; Orem (1991), Watson (1988), Peplau (1988), Rogers (1970), and the British: Roper, Logan and Tierney (1990).

An interpretative approach

Nevertheless I have come to recognise that my research sensibility has some sympathies with an interpretative tradition and is based around a loose cluster of propositions with three basic assumptions. Firstly, whilst recognising human life has a biological basis, it is known and understood through social life as individuals through interaction with others produce their own understanding of social reality. Secondly, individuals are able to self reflect and “engage in minded, self reflexive behaviour” (Denzin 1989: 5). As behaviour takes place in the company of others, yet can be rehearsed prior to interaction and or re-visited following it, it is potentially limited by the constraints others put on us (Annandale 1998). Further we learn to

understand through interaction and are called upon to be “artful in our everyday lives” (Annandale 1998:21) and engage in a process of “negotiation, impression management, and meaning creation” (Fine 1993:63). Moreover interaction is said to be symbolic as it involves the manipulation of symbols predominantly in the form of words and language. Nevertheless whilst I remain sympathetic to that position it appeared limited in two ways. It assumes the individual has control in his or her social life and fails to recognise the effect determining constraints such as economic factors or other influences such as gender, class, race, or disability may have upon social reality. Nor does it recognise “that the social actors that populate their theories have bodies that are integral to human existence and thus a central consideration in any theory” (Freund 1988: 840).

Yet is it enough to lay claim to ‘doing feminist research ‘ as if there is one common feminist vision? Some justification of affinity to the label is no doubt warranted. Annandale (1998: 63) writes: “all feminisms share an understanding that patriarchy privileges men by taking the male body as the ‘standard’ and fashioning upon it a plethora of valued characteristics” and the “major task of feminism has been to question this elision between sex and gender by showing that gender is socially constructed; the social processes that construct the female body as inferior and that discriminate against women (and favour men) can then be identified and acted upon to improve the conditions of women’s lives, including their health”. However there are myriad positions expressed as feminist theories and increasingly the use of the term “feminisms” is used to reflect that variety. Authors have attempted to categorise the strands within feminisms such as: liberal, radical, marxist, post modernist (Annandale 1998), alternatively liberal, marxist, radical, psychoanalytical, socialist, existentialist, postmodern (Tong 1989) or even empiricist, standpoint and postmodern (Schwandt 1997). The absence of a clearly defined account of what are feminisms has been argued as strength and illustrative of the diversity of women and commitment to healthy debate.

The problem facing me was that I could not specify the brand label within feminisms in which this work fits. It began couched in terms of binary oppositions with women being other than and therefore less than man which I now understand to be “dichotomous epistemology which dominates modernist thought” (Hekman 1999). Yet I did not wish merely to undertake an examination of the work of breast care nurses with women solely in terms of gender related work, or leave the feminism implicit rather than explicit, resulting in the researched becoming as if a product of their status and, in so doing, strip the researched from the social reality in which their lives take place. The purpose of this study was to uncover the meaning(s) women (patients and breast care nurses) hold of the breast cancer experience with particular emphasis upon the sexuality and body image aspects of that work. In order to access those meanings associated what can be broadly categorised as relating to sexuality and body image various other questions would need to be addressed such as: How did, if at all, women make sense of the impact of breast cancer on their lives, their bodies, their relationships? How did they bring their real world reality of breast cancer to the clinical setting? How does the delivery of care influence the impact of breast cancer on women’s lives in general and on the personal and intimate aspects of their lives in particular? What if anything is the contribution of breast care nurses to women’s experience of breast cancer in general and specifically in relation to sexuality? Do all breast care nurses do similar sorts of work or is there wide variation? Does the conceptualisation of sexuality and body image in the psycho-oncology literature bear any congruence with that as experienced by breast care nurses through their work with women? Or, more importantly, does it mirror the experience of the disease and its management as the women themselves understand it? These questions and many more generated by the research journey have remained a central aspect of the work and form the substance of the endeavour; nevertheless, the project as delivered is a different product from that as originally conceived. These questions have in fact been the basis for the iterative nature of data collection and analysis, while recognising those questions are explicitly contrasted against an assumption that contemporary breast cancer care as delivered in the English NHS is structured, constituted and mediated through the vision of a “ruling

gender” (Hartsock 1997: 153). Nevertheless that does not obviate the need to give due care and attention to how the particular, the work, the interaction between breast care nurse and woman with breast cancer has been examined through this project and has been interpreted within the context of that foreground. In effect how does this eclectic multiplicity of theoretical perspectives fit and bring coherence to the constituted research aims, *ultimate research design, and analysis?*

Starting point

As discussed in the introduction to this thesis I have been involved, if somewhat peripherally, in the education and training of breast care nurses since the late 1980s. My interest was spurred in part by my involvement in curriculum development and on an ad hoc basis the delivery of a post registration English National Board programme of education designed to serve as the required education for specialist breast care nurses (ENB A11). I was aware that the input intended to inform potential, and actual, breast care nurses about body image and sexuality was minimal. Moreover that deficit was reflected in other programmes elsewhere in England and probably nationwide. On the basis of that knowledge and the ‘psychological morbidity’ associated with breast cancer treatment the justification for undertaking the work was apparent. A separate but important consideration was the nature of nurse specialism or rather the work clinical nurse specialists do which provides through interaction the potential to understand the patient (client) experience. This in conjunction with an assertion offered by Street (1992) about the spoken nature of nursing knowledge framed the original research design. These strands led to the formulation of the following research aims:

1. To assess knowledge and attitudes of breast care nurses in relation to sexuality
2. To explore the knowledge and understanding gained through clinical practice by breast care nurses in their work with clients in relation to sexuality
3. To explore with women with breast cancer their experiences and the impact of the disease on their construction of self in relation to sexuality

4. To identify the congruence/dissonance between the client's lived experience and the experience of breast care nurses working with them
5. To identify implications for practice and/or education and training of breast care nurses and others working with this client group.

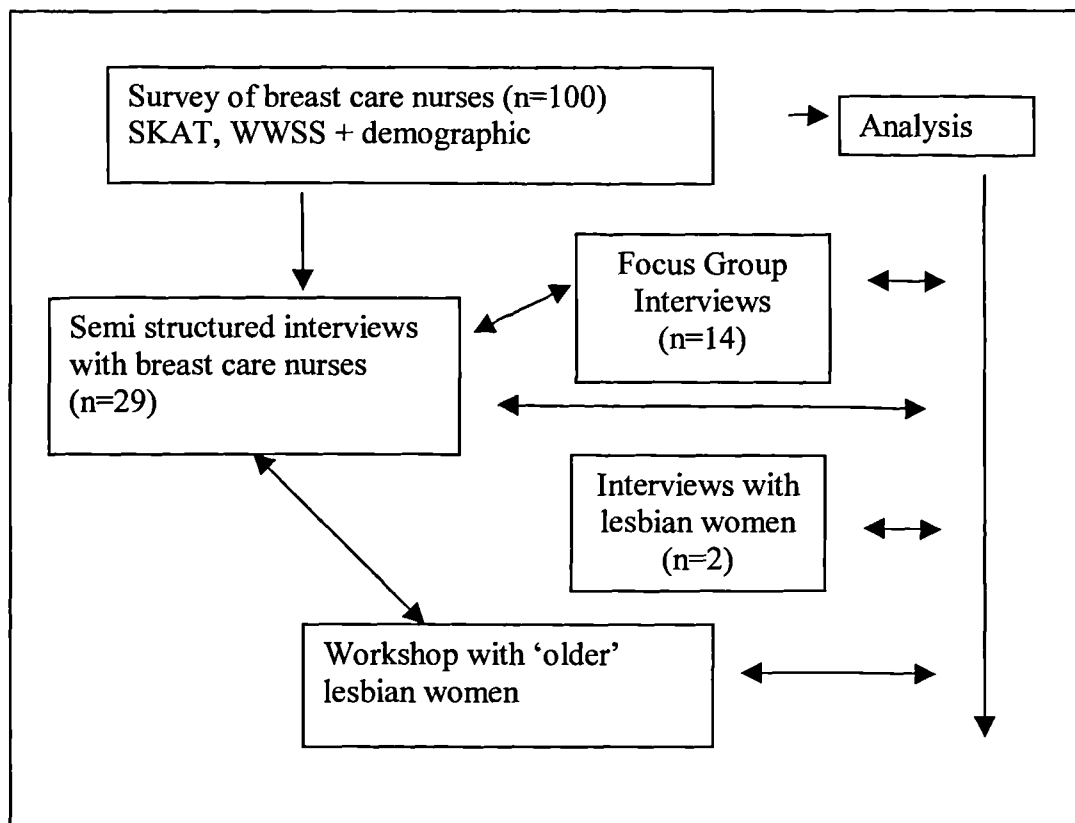
This was to be achieved by a three phased sequential approach see Table 3.1.

Table 3.1: Overview of proposed research design

Phase	Proposed Data Collection Strategies
Phase I	Postal survey of breast care nurses using a modified Sex, Knowledge, & Attitudes Test [SKAT] (Lief and Reed 1972) and a modified Williams-Wilson Sexuality Survey Instrument [WWSS] (Wilson and Williams 1988) with some additional demographic questions.
Phase II	Semi-structured interviews with breast care nurses using critical incident technique (Cox et al,1993)
Phase III	Interviews with women who had undergone treatment for primary breast cancer

The phases were planned to be undertaken sequentially with each phase informing the next. It was envisaged the survey would provide areas to be expanded in the interviews with breast care nurses. Likewise the interviews with patients would be compared with the breast care nurse interviews for congruence. Ultimately the analysis of phases II and III would produce data that could inform curriculum development and/or illuminate gaps in current understanding. All phases were to assist in highlighting gaps, omissions and areas for curriculum development thereby meeting aim 5. The research project as completed deviates from that design. After completion of Phase I in response to the findings (see chapter four) an unexpected challenge emerged – the (in)visibility of lesbian women in breast cancer- that became a focus for the work. A diagrammatic representation of the revised research design is shown in figure 3.1.

Figure 3.1: Diagrammatic representation of research study



The sequence in which the work was undertaken therefore was as follows: The survey was undertaken and completed 1995 to 1996. The focus group interviews with women with breast cancer were undertaken in autumn 1997. The interviews with breast care nurses were undertaken during the autumn of 1998 and spring of 1999. The two interviews with identified lesbian women were completed in January and February 1999 and this was followed by my attendance at a workshop event at the invitation of a group of lesbian women where selected findings were presented and discussed in October 1999. Data analysis has been concurrent with data collection and a range of literature has been explored including autobiographical and biographical literature to inform the iterative data analysis style adopted.

Why mixed methods?

This study was designed using a variety of research strategies (survey, interviews, and focus groups) in order to effect the research aims. The purpose was designed to layer the understanding each approach delivered in order to produce a more complete representation of the work of breast care nurses with women with breast cancer. Reinharz (1992) in her authoritative text sees no difficulty with feminist researchers using multiple methods; moreover, she suggests they “enable feminist researchers to link past and present, ‘data gathering’ and action, and individual behaviour with social frameworks” (p 197). This use of multiple methods is known as triangulation - “the combination of methodologies in the study of the same phenomena” (Denzin 1989:234) and is a strategy to bring “corroborating evidence from different sources to shed light on a theme or perspective” (Cresswell 1998: 202). Triangulation can take many forms – data, investigator, theory, and method. Data triangulation involves using, and as Denzin suggests searching for, as many data sources that can shed light on a particular phenomenon and suggests theoretical sampling (Glaser 1967) as a form of data triangulation. In this study the participation of breast care nurses, women with breast cancer and lesbian women with breast cancer and ultimately a group of lesbian women were used to effect data triangulation and the examination of what came to be seen as ‘lesbian women’s (in)visibility’ was a form of theoretical sampling. Investigator triangulation is defined as when more than one researcher participates in data collection. Within this project I had assistance in managing the focus groups interviews undertaken with women with breast cancer. That involvement could not however be construed as investigator triangulation. The conduct of the focus groups will be discussed later in this chapter. Theoretical triangulation is where competing theory is used to assess its utility against the data and vice versa (see Johnson and Webb 1995). Both forms of methodological triangulation were used in this study: ‘Within method’, as different strategies are used to examine the same type of data, as in this study by the use of two instruments (SKAT and WWSS) in the survey; ‘between’ or across method’,

where dissimilar data collection strategies are utilised to illuminate the same phenomenon seen in the use of individual and focus group interviews and literature.

Whilst Denzin states that “sophisticated rigor” best describes those researchers “who employ multiple methods, seek out diverse empirical sources, and attempt to develop interactionally grounded interpretations” (1989: 235). Reinharz (1992: 197) suggests the aim underlying the use of multiple methods is a reasoned choice related to the “intellectual, emotional and political commitments” of the researcher and facilitate responsiveness to participants. Nevertheless triangulation is not without its critics. Silverman (1985: 105) argues that “within method triangulation” that is the use of for example of observation, interviewing, field notes, data sources may be non contentious and moreover act as a reminder of “the partiality of any one context of data collection”. However, he goes on to develop his critique of triangulation by arguing that allegiance to its use as a form of confirmation of evidence is an assumption of a positivistic frame of reference which is contrary to the notion of the ‘situatedness’ of data within its social contexts. In effect using data to confirm or verify a reality assumes there is only ultimately one ‘true’ reality which is verifiable. Other criticisms which have been levelled at triangulation include non comparability of the ‘unit of measurement’ i.e. it is impossible to compare in a meaningful way the product of an attitudinal questionnaire and a narrative extracted from a semi structured interview. Arguing that it is like comparing conceptual apples and pears on the assumption they are the same. Yet is it problematic? As the different approaches bring different approximations and taking the analogy of apples and pears bring different flavours and textures to an understanding of social reality. Some would take the view that the problem of philosophical incongruity, namely that the inherent tensions between positivism based on an assumption of an objective truth irrespective of context, and interpretative traditions which make no claims to one reality and recognise the situatedness of knowing are too great (Johnson, et al. 2000).

My defence of the use multiple methods in this study was primarily to use the appropriate tools for the defined tasks. Secondly it was envisaged at the outset that this project was likely to be of a long duration. I recognised that the context of breast care nursing would change over the period of the study and the selected methods had to be capable of capturing the shifting nature of health care whilst being responsive to emergent issues within the data (Reinharz 1992). Finally the paramount issue for me as a developing researcher was a commitment to the participants and data rather than adherence to a particular partisan position.

Survey of breast care nurses

The research aim of this phase of the project at outset was to establish the sex knowledge of breast care nurses and attitudes to sexuality held by those practitioners. This was to be achieved by the administration of a postal self report instrument made up of two existing tests modified for this study namely the Sex Knowledge and Attitudes Test (SKAT) (Lief and Reed 1972) and the Williams-Wilson Sexuality Survey (WWSS) (Wilson and Williams 1988) . Two items were added eliciting demographic data and experience with patients and their partners of a non-heterosexual orientation to the WWSS test. This was done, as will be developed further in chapter four, as it has been reported that nurses in general (Lief and Payne 1985; Webb 1987b), and cancer nurses (Fisher and Levine 1983; Fisher 1985; Wilson and Williams 1988) specifically, have poor knowledge in relation to sexuality and avoid or feel uncomfortable initiating discussions with patients about the impact of illness upon sexuality and sexual functioning. The justification for this phase of the project was that an evaluation of a group of specialist nurse practitioners who work with a client group with a well established morbidity associated with sexuality and body image problems would provide a useful insight and a foundation for the later aspects. This rationale along with the benefit of using already developed and tested instruments far outweighed the value of designing a questionnaire specifically for this study. This approach had the added utility of

producing a comparison of results of this survey with other UK studies who used the SKAT instrument with general nurses working in acute adult settings (Lewis and Bor 1994) and nurses specialising in gynaecological care (Webb 1987b). Further the use of WWSS (Wilson and Williams 1988), which was developed to be administered to cancer nurses, might provide greater specificity. The additional benefit of this replication was to establish the reliability and validity of SKAT over time and the transferability of US developed instruments (WWSS) for use in the UK.

The sex knowledge and attitude test (SKAT)

Permission to use the SKAT instrument was obtained from Dr Lief (co-author) along with rights to reproduce the questionnaire. The original instrument had three sections: attitudes, knowledge and experience (see appendix 1). The attitudes section has thirty-five item likert type statements with a five point scale graded from strongly agree through to strongly disagree. These are forward or reverse scored on a one to five scale according the user's manual (Lief and Reed 1972), then sub classified into attitudes to heterosexual relationships, sexual myths, autoeroticism (masturbation) and abortion. A score can then be determined of the total or sub set correlated to a gradient from conservative attitudes (low score) to liberal ones (high score). The SKAT Knowledge section has seventy-one true or false items that were designed to establish the respondent's knowledge of physiological, psychological, and social aspects of sexuality. In this study amended attitudes and knowledge sections were used in the both the pilot and main study (sixty-seven items) and the sexual experience section was omitted. The amended version used in this study can be seen in appendix 3.

The wording of some items was modified, as the language might have been alien or misleading to an English population. Therefore "physician" was translated to "doctor", "sexual self-stimulation" to "masturbation", "a committee of physicians" to "independent medical approval", "college" to "university", "intercourse" to "sexual intercourse", "nursing" to "breast feeding", "religious devoutness" to

“religious beliefs”, “coital techniques” to “sexual practices”, etc. Some questions were reworded e.g. question 20 “A physician has the responsibility to inform the husband or parents of any female he aborts” became “A doctor who performs an abortion has a responsibility to inform the husband or parents of the woman”. Question 30, a knowledge question, comparing frequency of sexual intercourse of white versus black teenage US women was omitted as I was unable to establish any reliable information on comparable UK statistics. Question 38 relating to artificial insemination by donor (AID) was also omitted as it was considered irrelevant to the study. A further two questions were omitted following piloting (question 31, religion and premarital sex, and question 67, The effects of LSD on sex drive). Lief and Reed (1972:14) claim “high stability and internal consistency as estimated through factor analysis (alpha coefficient) as between 0.71 and 0.81 with one cohort and 0.68 and 0.86 with different cohort across the sub-scales within the attitude element of the questionnaire.

Williams-Wilson sexuality survey

Permission to use and adapt the questionnaire was received from Dr Wilson (Co-author). The instrument has three sections: demographic information, attitudes and practice related behaviour (see appendix 2). Only the attitudes and behaviour sections were used in this study (see appendix 3). Six questions concerned with attitudes specific to paediatric cancer patients were omitted, as they were considered irrelevant to the study as this client group is outside the normal remit of breast care nurses practice. Similarly the behaviour section was edited on the advice of Williams (Wilson 1993) and those questions related specifically to US nursing practices for example “grand rounds” and “educational and staff development programmes” were omitted.

A further area which was added to the WWSS instrument were items intended to elicit information regarding the level of contact, and indication of interactions with lesbian clients rather than clients automatically labelled homosexual. The principle

motivation for these adaptations was a response to a paper given by Platzer and James (1996) and later published (Platzer and James 1997). They argue that there is a need to expand the understanding of lesbian and gay men's experience of nursing care and suggest that the current state of knowledge is based on "hearsay and anecdote" (1997: 626). A harsh criticism claimed by Platzer and James to be directed at work in this area is that it is ungeneralisable opinion voiced by "insiders" and "zealots" (1997: 627) and fails to reflect the range of experiences of gay and lesbian users of health care services. "Insiders" and "zealots" in the context of their work were terms used to describe individuals who had chosen to disclose their sexual orientation and therefore are 'known' to be lesbian or homosexual. "Zealots" are individuals who could be perceived as "having an axe to grind in less academic circles" (1997: 627). They discussed the problems in conducting research when "parading insider status" (1997: 630). Their work however illuminated the context of health care delivery as experienced by lesbian and homosexual individuals which suggested an environment non-conducive to disclosures about sexual orientation.

This 'road to Damascus' moment in the research journey precipitated my exploration of an area not really given anything other than cursory consideration previously. The four part item amended was question 32(i) and (ii a) and b) in Section B - WWSS, asked:

"When caring for a known lesbian or homosexual patient with breast cancer do you discuss aspects of sexuality that relate to having cancer or treatment?"

A "yes" or "no" response was required. This was followed by inquiring if the breast care nurse had ever cared for a lesbian or homosexual patient with cancer (question 32ii) followed by a request for information about their contact with partners of lesbian or homosexual patients. The questions were included without any real estimation of construct validity or item reliability. In the absence of a robust assessment of item reliability or validity it is highly probable that there are a number of design errors in these items. Firstly, the inclusion of both terms, lesbian and homosexual, may have confused respondents particularly in the context of a

predominantly female disease. Whilst one per cent of recorded cases of breast cancer relate to men the likelihood of breast care nurses encountering a known homosexual patient is minimal. In retrospect this might reflect a naive attempt at inclusivity that the expression 'known lesbian or homosexual patient' was adopted. Secondly, it may well be problematic for breast care nurses to engage with partners for a variety of reasons such as they may not accompany the patient to outpatient appointments, may well be at work, or unavailable when the breast care nurse meets with the woman. Thirdly, partners may not perceive the breast care nurse as being responsible for their care and support. Lastly, if present, they may not introduce themselves as sexual partners in their interactions with health care professionals and their presence may themselves be interpreted as a friend or female relative rather than a sexual or life partner. These insights into the problematic nature of the item are of course made with the benefit of hindsight and are discussed in greater detail in chapters four and six.

Demographic information

Seven questions were developed which elicited information on age, professional registration(s), post qualifying education, membership of a special interest group (RCN Breast Care Nursing Society), and clinical grade and job title. The latter two questions were included as there is (anecdotally) reported to be considerable variation across the country in relation to salary scale and job title. It was considered at the design stage pertinent to gain some evidence about these regional variations. A number of participants omitted to complete these questions; and the results of those who did complete the items demonstrated no particularly interesting relationships to other items. It was, in retrospect, unnecessary. As no attempt was made to elicit information about geographical location of respondent, as it was felt that would compromise response, it would have been impossible to correlate grade to geography. This might have provided information about clinical grades being related more to labour market pressures associated with geography than estimation of skills inherent in the job.

Pilot of Phase I

A pilot was undertaken in November 1995. Fifteen questionnaires were sent to nurses working in similar roles to breast care nurses in other aspects of cancer care or to ward sisters/ward managers of designated breast cancer units with considerable experience with breast cancer patients and/or who had undertaken the ENB A11 Breast Care Course. The profile of the respondents who were approached to participate in the pilot is indicated in table 3.2. Ten individuals responded giving a response rate of sixty seven per cent. The questionnaires were not formally analysed but adaptations were made based on feedback from the participants. The covering letter encouraged feedback and two telephoned me with their comments. The consensus was to omit two questions from the modified SKAT instrument but otherwise the response was positive. These two questions were subsequently omitted.

Table 3.2: Profile of pilot sample of respondents

Number	Job Title	Work Setting
3	Ward Sister/Ward Manager	Regional Cancer Centre Breast Unit
3	Ward Sister/Ward Manager	National Cancer Centre
1	Ward Sister/Ward Manager	Cancer Unit (DGH)
2	Ward Sister/Ward Manager	Female Surgical Unit specialising in breast cancer patients
2	Palliative Care Nurse Specialists ¹⁴	Acute and Community NHS Trust
2	Staff Nurses	Breast Unit - Cancer Centre
1	Clinical Nurse Manager	Regional Cancer Centre
1	Information Manager ¹⁵	Cancer Charity

¹⁴ Palliative care nurses are normally part of the extended breast care team and are frequently involved in care and support of the breast care patient receiving care for palliation rather than curative management.

¹⁵ This individual was included in the pilot sample as telephone help lines are frequently used to access information and support relating to intimate and sensitive issues.

Accessing the population

A number of difficulties arose in accessing the population of breast care nurses in England. Since the publication of the Forrest Report (Forrest 1986) which advocated the employment of a specialist nurse for breast cancer patients in every NHS Trust there has been a substantial increase in posts. Many of these are funded, or pump primed for an initial period, by Cancer Relief Macmillan Fund (CRMF), a charitable agency which has been instrumental in developing services in alliance with NHS providers for individuals with cancer. That organisation was unable, or unwilling, to supply me with any detailed information. They were at that time involved in an exercise to identify breast cancer service provision across the UK including nurse specialist posts. This information was not available for the purposes of this project and was published after the survey was conducted (Cancer Relief Macmillan Fund 1996). The directory describes breast cancer services including breast care nurses but does not give details such as numbers of postholders. When published the directory indicated that one hundred and eighty three NHS Trusts in England offered a breast care nursing service and it was estimated that at a minimum that number of breast care nurses were in post and constituted the population.

The RCN Breast Care Nursing Society's professional advisor was approached and proved unable to provide information detailing number of postholders or contact information. There was no central information held by the advisor of membership and it was considered by the society's officers that membership was far larger than the number of breast care nurses in the country. In addition, it was recognised that not all breast care nurses would participate in the organisation therefore any attempt to target breast care nurses via membership lists would be problematic.

After numerous attempts at eliciting an accurate listing of the population of breast care nurses in England two hundred and twenty-one questionnaires (n=221) were sent to an assortment of addresses provided by the Department of Health, an address list supplied by the Yorkshire Breast Care Nurses Organisation and a similar

grouping in the North West and Merseyside. No claims to randomisation or accurate targeting of the population can be made. Lesley Thompson, at that time Chairperson, of the RCN Breast Care Nursing Society (Thompson 1996) considered three hundred and fifty to four hundred as a reasonable estimate of number of postholders at that time and therefore two hundred and twenty-one ($n=221$) can be considered to be a sizeable proportion of the population. More recently Stewart (2000) has given the figure of four hundred postholders.

Administration of the survey

Two hundred and twenty-one questionnaires were mailed along with a covering letter (appendix 4) and a reply sheet (appendix 5). Two envelopes were supplied to allow the completed questionnaire and/or reply sheet to be returned separately. This was done to demonstrate the anonymity of the method of administration and reinforce the claims of confidentiality given to potential informants. It also meant individuals could offer to participate in individual interviews yet choose not to complete the questionnaire. One hundred completed, and four uncompleted questionnaires were returned. The response rate was forty five percent. This compares favourably with a response rate of forty five percent reported by Lewis and Bor (1994) who delivered and collected questionnaires in person from nurses in their work place and the thirty one percent response rate Matocha and Waterhouse (1993) achieved using the US postal service. The reply sheet (see appendix 5) inviting people to participate in an interview at a later, undisclosed date, were returned by forty breast care nurses. Despite the response rate of forty five percent no second posting was undertaken. A variety of factors informed this decision including an assumption that, given the sensitivities of the subject matter, non-response indicated individuals who did not wish to participate. As response was anonymous a repeat posting would have been delivered to both responders and non-responders. This might have been interpreted as profligate and possibly viewed as time wasting by both groups.

One questionnaire was returned with an accompanying letter which suggested the questions were “both deeply personal and provocative” and attested that the use of open-ended questions would have been more revealing. She also suggested that the use of a reply form accompanying the questionnaire (although supplied with a separate stamped addressed envelope for return) impacted upon any reassurances of confidentiality.

I also received two telephone calls from different officers of the same charitable organisation which reflected some concerns that a questionnaire of this nature might impact detrimentally upon the name of the organisation. These concerns were discussed at executive level within the organisation following my description of the project and no further contact was made by either party.

It is in retrospect recognised that the sensitivities of the subject matter of this study to potential informants were possibly not fully considered and this does raise an unforeseen ethical issue. The accepted canon in relation to questionnaire surveys is that non-completion is the indicator of unwillingness to participate (Robson 1995). In effect on receipt an autonomous individual reads the letter, perhaps is interested enough to pursue the questionnaire and makes a decision whether to participate or not. Whether that decision is informed is of course open to debate as is the principle of what in reality constitutes the level and scope of information needed to make an informed decision. However the primary ethical principal of research is that "one should do no harm" with the addendum that participants can knowingly agree to participate even if harmful if they are in full cognisance of the facts. The reasonable basis of the extent of cognisance can be debated *ad nauseum*, but the question whether the receipt of an unsolicited questionnaires contravenes the principal of "no harm" warrants examination. In a recent paper, Platzer and James (1996) suggest that harm may result from receipt alone. There is no evidence the questionnaire caused actual distress however the level of response (45%) could be used as an indication of recipient disinterest at best. It could however indicate that the questionnaires failed to reach the target recipients and the forty five percent response

is in fact a far greater response from those questionnaires appropriately targeted. A second consideration is the complaint I received from a potential participant who deemed the questions "both deeply personal and provocative". I believe the covering letter warned recipients of content in a sensitive but informative manner.

Considering the context, it does seem somewhat surprising that a specialist nurse working with a client group of whom a proportion will encounter difficulties in this area found the questionnaire disturbing and is a telling response.

Analysis of survey of breast care nurses

Data obtained from this phase of the study was coded for statistic analysis using Statistic Package for the Social Sciences (SPSS for Windows 9.0). The initial phase of preparing the data for analysis highlighted a number of omitted answers resulting in a number of incomplete data sets. Robson (1995) suggests there is really no satisfactory way of dealing with missing data. Lief and Reed (1972) suggest in relation to SKAT that this does not necessarily mean exclusion of whole data sets. They suggest data relating to specific attitudinal test scores should be treated separately for each scale (heterosexual relations, sexual myths, abortion and autoeroticism) and therefore the data can be included if the individual scale is complete. These scales should be regarded as ordinal measures. The knowledge section includes items designed for educational purposes and these are excluded for analysis purposes. SKAT was designed to be administered to entire populations¹⁶ but can be used on random samples and then the standard error of the mean is the appropriate calculation to determine how representative a particular scale is of a given population (Lief and Reed 1972).

Wilson (1993) found that some of the items both in the attitude and behaviour scales were not useful as informants either chose not to complete them or the item obtained a low factor loading in the factor analysis. She also reported omitting from analysis

¹⁶ The authors use the term population to mean a group undergoing a programme of study for example a cohort of medical students

those items which were beyond the control of individual nurses although failed to indicate which these were so direct comparisons of reported results is problematic (Wilson and Williams 1988). The results of the analysis are presented in chapter four.

Focus group interviews with women with breast cancer

In 1997, I was invited as part of a northern NHS Trust's quality assurance strategy for breast cancer services to undertake a series of focus group interviews to examine patient satisfaction with service provision¹⁷. Two focus group interviews were undertaken with women participants (n=14) who had either completed or were progressing to the end of the initial treatment for primary breast cancer. The participants had all had access to one of two breast care nurses as part of care management. The women who participated in these interviews were selected and recruited by the breast care nurses working in that NHS Trust from their active caseloads. This was achieved by a verbal invitation followed by a letter confirming date, venue, and brief summary of purpose of the focus groups. The only criteria imposed on the selection process was that potential participants should be understood, based on medical criteria, to be responding to primary treatment at the point when the invitation to participate was issued.

The interviews were held in a small newly furnished and decorated discussion room in the designated cancer unit's facilities. The breast care nurses supplied refreshments. The participants seven in Focus Group 1 (FG1) and seven in Focus Group 2 (FG2) were asked to sit in a semi-circle around a coffee table, which held an audio tape recorder and microphone. The interviews were led by myself (AT) but a colleague (RM) assisted with hotel arrangements and made some written notes to aid analysis. This included mapping out the participants' seating positions and any striking issues that were felt would be pertinent to analysis.

¹⁷ The full citation for the completed report is not included to protect the identity of the NHS Trust

In a short preamble to the actual interview, the participants were informed again of the nature and purpose of the study in order to confirm their agreement to the interview being audiotaped. Assurances were given that names would be omitted from typed transcripts of the interview thereby cleansing narratives. Due to the local nature of the project it was explained to participants that attempts would be made to minimise threats to anonymity however the difficulties with assuring confidentiality were discussed. Information was given about the use of interviews and who would have access to the raw data. Assurances were given that the commissioning agency would not have access to tapes nor full transcripts of the interviews. It is suggested in the literature (Morgan 1995) and from personal experience (Topping and Lovatt 1998) that to achieve optimum group size (six to ten participants) over recruitment is advocated. The breast care nurses approached eighteen women and fourteen agreed to participate. Participants were not asked to sign a written consent form but verbal consent was elicited and recorded on tape prior to the beginning of the interviews. The interviews were audio taped and transcribed verbatim for purposes of analysis. Strategies including names and addresses of organisations and individuals who would be available to offer support and counselling were identified and organised in advance with the commissioners for any participant who became distressed during or following interviewing. This proved to be an unnecessary precaution.

Participants, following brief introductions and discussion about how to make and contribute their experiences to the group, were asked to share their recollections of their journey through the breast care experience to date. They were asked to focus their stories upon their contact with health care providers. Nevertheless the discussions were wide ranging and covered topics such as relationships with friends, family, partners, and in addition a number of issues arose related to work and employment. Kreugar (1995) suggests that focus group research has gone beyond the confines of the white middle class; he stresses the importance of gaining trust and co-operation as ingredients for success. While it is relatively easy to measure co-operation by willingness to participate both by response to the invitation and then by the contribution to the group dynamic, it is more difficult to judge whether trust has

been achieved. Willingness to disclose, and within the context of patient satisfaction almost 'name and shame', might be considered an indication of trust implicit in the participant-researcher relationship. Although that could be a manifestation of some other axe to grind and possibly more related to the experience of cancer and its treatment than indicative of co-operation the free ranging quality of both interviews could be taken as a demonstration of trust.

The audiotapes were initially transcribed and analysis was undertaken using a method based on Kruegar (1994) described as transcript based analysis for the commissioned project. The aim was to produce a detailed and systematic recording of the themes and issues emergent in the interviews relevant to patient satisfaction with service provision and this was subsequently the focus of the report to the funding agency.

After lengthy deliberation and consideration the transcripts which were generated from the original project were re-examined for this project and a secondary analysis was undertaken. This approach known as retrospective interpretation (Thorne 1998) is where a further interpretation is undertaken to examine new or extended questions. This strategy can be seen as problematic for a variety of reasons but most relate to a second researcher coming fresh to a data set. In this instance problems such as the influence of the first researcher on the data collection, the absence of knowledge of context and nuance which could obscure meaning, and an articulation of an auditable decision trail do not apply. In addition the commissioned work was undertaken separately from but during the timeframe of this project and therefore the interaction with the data remains fresh. Nevertheless it remains questionable whether data collected under the auspices of one research design fits with the new avenue of a new inquiry. Other issues relate to ethical dimensions of secondary data analysis. Permission to (re)use the material was sought from the commissioning senior executive nurse of the organisation for use in this project.

The commissioned project was undertaken under the auspices of quality monitoring of cancer services, which is an element of the accreditation process demanded in the post Calman-Hine accreditation of cancer units (Department of Health 1995). Labelled as “quality assurance”, the project fell outside the remit of the local ethics committee. At design stage this was the position adopted by the commissioners on advice from the chair of the local ethics committee. There is dispute within health care about what is constituted as falling inside and outwith the work of ethics committees. Despite government guidelines (Department of Health 1991) there would appear to be wide diversity in the practice of ethical committees and boundaries of ethical committee scrutiny (Blunt, et al. 1998). Some would take the position that it is for the local research ethics committee (LREC) to scrutinise all proposals which could be deemed research whereas others divide research proposals from audit and quality assurance prior to committee scrutiny.

The women informants had accepted the invitation to participate on the basis of information given by a health care professional (breast care nurse) known to them. Prior to the start of the focus group they attended that information was reinforced, and the purpose and use of the material was explained at length. They were afforded an opportunity to exit at that point. The participants were not explicitly asked to consent to the repeated use of the material generated. However no assurances were given concerning limitations on use. Nevertheless the argument that data can be reused on the basis that the researcher had not received refusal for use beyond its original purpose remains rather weak in terms of an interpretation of informed consent and ethical behaviour. Indeed Thorne (1998) raises a number of applicable ethical issues associated with secondary analysis including informed consent. She concludes: “whereas subjects may have volunteered to share their experiences about a phenomenon for an identified purpose, a radical departure from the stated purpose could well violate the conditions under which consent was obtained” (Thorne 1998: 551). At the beginning of each focus group a verbal affirmation of willingness to participate was sought. In addition the letter inviting participants indicated that the aim of the interview was to examine their perceptions of the care they received and

they could and did chose to accept or reject that invitation. Nevertheless if question of conduct is approached from the principle of non-maleficence namely the researcher's obligation 'to do no harm' then does re-analysis exert any harm? I argue that no harm is likely to be caused by re-examining the transcript within the context of this study nor any further breeches of confidentiality than those incurred in the formulation of the original report for which informed consent was obtained.

A secondary issue is related in part to the ethical imperative of respect for persons or as Thorne rather pithily interprets this principle: "research subjects should be treated as an end in themselves rather than a means to an end" (Thorne 1998: 551). My actions might be seen on less substantial ground particularly if the use of the interviews had compromised the individuals in any way. Nevertheless it could be argued I have not given due concern to the participants by failing to elicit whether re-use was acceptable and therefore could be criticised. My rationalisation relates, and could be judged paternalistic, to the context of their involvement. The women participated in the focus groups at a point in their cancer 'careers' when they were undergoing and had completed primary active treatment and prognosis was hopeful. Time elapsed between the interviews, publication of original report, and the decision to undertake the secondary analysis. In that period it is probable that one or more of the women will have relapsed; a further possibility is that one or more could be terminally ill or in fact have died. Approaching the women, assuming I had agreement of all parties (clinicians i.e. breast care nurse, consultants, general practitioners, local research ethics committee) to that approach, might incur greater harm. Barker (1998: 392) in a letter to the British Medical Journal suggests that: "sensitive ethical thinking, rather than reflex absolutism, is required to balance and judge between the claims of competing imperatives".

Nevertheless that position is contrary to the Royal College of Nursing's guidance on research ethics which proposes: "if a research study involves the use of information, materials or specimens gathered for another purpose, separate consent must be obtained even if consent was obtained for the original use of the information,

material or specimen. The exception to this is information which may be regarded as being within the ownership of an institution, such as information used for audit.” (Royal College of Nursing 1998:17).

My position, and one which I will defend, is that I had permission to use the material from the commissioning organisation. Moreover, I have made all reasonable efforts to ensure that the data is anonymised and that verbatim material used in this thesis were chosen with due care and attention to any sensitivities that the material may engender for participants.

Interviews with breast care nurses

Enclosed in the documents accompanying the survey instrument was a short form, which invited the breast care nurses to participate in the interview phase of the study. This was returned by forty individuals across England who either agreed to be interviewed, or requested further information about the interviews assumably to inform a decision to participate. In 1998 those potential informants were approached and twenty nine agreed to participate. The following reasons were offered by those breast care nurses who had originally volunteered, or requested further information, and subsequently chose not to participate: six breast care nurses had left post or the post had been reconfigured; one was temporarily seconded from her post to project work; one indicated being too busy to participate, the remainder chose not to respond to repeated (3) telephone messages left on answering machines. As these nurses have demanding caseloads I chose not to persist beyond three attempts and interpreted this as being unwilling to participate. The remaining twenty nine breast care nurses were interviewed over a period from November 1998 and June 1999. A table giving information about individual participants and the service provided by the breast unit they work within can be found in appendices 6 and 7.

The individual breast care nurses were informed of the purpose and nature of the interviews on the initial telephone contact when arrangements were made to proceed

to interview. With one exception (BCN 20) the interviews were held in the breast care nurse's place of work. Breast care nurse 20 chose to be interviewed in an office at the University of Huddersfield. All the interviews started with a preamble explaining the project and the relevance of interviews with breast care nurses. I explained that the interview was to be audiotaped and subsequently transcribed. That any information which could be deemed as threatening anonymity such as people and place names would be edited during transcription and not used for purposes of analysis. Further stringent efforts would be made not to prevent inadvertent disclosure, which could compromise the identity of individual breast care nurses, or their clients. Nevertheless the problematic nature of confidentiality in qualitative research was explained to the participant breast care nurses.

Originally it was planned to undertake semi-structured interviews with a purposive sample of breast care nurses using 'critical incident technique'(Cox, et al. 1993). The interviews were intended to cover an agenda based upon examination of the individual nurse's 'repertoire of clients', critical incidents in relation to sexuality and body image concerns or problems emanating from nurse-client interaction, and issues emergent from the survey data. The use of 'critical incident technique' was in retrospect popular in the nursing literature during the period when the design for this study was being conceived (Norman, et al. 1992; Wilde 1992; Cox, et al. 1993; Andersson 1995). This use of the technique can be directly linked to the influence of Patricia Benner's work and her book *From Novice to Expert* (Benner 1984) and the enduring, and some would argue uncritical, interest in reflection as a basis for unearthing of the value and expertise of nursing.

Further consideration was given to this prior to setting forth on the interviewing and a slightly different approach was adopted for the ultimate study. My reservations associated with adoption of a 'critical incident' approach related to the possible limitations that would impose on the participants. Limiting their knowledge acquired through practice with women to one or two case examples as a basis for an understanding of the nature and scope of an individual breast care nurse's practice

was potentially defeating. Although the examples selected could well be paradigm cases they could equally be the unusual, bizarre, or the interesting ones, almost 'tabloid' examples of patient interaction. This reservation was in fact borne out as some of the case examples selected by the breast care nurses to illustrate particular aspects of the work could be described as unusual. For example one account related to prosthesis fitting involved a tall well-built patient who had undergone gender re-orientation treatment and his partner, a wheelchair-bound male of diminutive stature (BCN14). Another very moving account offered by Breast Care Nurse 6 involved a woman disclosing being sexually abused as a child in the centre of a female surgical ward within hearing of fellow patients. This particular account also appeared in Tait's (1996) study. This may suggest we both interviewed the same respondent who repeated, as a paradigm case, the particular incident.

One strategy which might have overcome any tendency to provide 'dramatic' rather than everyday 'critical incidents' would have been to impose restrictions on the informant about the type, nature, and scope of the 'critical incident'. This could be construed as a form of premature sanitisation or censorship. Particularly as the approach is in advance of assessing the status of the 'critical incident' and one that could attract criticisms of constructing data to fit the theoretical framework (Johnson 1998). The strategy adopted, which appeared more naturalistic within the context of the conversation approach ultimately adopted, was to encourage disclosures about patients which best illustrated particular client groups, or events at specific points in the patient's journeys, the work breast care nurses undertake. Some of these were spontaneous 'stories' within the telling of their work whereas others were encouraged by prompts such as: "Can you give me an example?" This produced forty two specific patient examples, which appeared to cover a range of clients from what could be deemed routine to the more 'unusual'. I argue that giving free rein – freedom to talk - to the informant to use examples as they saw as appropriate produced a greater range. Moreover this prevented a researcher imposed circumscription on the raw data, it gave responsibility of editing to the breast care nurse thereby giving them control upon the telling of the story, and ultimately gave

me insight into their work. These incidents were unpacked during the interviews and subsequently during data analysis.

A loose structure was adopted for the interviews, as they were exploratory and potentially demanding. I asked the participant to talk me through the system that was in place for the management of breast cancer patients. I suggested they started with explaining the referral system by imagining I had been to my GP that day with a suspicious lump in my breast. In the ensuing narrative when they reached a juncture where a description was offered of what appeared to be a 'significant' interaction to the breast care nurse I would, if not readily forthcoming, elicit further details. For example if the breast care nurse referred to undertaking a role in prosthetic fitting¹⁸ I would seek through probing to explore the breast care nurses' perception of the purpose of the encounter, what she hoped to achieve, what was the desired patient outcome for the session, etc. All the participants were aware that my particular interest within the study was upon the sexuality and body image ramifications of breast cancer and therefore probing to obtain disclosures around this aspect of the breast care nurses' practice was not often necessary. The interviews lasted between fifty minutes and two and a half hours: most lasting in the region of one and half hours.

In addition to the audio tape recordings fieldnotes were made immediately following the interviews. As most of the interviews were undertaken in the breast care nurses' working environment I was able to see their offices, separate 'counselling' rooms, in some cases patient consultation areas, waiting areas, and prosthetic fitting rooms. A number of the breast care nurses were located in designated areas in hospital settings. Frequently these had been decorated with resources from fund raising activities of ex-patients. I became very aware as I travelled the country of trends in soft furnishing and colour schemes which contrasted quite strikingly with other areas in the same hospital and sometimes immediate vicinity of the designated breast care

¹⁸ This is normally arranged six weeks following mastectomy when local swelling has reduced, wound healing occurred, and pain and discomfort resolved.

space. All these details were recorded in fieldnotes. Other information included details of sitting positions during the interview, management of disturbances such as telephone interruptions, pager calls, people entering the interview room. As the majority of interviews were in work time and at the discretion of the breast care nurse I made no request for interruptions to be minimised.

Following each interview I wrote fieldnotes relating to my initial impressions. For example:

“On entering reception area had a feel of a Doctors (GP) reception area with lots of files and X-rays. The waiting area had comfortable chairs and glossy magazines. Lots of neat information leaflets mostly authored by BCN 6. BCN 6 came to meet me. She was wearing a tweed jacket, slacks, dangling earrings, polo jumper, flat shoes. Very muted colours earthy. Short hair no make up. Counselling room decorated in same pink and grey. Dried flower arrangements, coasters, tissues, etc. Room away from waiting area down a corridor.”

(Fieldnote from interview with BCN 6)

This was followed by a summarised description of service and main issues that emerged in the interview and concluded with:

“Overall got the feeling that she saw her work as a form of psychosocial surveillance.”

(Fieldnote from interview with BCN 7)

The interviews were firstly transcribed verbatim, then checked against original recordings, and finally ‘cleaned’ by removing names, dates, and location.

I recognise that no matter how valuable the insights into nurse-client interaction gained through interviewing breast care nurses they remain one sided. An attempt to offset was the use of material generated from focus groups with patients and other sources such as White et al (1998) recent study eliciting patient and district nurses perceptions of a breast care service. In addition I immersed myself in the ever increasing auto/biographical literature (Lorde 1985; Louw 1987; Batt 1994; Butler and Rosenbaum 1994; Wadler 1994; Moch 1995; Segrave 1995; Dunckner and Wilson 1996; Diamond 1998; Picardie 1998) and art (Art.Rage.Us 1998) which has

emerged over recent years as a strategy to sensitise me to ‘lay’ interpretations of the experience of breast cancer. I saw this as an attempt to distance myself, if that is possible, from seeing as a partial insider. These were all strategies to enhance my theoretical sensitivity (Glaser 1978) and to promote criticality through seeing things differently. The main purpose was to enhance the analytic process yet keep the experience of the disease foregrounded within the context of care delivery thereby ensuring that the product has ‘thick description’ (Holloway 1997). Before outlining the approach adopted to analyse the data I intend to describe an unexpected avenue which was pursued and became an important aspect of this work.

This study makes no claims to have used the research approach grounded theory either in its original conceptualisation (Glaser 1967) or in the more prescriptive formulation developed by Strauss and Corbin (Strauss and Corbin 1990; Strauss and Corbin 1998). One of key features of grounded theory is the use of theoretical sampling. This is defined as:

“Data gathering driven by concepts derived from the evolving theory and based on the concept of “making comparisons” whose purpose is to go to places, people, or events that will maximize opportunities or variations among concepts and to densify categories in terms of their properties and dimensions”

(Strauss and Corbin 1998: 201)

As discussed earlier in this chapter a decision was taken very early in the project in response to a conference paper (Platzer and James 1996) to adapt the WWSS questionnaire. The addition related to items that sought to elicit information regarding the level of contact, and crude indication of nature of interaction with lesbian and homosexual clients. This addendum produced some very valuable data in terms of response behaviour and a beginning emergence of recognition of lesbian (in)visibility that is discussed in chapters four, six, and eight. The interviews with the breast care nurses afforded another opportunity to sample theoretically within the research process in order to elicit accounts, or absence of encounters, with lesbian women within the context of breast cancer care. Paralleling the period interviewing of breast care nurses I attempted to access what was becoming increasingly striking

as an invisible population. This next section will describe that element of the research journey.

Many of the breast care nurses with relatively long careers in the field had only encountered one or two women who they knew to be lesbian. What could be deduced from the phenomenon is that few lesbian women present with breast cancer albeit a highly improbable conjecture. Nevertheless, the absence of lesbian women presented difficulties in terms of accessing the population if they exist. I made a decision not to attempt to approach lesbian women with breast cancer through NHS organisations. My rationalization was that those few women known to breast care nurses may have disclosed that information believing it to be confidential. Therefore irrespective of strategies put in place to protect the individual any approach via the breast care nurse was considered to be a potential threat to the nurse – patient relationship. Secondly what was becoming conspicuous was that the breast care nurses might be aware of a patient's sexual orientation but it was not necessarily common knowledge among other members of the breast care multidisciplinary team. I therefore had reservations about developing a formal protocol and seeking ethical committee approval that if granted would potentially result in a poor outcome with few participants. Moreover it was a risky strategy in terms of the women becoming 'known' in the system by their sexual orientation. The additional concern was the number of ethical committees that would have to be approached despite the development of multicentre ethical committees therefore I chose not to take that approach.

A variety of strategies and agencies were approached which are described in Table 3.3 and represent the difficulties encountered with recruitment. Platzer and James (1997) argue that their 'insider status' within the lesbian and gay community minimised many of these problems for them. They suggest the outsider can experience difficulties with: " access, rapport with subjects, ethical concerns, and stigma contagion " yet recognise that the benefits can produce charges "by the same

token lays us open to the charge of bias thought to be inherent in going native, or rather in this case being native” (Platzer and James 1997: 627).

However, I was an outsider and moreover disclosed my outsider status by informing all potential gatekeepers and informants of my credentials: nurse, heterosexual, and a researcher. This may in all probability have worked against successful recruitment in two ways: Firstly by my ‘doing it wrong’ by not knowing how to access and secondly on one occasion ‘failing to pass the test’ when the partner of a potential informant interviewed me for the job of interviewer. Ultimately I was successful and recruited two women who described themselves as lesbian who had undergone treatment for breast cancer. In addition I was asked to speak at a lesbian workshop specifically targeted at an ‘older’ age group of lesbian women. There I presented data around emergent issues associated with invisibility of lesbian women and breast care nurses responses to lesbian women and these were debated by the group in I believe a mutually constructive way and provided a forum for verification of my reading of the data.

Interviews with lesbian women

As indicated in table 3.3 the result of the labour associated with attempts to access an elusive population was largely unproductive. Luckily I was able to recruit two women who were willing to participate in the study. Both approached me directly by phone where their willingness to participate was elicited after a lengthy discussion of what would be involved and the implications of their involvement. The interviews were arranged at the convenience of the participant. One was undertaken in the home of the informant (Janet) and the other (Liz) was recorded in an educational institution. Information about the project and findings to date were discussed with the two women immediately prior to the interviews. Again the information given over the telephone regarding the conduct and purpose of the research was repeated. Consent to proceed was obtained verbally, recorded and subsequently transcribed verbatim from the audio taped interviews.

Table 3.3: Overview of strategies to recruit lesbian and bisexual informants

Contact	Approach	Response
Lesbian and Bisexual Women's Health Networks (6)	Letter Telephone	One organisation responded with a telephone call. This was followed by agreement to circulate details of the study in a Newsletter. This produced one informant (January 1999) and an invitation to speak at a workshop (Oct 1999).
Breast Cancer Organisation for Lesbian & Bisexual women	Telephone Letter	Agreement to discuss with the "management committee". Produced one telephone contact from a possible informant and a letter of support for the work from an individual.
North American Lesbian Health Network	Email	Interest from an organisation who circulated details on an email database. Produced three respondents who briefly communicated but ceased after responding to initial mailing.
Breast Net Mailing (Australian)	Email	No response from posting
Gay Press	Telephone and email	Journalist interested in copy when the study is complete.
Other	Word of mouth	Produced an informant who was interviewed (February 1999) Given contact for a lesbian and bisexual women's health organisation.

A similar approach was adopted for both interviews although the ultimate product was very different. Both women were asked to "tell their breast cancer story". Liz interpreted this as starting with discovery of the breast lump and finishing with experiences of follow up on an outpatient basis. The interview lasted one and quarter hours. Janet started with her story with details of her personal journey of 'becoming' a lesbian and situated her story in terms of her relationships past and present and conjectures about the future. This interview lasted three hours. It was punctuated by cups of tea and at one point a lengthy discussion where Janet sought to discuss my

motivations for pursuing this avenue of inquiry. Table 3.4 gives details of the participant's personal histories shared during the interviews.

Table 3.4 Details of lesbian women participants

Pseudonym	Description
Liz	40's. Professional. Participation in the study as a 'political act'. 2 years since diagnosis. Treatment: lumpectomy and radiotherapy Currently not involved in an enduring sexual relationship.
Janet	50's. Professional. Described herself as a 'feminist'. 9 months since diagnosis. Treatment: lumpectomy and radiotherapy. Currently not involved in an enduring sexual relationship.

In what has become a seminal piece of work examining 'interviewing women' Oakley sets out in a reasoned account to exonerate the use of a different approach to interviewing (Oakley 1981). She incisively questions the "mythology of hygienic research with its accompanying mystification of the researcher and the researched as objective instruments of data production" (Oakley 1981: 58). Further, she argues that personal involvement with participants is a condition for understanding, knowing others. Her position which has been adopted as 'norm' in studies where the aim is to listen and then through the agency of research give voice to women's lives, stories, ways of knowing (Reinharz 1992). In this study various women have been interviewed in different settings using a variety of approaches. The purpose has been to engage through purposeful conversation with women in uncovering the meaning of their breast cancer experiences to them. Those experiences being the meaning of their work (breast care nurses), the meaning of care received (focus group participants), and the meaning difference may bring to care received (lesbian women). All these interviews shared a number of characteristics. Firstly the women were encouraged to participate not merely passively give information. Secondly the

product, the audio tapes and transcript resulted from interaction between participant(s) and interviewer. Thirdly, my role of interviewer often meant being questioned as someone who was perceived to have authority or knowledge. This occurred in all three forms of interviewing if not in all interviews. My responses were immediate although may have been on occasion construed as evasive when I did not know the answer or as during one interview, felt if I responded truthfully it might be perceived as challenging at best and confrontational at worst (BCN 9).

Data analysis

All interview data were transcribed verbatim, checked against the recordings, and then anonymised by removing names and places. With the assistance of Atlas .ti Version 4.1 (Muhir 1997) the data was first read, then fractured, and code labels attached to corresponding narrative sections within each transcript. These labels were phrases or words which best described i.e. captured the meaning, of the particular segment of the data. Specific phrases used by individual nurses were used when they offered a better description of meaning. For example “all weather and washing”¹⁹ (BCN 23) was used to describe the content of communication ‘normally’ occurring within interactions during breast care nurse’s encounters with women whilst they were hospitalised during the period around initial surgical intervention. In total 136 codes were developed in the initial phase of analysing the breast care nurse interviews, eight pertinent to this study emerged from the focus group interviews and seventeen in the interviews from the two lesbian participants. These were then collapsed where codes and attached narrative were clustered into ‘families’. These were given a descriptive label and a theoretical description of the family was written to describe the properties or connectedness of the codes. This data management feature of the programme (Muhir 1997) allows parts of the primary documents, the codes that have been attached to them, and any memos written (explanatory notes) during and subsequent to initial fracturing, to be examined for

coherence and reconfigured if they appeared not to fit. The test of fitness was the ability to communicate an explanatory description or storyline²⁰ when congregated. These families were then further collapsed when it became clear that the initial thematic conceptualisation was limited and greater density would yield better linkage to what became significant themes and ultimately best describe the work of breast care nurses.

The principles underpinning data analysis were loosely based upon Tesch's (1990) work. She proposed the following as underpinning qualitative scholarship: that analysis should be concurrent with data collection assisted by an orderly and disciplined process. The production of analytical notes guides the process at a conceptual level. Initially data is divided or segmented into meaningful chunks and then categorised and compared with other narratives, texts, categories, and literature. Categorisation is tentative recognising that no imposed order necessarily produces an exact fit. The procedures are not mechanistic, nor ritualistic, and demand creating an individualised process for data management. The process of disassembly and reconstitution facilitates the "emergence of a larger consolidated picture" (Tesch 1990:97).

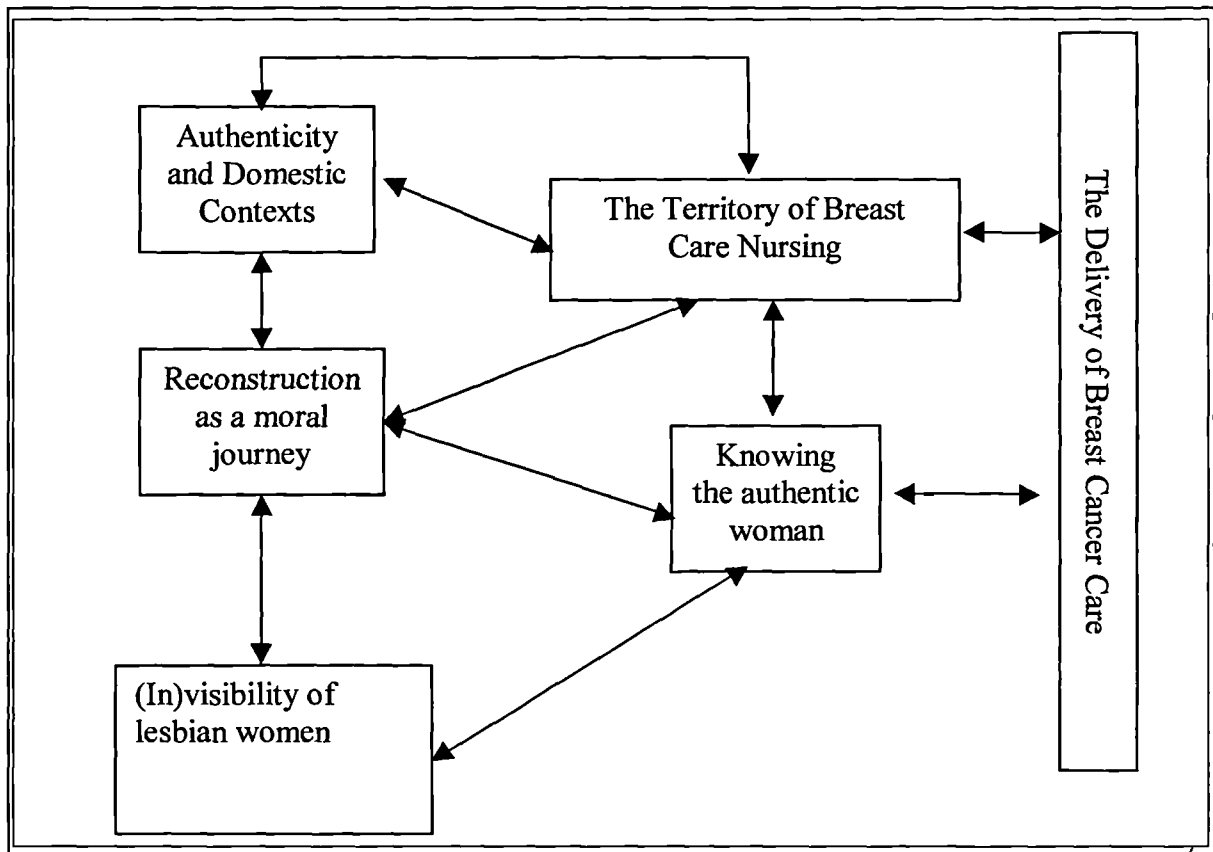
Analysis in this study started with return of the completed questionnaires in 1996 and then continued until Summer 2000. This period also involved data collection and the constant interplay between both activities informed the process. Nevertheless the whole period was characterised by varying degrees of uncertainty and engendered generalised feelings of wariness in relation to significance of aspects of the data. From relatively early in the project trajectory the issue of (in)visibility was one area of clarity whereas other suppositions were more illusory. However, the

¹⁹ The description of conversation as all about "weather" referring to general everyday conversation and "washing" context specific but non personal aspects/information associated with surgical recovery.

²⁰ In grounded theory the storyline is the term given to the description that links all emergent categories and literature into a cohesive conceptualisation of the whole study. Whereas the use of the term storyline in this study relates to the development of a description in order to examine the interconnectedness of codes which appeared to fit within a family. In effect if the storyline could not connect the codes then the family was reconsidered.

importance or balance of this concept within the overall project was not always as clear. A point comes in many projects when the researcher is forced whether willingly, or full of trepidation, with the phrase “the following themes emerged”. That juncture arrived and figure 3.2 attempts to illustrate that thematic analysis.

Figure 3:2 Diagrammatic Representation of Thematic Analysis



One area that emerged as a constant within data and emerged in the analysis of all the interviews with all groups of participants was the treatment trajectory titled in the thematic framework as “The delivery of breast cancer care”. I have used this as an anchor to contextualise the work of breast care nurses, the experience of the women, and describe the structure of services and the breast care nurse contribution (chapter five). This provides the background against which the scene is set for a more in depth analysis of the work of breast care nurses undertaken to “know” women (chapter six). The limits of breast care nurses’ knowing is examined through exploration of three themes: authenticity and domestic contexts; (in)visibility of

lesbian women, and the moral journey of reconstruction. In chapter seven the colonising project undertaken to define the territory of breast care nursing will be examined. Finally chapter eight will draw together the emergent themes to present a critical examination of the assumption that breast care nurses are “there for women”.

CHAPTER 4

THE SURVEY

Introduction

This chapter will present the first phase of this study which was undertaken in order to assess knowledge and attitudes of breast care nurses in relation to sexuality (Aim 1). This was achieved through the administration of a postal survey of breast care nurses using modified versions of the Sex, Knowledge and Attitude Test [SKAT] (Lief and Reed 1972), and the Wilson-Williams Sexuality Scale [WWSS] (Wilson and Williams 1988) and demographic information of breast care nurses working in National Health Service organisations in England. The overall purpose of this survey was to obtain baseline evidence of the level of sex knowledge and attitudes to sexuality held by breast care nurses working in England so as to provide a context against which other parts of the study can be contrasted. The style adopted for this chapter deviates from the traditional approach for presentation of findings in a thesis. Firstly, I intend to present a review of the literature relating to sex knowledge, attitudes and practice behaviour of nurses. Secondly I will provide a brief summary of the approach adopted to administer the survey although a more comprehensive explanation was presented in chapter three. Thirdly the results will be presented followed by a short discussion. The survey was undertaken in the period 1995 to 1996 and therefore has to be treated as a historical snapshot in the development of a group of specialist nurses working in a health service undergoing constant change and revision.

Literature review: health care professions and sexuality - the problematic

It is said that contemporary society is preoccupied with sexuality. That preoccupation is manifest in the media representations of the variety of sexuality but according to Evans (1998) is rarely examined with rationality. Merchandise is sold using sexual imagery from yoghurts to cars, the sexual proclivities of individuals are presented, discussed and debated as entertainment seen particularly in programmes on television (Plummer 1995), and sex is presented as a leisure commodity as seen in the 'packaging' of "18 to 30" holidays. It is as if sexuality has become the means

by which individuals define themselves; construct personalities, establish identity, and become conscious of themselves (Foucault 1976). Nevertheless the paradox of sex is that although ever present in daily life and “we can deal with the external manifestations of our sexuality” (Hawkes 1996: 8) the vestiges of repression of sexuality, which it is argued are historical (Foucault 1976), have reduced aspects of sexuality to problematisation. This is particularly manifest in the medical discourse associated with sexuality. I intend to give a short account of the reduction of sexuality to a medical problem before examining the literature relating to the knowledge and attitudes of health care professionals engaged in the execution of that project.

The medicalisation of sex

The main characteristic of the science, and medicalisation, of sex is that sex became an object of study and therefore the focus shifted and produced different expressions of disquiet about sexuality (Hawkes 1996). This can be seen in the (re)definition of homosexuality as a mental disorder by the American Psychiatric Association and treated with various strategies labelled ‘aversion therapy’ until revised in the 1980s (Schulman and Hammer 1988). Over the twentieth century there have been a number of trends in the science of sexuality. One, characterised by the work of Masters and Johnson (1966) has focused on the mechanistic aspects of sexual behaviour; another trend has been the mass surveys to quantify sexual behaviour (Kinsey, et al. 1948; Kinsey, et al. 1953); and the third adopting a psychoanalytic basis for understanding human sexuality initiated by Freud. This latter trend has been particularly influential in conceptualisations of body image. Vestiges of all these influences can be seen in the work reviewed in chapter two examining the psychological morbidity associated with breast cancer. It can be seen in such assumptions as the resumption of sexual intercourse as an indicator of adaptation to loss. That physical restoration, or avoiding disfigurement, will produce a more positive outcome in terms of self esteem and self image. Also approaches that “challenge the negative thoughts and cognitive distortions that are frequently

associated with failure to accept the loss of a breast. As a result the patient learns to substitute a more positive attitude towards her body image, which in turn results in enhanced self-esteem” (Hopwood and Maguire 1988:49).

The impact of the manufacture of a science of sex, and bringing sexuality into the domain of health care, is it becomes the responsibility of practitioners to examine and manage sex. Hawkes (1996: 70) suggests that science offers “the antidote to both fear and ignorance, by providing the tools to disentangle myth from reality”. However, the capability of health care professionals to undertake those responsibilities remains to be seen.

Sex knowledge, attitudes and practice behaviour of nurses

It has been repeatedly noted that health care professionals have particular problems in communicating with clients about sensitive issues of which sexuality is one (Lief and Payne 1985; Fisher and Levine 1983; Webb 1987a; Wilson and Williams 1988; Waterhouse and Metcalfe 1991; Lewis and Bor 1994). As far back as 1974 the World Health Organisation (WHO) examined the absence of discussion concerning sexuality from clinical work and attributed the causes of this omission to be the result of one or a number of factors. These included: the nature of scientific training; training deficits which transferred into clinical practice as a challenge to be avoided; poor knowledge of the physiology of sexual functioning; the complexity of sexuality making the work more demanding; and personal insecurities (Mace, et al. 1974). Following a WHO report Mace, et al. (1974) suggested a curriculum for health care professionals which focused on sexuality as: enjoyment; emphasis on individual control over sexual and reproductive activities; freedom from shame and prejudice; and freedom from organic disease. This curriculum outline may reflect contemporary ideology at that time particularly as it was based on a pre-HIV agenda.

At that time a number of measurement tool were developed to estimate the knowledge and attitudes of health care professionals. The Sex Knowledge, and

Attitudes Test [SKAT] (Lief and Reed 1972; Miller 1979) was one such instrument. SKAT was considered to have a value as a 'snapshot' attitudinal scale and possibly to have a place as an education tool to identify key areas for instruction and for evaluation of sexuality educational programmes particularly in health care. The instrument was designed to describe and compare groups rather than individuals. However it is suggested by Miller (1979) that liberal attitudes and demonstrable higher knowledge scores may correlate with a willingness to discuss sexuality in health care settings. That relationship has not been demonstrated and the behaviour of health care professionals could well be more complex than an attitude set and a knowledge base. A further problem in demonstrating relationships in this area for those authors (Webb and Askham 1987a; Wilson and Williams 1988; Motacha and Waterhouse 1993; Lewis and Bor 1994), who have tried to correlate attitudes and knowledge with practice behaviours, has been the dependence upon self report measures of practice behaviour rather than an attempt at examination, or measurement, of the realities of individual practitioners' clinical interventions.

An overview of the studies that targeted nursing populations, using one or other of the instruments adopted for this study, or using similar methods for administration, are given in table 4.1. One of the features that emerged from the examination of the sex knowledge and attitudes literature was the difficulty in establishing whether differences between studies in terms of sample populations, different sampling techniques, alterations to and different approaches to administration, obviates meaningful comparison.

Nevertheless a number of issues emerged from analysis of the literature. These focus upon the possible correlation between attitudes and knowledge and behaviour. The interesting feature with comparison, however crudely, across the studies using SKAT was that there appears to be trend over time towards lower attitude, which supposedly indicates conservatism, and lower knowledge scores. That finding if communicated into practice behaviour would suggest according to Lief and Reed (1972), a similar trend i.e., less interaction occurring in clinical encounters with

clients in relation to sexuality. A second interesting feature is in those studies where an attempt was made to elicit what occurs in practice (Webb and Askham 1987a; Wilson and Williams 1988; Motacha and Waterhouse 1993; Lewis and Bor 1994), a confused picture emerges. Whereas most of the studies agree that nurses view sexuality concerns of patients as a nursing responsibility there was considerable variation found in the theoretical knowledge to underpin that capability. In most studies a majority claimed to feel comfortable discussing sexuality concerns with clients. Although in the most recent UK study (Lewis and Bor 1994) fifty four percent of informants claimed personal embarrassment as a major reason for not raising sexuality issues with clients. Consistently in studies nurses reported feeling more comfortable when clients initiated discussions rather than when a nurse initiated interaction. They also rated proactively interventions such as starting a discussion only occurring with less than ten per cent of patients. However, to judge the meaning of a claimed ten per cent level of intervention in clinical practice without knowing more of the context could be construed as an oversimplification of the issues. Particularly as a factor identified by Webb and Askham (1987a) as influential was that the environment where a nurse worked may influence interventions in relation to sexuality.

Table 4:1 Overview of relevant sex knowledge, and attitude literature

AUTHOR	DATE	SAMPLE	INSTRUMENT	WHERE	RESULTS
Payne (1976) <u>Nursing Research</u> 25(4) 286-292	1976	108 Family Practice Nurses 62 Baccalaureate Student Nurses	SKAT Professional Sexual Role Inventory (PSRI) Postal Questionnaire	Louisiana, USA	Student nurses significantly higher on all elements except sexual myths Religious beliefs, rural location and age had negative effect on score.
Fisher and Levine (1983) <u>Cancer Nursing</u> (6) 55-61	1983	120 Registered Nurses Response rate 83%	SKAT Personal administration and follow up	National Cancer Institute (NCI) Bethesda, USA	Cancer nurses scored lower on attitudes and knowledge than graduate nurses. Education, age and religious beliefs had an effect
Webb (1987b) <u>Nurse Education Today</u> (7) 209-214	1987	50 Registered General Nurses Questionnaire administered whilst on duty or in class. Researcher waited for completion.	SKAT Attitudes Towards Women Scale (AWS) Patient Advice Situations (PAS) Questionnaire administered whilst on duty or in class. Researcher waited for completion.	2 Regional Health Authorities UK	No difference in SKAT scores between 4 sub sample groups (from gynaecological settings, one general surgery, one post registration students undertaking a Diploma in Professional Studies in Nursing - DPSN). One group of gynaecology nurses scored higher in AWS. In PAS physical aspects of sexual functioning mentioned more frequently. Gynaecology focussed responses more frequently mentioned. No demographic variations were significant.

AUTHOR	DATE	SAMPLE	INSTRUMENT	WHERE	RESULTS
Wilson and Williams (1988) <u>Oncology Nursing Forum</u> 15 (1) 49-53	1988	937 Registered Nurses Random sample from Oncology Nursing Society (US) (ONS) and Association of Paediatric Oncology Nurses (US) (APON) membership Response Rate 62%	WWSS Postal Questionnaire	USA	Attitude range 33-90. 91% indicated sexuality should be an aspect of practice. 58% reported being comfortable initiating discussions with patients about sexuality. 92% were comfortable if the patient initiated discussions.
Matocha and Waterhouse (1993) <u>Research in Nursing and Health</u> 16 371-378 17	1993	154 Registered Nurses Probability Sample Response Rate 31%	Survey in Sexuality in Nursing Practice (SSNP). Postal Questionnaire	South Western State. USA	34% not assessed sexuality. 42% not assessed sexuality in <10% of clients 71% provided information to <10% of clients 31% believed themselves to be knowledgeable about sexuality. 59% perceived sexuality a nursing responsibility.
Lewis and Bor (1994) <u>Journal of Advanced Nursing</u> 20 251-259	1994	161 Registered General Nurses Response rate 45%	SKAT 14 item practice test	London Teaching Hospital	Lower mean score than graduate registered nurses (US:1972) Higher mean for attitudes to heterosexual relations, sexual myths, and masturbation. 54% embarrassed discussing sexuality with patients 78% felt adequately educated 87% felt sexuality counselling a nursing role. No significant correlation between SKAT and Practice Score

To summarise the main points from that short review of the sex knowledge literature the consensus suggests that nurses believe they should address sexuality concerns with patients and this improves outcomes. However, their knowledge base to sustain interactions is low as estimated on the rating scales used. The nurses prefer patients to initiate discussions, although some reasons for this preference have been suggested i.e. embarrassment and lack of knowledge, they are largely unknown although context may be influential.

Breast care nurses, similarly to family planning and nurses working in gynaecological settings, work almost exclusively with women patients. Accepting that a few men may use family planning nurses for advice in the UK and one percent of breast cancer is male. It would be easy to assume that same sex discussions about sexuality concerns might be less demanding, yet neither gynaecological or family planning nurses have been shown to have greater knowledge or more liberal attitudes than other groups (Payne 1976; Webb 1987b). Breast care nurses are a group that have not as yet been the focus of work to establish their attitudes to, or knowledge base for their work with, women associated with sexuality. The remainder of this chapter will present the results of a survey designed to rectify that omission.

The survey findings

As discussed in chapter three, two hundred and twenty one questionnaires were sent to addresses obtained from a variety of sources: Department of Health list of NHS Trusts and regional breast care nurses groups. One hundred completed (and four uncompleted questionnaires) were returned giving a response rate of forty five per cent. This compares with other postal sex surveys (Motacha and Waterhouse 1993; Lewis and Bor 1994). One hundred questionnaires were used as the basis for the analysis of findings.

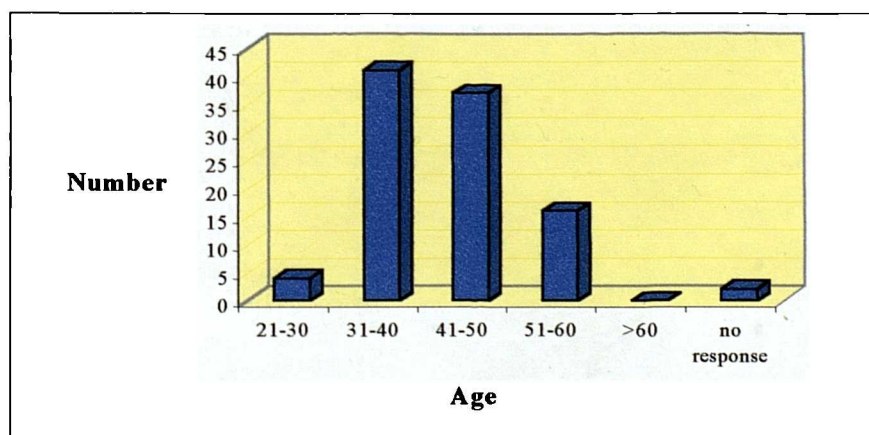
The results presented are primarily descriptive statistics. They are meant to provide an insight into some general characteristics of English breast care nurses as a group rather than to draw any detailed analytic conclusions about individuals within the sample. The

findings will be presented in the following sequence: demographic information, sex attitude scores (SKAT and WWSS), sex knowledge (SKAT), and practice behaviour (WWSS). This order was adopted as it best illustrates the development of a picture of participant attitudes, knowledge base and espoused practice behaviour within the context of breast care nursing. A number of respondents chose to exercise a personal veto, by omitting to complete individual items in one, or all, sections of the questionnaire and therefore the number of participants who responded to each question, and in some cases the number of missing cases, is given. 'Permission' was given to potential participants to omit items in the covering letter, which was sent with the survey instrument (see appendix 4). This approach was adopted in an attempt to increase overall response rate, this was balanced against concerns about missing cases.

Demographic information

The majority of the respondents (n=100) were between the ages of thirty one and fifty years which may reflect the prior experience required to fulfill the responsibilities of a specialist nursing post. Four participants chose not to answer this question. Figure 4.1 shows the age profile of the breast care nurses who responded to the questionnaire (question 148).

Figure 4.1: Bar chart showing age distribution of respondents (n=100)



Question 149 asked respondents to indicate their professional qualifications registered with the United Kingdom Central Council for Nurses, Midwives and Health Visitors (UKCC).

Figure 4.2: Bar Chart showing recorded professional qualifications of respondents (n=98)

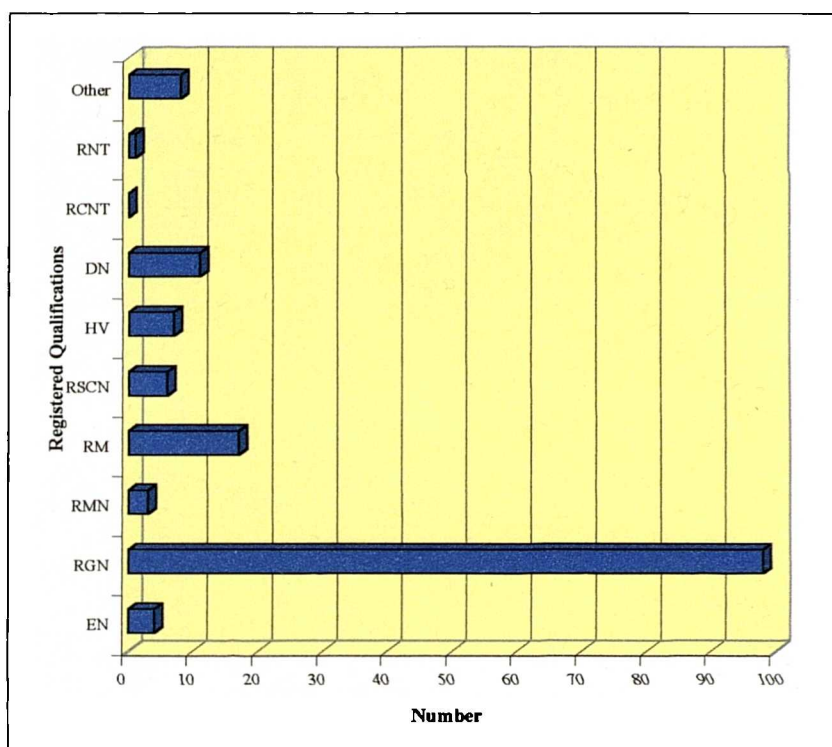


Figure 4.2 shows all respondents (n=97) held a registered general nurse (RGN) qualification, seven respondents indicated they had in addition an enrolled nurse (EN) qualification. No participant solely held an EN registration. The largest number of second qualifications recorded with the UKCC were those of Registered Midwife (RM) and District Nursing (DN) fourteen and eleven respondents respectively. This high proportion of participants with the second qualification of Registered Midwife may The largest number of second qualifications recorded with the UKCC were those of Registered Midwife (RM) and District Nursing (DN) fourteen and eleven respondents respectively. This high proportion of participants with the second qualification of Registered Midwife may reflect a historical tendency, particular pre-1980s, for many

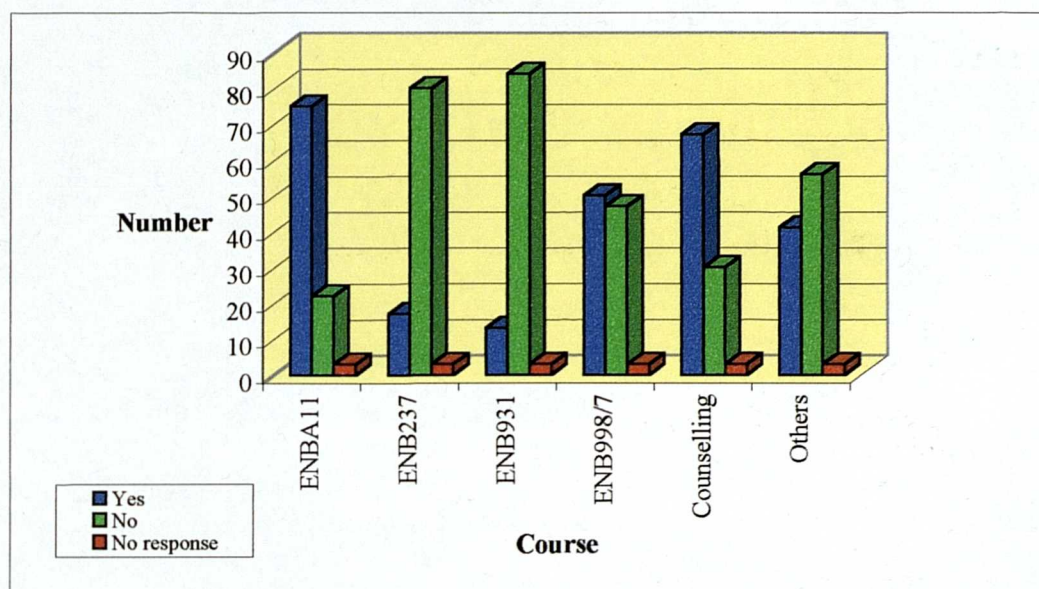
nurses to undertake midwifery training post qualification as it was often sought as a pre-requisite, or perceived as having value, for promotion. It may also reflect "women centredness" which Tait (1996) argues is a trait of this group of specialist nurses.

Question 150 elicited information about the professional educational and training undertaken by participants to enable them in their role of breast care nurse. Figure 4.3 shows the distribution of formal professional education undertaken by respondents. Seventy five respondents held the ENB A11 Breast Care Course (or the Royal Marsden Hospital Advanced Breast Care Course which predated the ENB validated provision). Sixty six participants indicated they had undertaken a counselling course of some type. The descriptions offered showed these ranged from a short course or module examining communication skills to a MA in Counselling. Seventeen nurses had undertaken the ENB237 in Cancer Nursing, which is considered the specialist preparation for cancer nursing, and a further thirteen had undertaken the ENB 931 Care of the Dying course. The outline curriculum for that programme covers many of the aspects of patient management which may be particularly pertinent to the work of the breast care nurse with women with advanced breast disease. Forty nine nurses indicated they held the ENB 997/8 Teaching and Assessing in Clinical Practice award which could be considered a basic yet essential preparation for any nurse to enable them to participate in mentorship or preceptorship roles with pre and post registered learners in clinical settings.

These results do suggest that a number of individuals in high cost and specialist roles within health service organisations have not undergone formal education to fulfill their roles. Twenty two individuals indicated they did not hold the ENB A11 and thirty one nurses indicated they had not undertaken a counselling course. This may be a reflection of the time lag between emergence of specialist posts and the development of appropriate education resulting in some individuals having acquired on the job experiential learning making the formal learning redundant. Nevertheless the Calman-Hine Report (Department of Health 1995), the Department of Health document "A First Class Service" (Department of Health 1998b) and more recent policy (Department of

Health 2000a, 2000b) have recognised the imperative of appropriately qualified staff to underpin an effective and quality service.

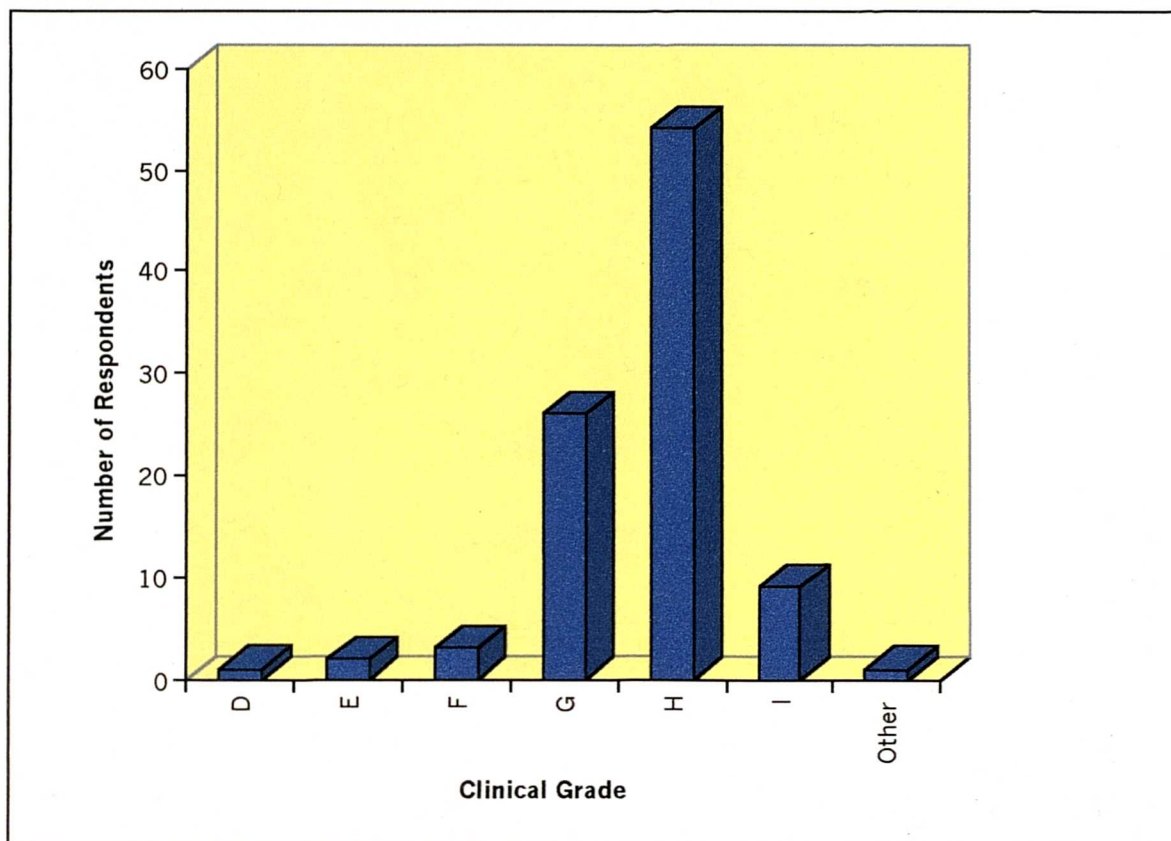
Figure 4.3: Bar Chart showing number of breast care nurses holding professional 'specialist' qualifications



Question 153 asked respondents to indicate their clinical grade. Figure 4.4 illustrates the profile across the sample and indicates that the majority, ninety breast care nurses, were graded G or above, with most, fifty four, holding an H grade. Currently in the UK qualified nursing staff working in the NHS can be employed in posts that have been graded D to I. These equate crudely to staff nurse grades (D and E), sister or charge nurse grades (F and G), and nurse specialist and some nurse managerial posts (H and I). In recent documents emanating from the Department of Health (Department of Health 1999; Department of Health 2000a) a new structure has been announced to reflect the shifting boundaries and role demarcations in nursing posts. This have yet to be implemented but may have implications for nurse specialists such as breast care nurses. Nevertheless the profile of breast care respondents in this study would appear to hold grades at the upper end of the nursing scale which may well represent the expertise of, and value perceived within NHS organisations of, these postholders. Question 155 asked respondents to indicate their job title. Those who completed this section provided

descriptors which included specialist nurse or nurse counsellor. Twenty two respondents indicated their job title included the name Macmillan: six chose not to complete this item.

Figure 4.4: Bar chart showing clinical grade of respondents (n=96)

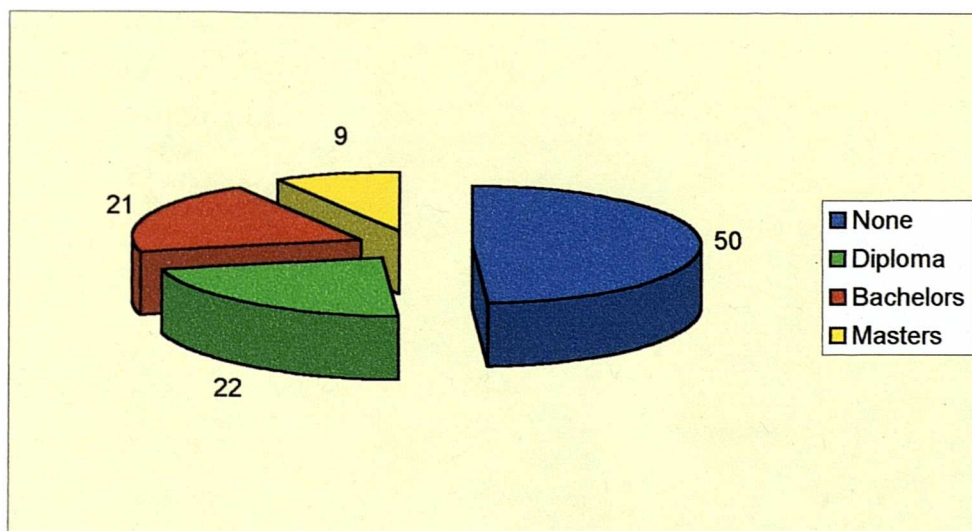


Cancer Relief Macmillan has been proactive in pump priming breast care nursing posts within the National Health Service and holders of Macmillan funded posts retain the title after initial non NHS funding has ceased and have access to education and training offered by that organisation. The “Macmillan” prefix is adopted and used after funding from the organisation has ceased and therefore is not contingent on the identity of the original postholder.

As with the results obtained relating to formal specialist education preparation (question 149), when clinical grading is compared against formal academic qualifications held, or currently, in progress (question 151), the profile does not equate with expectations for

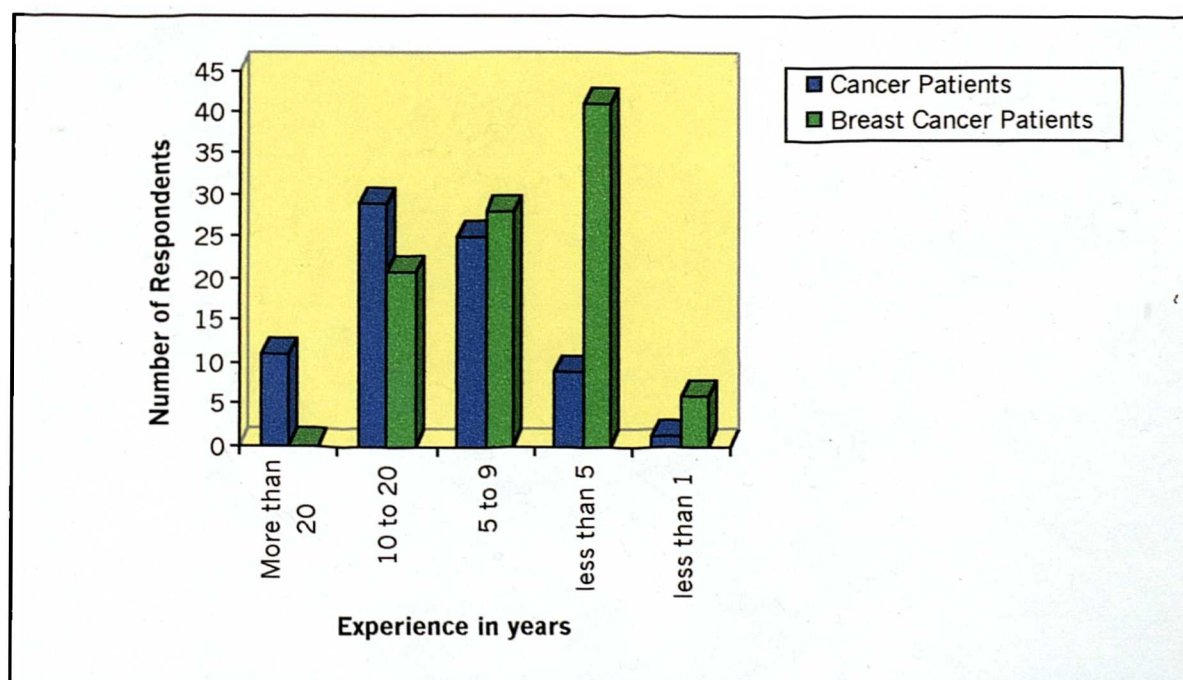
specialist practice. The recent UKCC consultation paper (United Kingdom Central Council for Nursing Midwifery and Health Visiting 1999) indicates for those working at a higher level of practice, including specialist practitioners, the minimum standard should be preparation to graduate level. Twenty eight breast care nurses indicated they held no formal educational qualifications, twenty respondents did not complete this item (question 151h). A problem trying to differentiate between between academic and professional awards is that many of the latter are frequently embedded in academic awards. For example: a respondent could undertake the ENB A11 as part of a bachelors degree, and in some parts of the country a masters award. This presents difficulty in extrapolating one from the other in terms of response. In addition respondents often indicated they had more than one academic award i.e. an individual with a diploma, degree (BSc) and a masters award in counselling but in fact had not completed the ENB A11. Whereas there was an another respondent who indicated diploma level education including ENB A11, ENB 237 and indicated they had completed a course in counselling. Figure 4.5 shows the number of breast care nurses holding academic awards. The number of awards exceeds number of respondents indicating that some informants hold more than one academic award.

Figure 4.5: Pie chart illustrating academic qualifications of respondents (n=100)



Question 146 and 147 (see figure 4.6) show the years of experience with cancer patients and breast cancer patients. Most respondents have had in excess of ten years experience with breast cancer patients. It should however be recognised that this may not reflect experience as a specialist breast care nurse. No information was offered or asked for which would indicate how respondents defined experience. This item could have been interpreted as meaning any experience with cancer or breast cancer patients from the outset of nurse training and in a variety of contexts and therefore may not relate to meaningful or intensive exposure with this client group. This could also explain the result that five respondents claimed to have limited experience with cancer patients and one with breast cancer patients.

Figure 4.6 Bar chart comparing the years of experience of respondents caring for cancer (n=75) and breast cancer patients (n=96)



Sex knowledge test

The mean score for sex knowledge was derived from calculating each informant's mean score for the fifty items suggested by the author to constitute the sex knowledge test. The extra twenty one items on the original instrument are considered to have a "heuristic" value only (Lief and Reed 1972: 15). The mean score for knowledge achieved by respondents in this study was 36.48, which is marginally higher than that attained by other groups of nurses but not medical students and non medical graduate students (Lief and Payne 1985; Lewis and Bor 1994). The items suggested by Lief (1972) for exclusion, as they were designed for teaching purposes, were omitted from the results. In table 4.2 below the mean SKAT Knowledge Scores from a number of studies are compared. These were corrected to fifty items for meaningful comparison as a number of the other studies that presented knowledge scores based on more than fifty items.

Table 4.2 Comparison of SKAT knowledge scores with US and UK studies

Author and Year	Sample Characteristics	Sample Size	Mean SKAT ²¹ Knowledge Score
Lief and Payne 1985 USA	Graduate Students Medical Students Nursing Students Registered Nurses College Students	n=589 n=1104 n=1174 n=828 n=1243	36.90 36.09 32.69 30.91 30.30
Lewis and Bor 1994 UK	Registered Nurses	n=161	34.96
Topping 2000 England	Registered Nurses (Breast Care Nurses)	n=100	36.48

²¹ All scores to corrected to mean score of 50 items

Attitudes

The results are categorised in relation to attitudes to four areas: sex myths, masturbation, abortion and heterosexual relationships. Lief and Reed (1972), the authors of the SKAT instrument suggest that the higher the score the more "liberal" the attitude set is expressed by the participant. For all categories the group (all participants) aggregated mean is presented not individual scores for each informant. Table 4.3 presents the mean aggregated group domain (i.e. sex myths, heterosexual relationships, abortion and masturbation) attitude scores achieved by the breast care nurses in this study derived from the SKAT instrument in comparison with other comparable studies. The results suggest a confusing picture, which may support criticisms associated with the validity of the instrument. Webb (Webb 1987b) casts some doubt on the utility of a North American instrument to translate to the UK context or maintain construct validity over time.

Table 4.3 Comparison of reported SKAT attitudes scores

	Sex Myths	Abortion	Heterosexual Relations	Masturbation
Lief 1972	36.11	27.34	26.78	26.04
Lewis and Bor 1994	37	24.62	28.37	26.86
Topping 2000	37.52	25.45	27.02	25.93

The breast care nurses in this study obtained higher attitude scores, more liberal attitudes towards sex myths and abortion than Lewis and Bor 's (1994) population. Yet lower attitude scores therefore more conservative attitudes to heterosexual relations and masturbation; although all differences were minor, of a value of less than one. A possible inference may be that this represents the differences in the profile, demographic and life experiences of the two sample populations. The mean age of Lewis and Bor's respondents was twenty seven years with the majority less than twenty five years old and included 11.9% male informants. Their study was conducted in a teaching hospital

in central London. Whereas in this study the majority of respondents are older than thirty one years, all the participants were female, and drawn from across England.

Attitude scores from the WWSS are presented as mean sample scores. The attitude items relate to questions 103 to 127 in the questionnaire. However Wilson (Wilson 1993), one of the authors, suggested that the calculation of attitude score should be based on fifteen items only as following their factor analysis the other items were considered to be unreliable or outside the control of the individual nurse. Unfortunately in the published paper (Williams and Wilson 1988) no indication is presented as to whether the results presented relate to all items, or those reported to be reliable. Table 4.4 shows the results of this study population compared with Wilson and Williams's cohort. Scores are given for all attitudinal items and the fifteen 'reliable' items and it should be noted that only seventy four respondents fully completed this section of the questionnaire.

Table 4.4 Comparison of reported WWSS attitude scores (n=74)

	Mean Score	Standard Deviation	Range
Wilson & Williams 1988	69.1	9.78	33-90
Topping - reliable ²² attitudinal items	43.96	5.96	31-71
Topping - all attitudinal items	87.99	7.91	61-103

Again comparison between the two groups may be difficult as the Wilson and Williams' sample included 29.9% participants less than thirty one years old as compared to 7.4% in this study and moreover 3.3% were male. That said the attitudinal statements in this instrument were specifically focused on cancer patients. Based on the results obtained from the fifteen items considered by the authors to be reliable this study population appear to have a more negative attitude to sexuality, denoted by lower mean score, than that achieved by US cancer nurses. However if the Wilson and Williams' published results are based on all the attitudinal items then the participant breast care nurses hold a

²² see earlier comment relating to Wilson's concerns following factor analysis

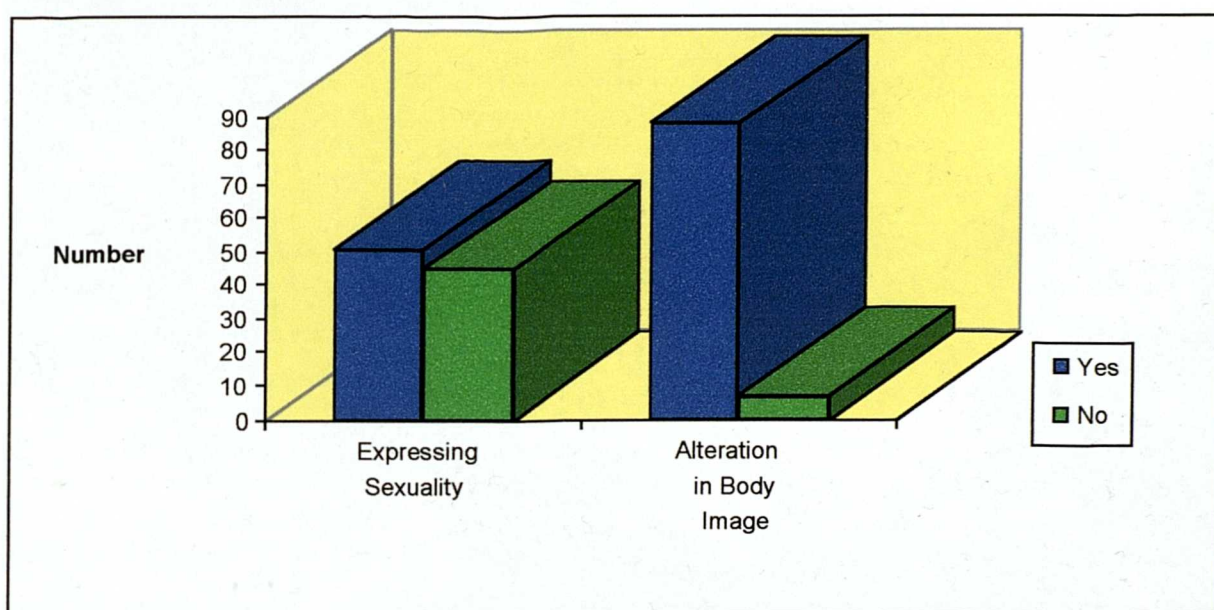
more positive attitude to sexuality than the US cancer nurses. The breast care nurse cohort (using either data set) appear to have more consistent attitudes as expressed in the range scores and standard deviation across the sample than the US group. It could be inferred that this relates to homogeneity of the breast care group.

Some of the individual items embedded in the WWSS attitude scale are however worthy of examination. Questions 116 and 117 relate to being comfortable when patients, or their partners, initiate discussions about sexuality. 76.5% (n= 75) agreed or strongly agreed with the statement "I am comfortable discussing sexuality if the client initiates the discussion" and 71.2 % (n= 69) agreed or strongly agreed with the statement "I am comfortable discussing sexuality if the client's partner initiates the discussion." When asked if discussing sexual concerns contributes to recovery 95.9% (n=94) strongly agreed, agreed, or slightly agreed with the statement. Nevertheless there remains a subset within the respondents who were more comfortable if the patient or partner initiate discussions rather than themselves. Fifteen breast care nurses agreed or strongly agreed that they felt uncomfortable discussing sexuality issues (question 111). This may have implications for quality of nurse-patient interaction.

Practice behaviour

Whilst recognising that it is naive to assume that what is said to be undertaken in practice accurately represents reality, a number of interesting features emerge from the data. Figure 4.7 compares the frequency of use of the nursing problems "expressing sexuality" (question 128) and "alteration in body image" (question 130). Nursing or patient problems are the standard approach for conceptualising and documenting the nature of patient's needs and prescribed nursing interventions and evaluation.

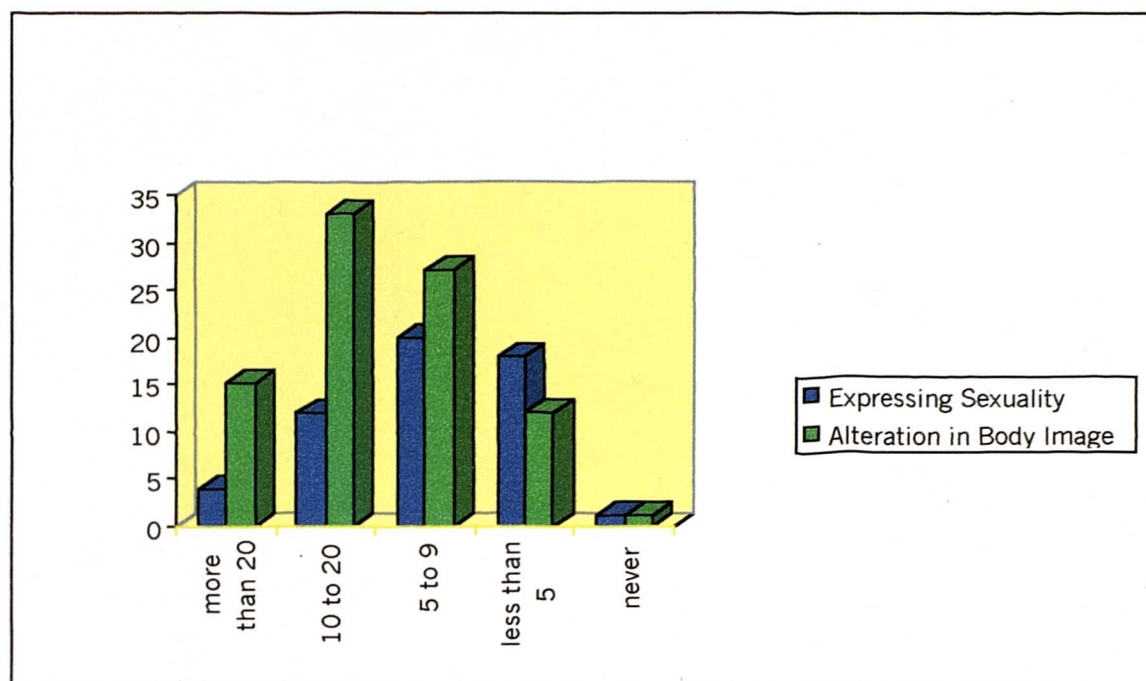
Figure 4.7 Bar chart comparing reported use of patient problems body image (n=96) and expressing sexuality (n=95) in care planning by respondents



Both descriptors were reportedly used in practice by respondents although alteration in body image appears to be used with greater frequency than expressing sexuality by the breast care nurses (see figure 4.8). Another feature was the number of respondents who chose not to answer questions 129 and 131. These specifically asked how often²³ the problem descriptors were used in terms of sexuality (n=55) and body image (n=88).

²³ Number of patients over a six month period

Figure 4.8 Bar chart comparing frequency of use of expressing sexuality (n=55) and body image (n=88) as nursing problems in care planning by respondents



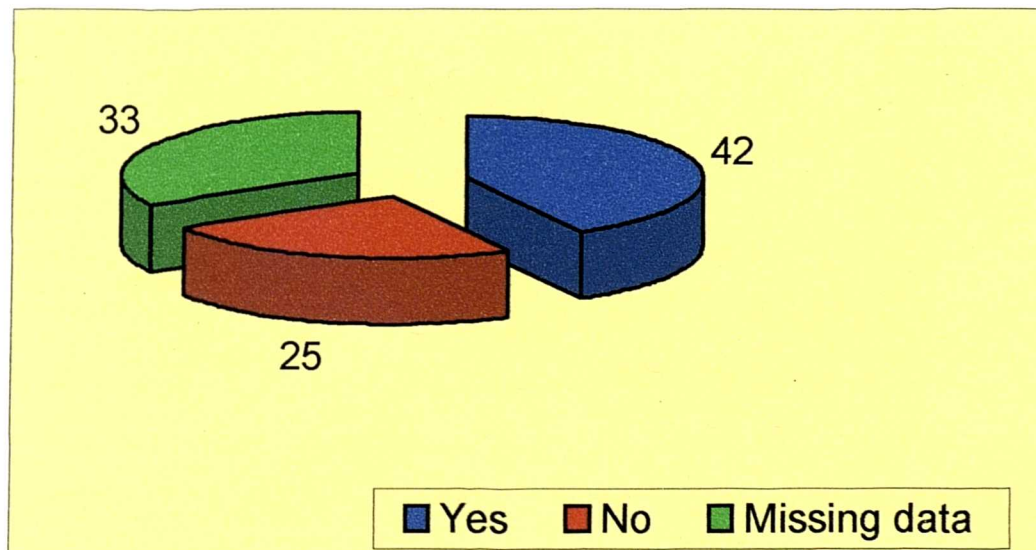
A number of factors could explain these findings: firstly, the different role responsibilities of specialist and ward based nurses may have influenced responses as specialist nurses may not document their activities in patient care plans held on wards or be the chief author of care plans. Another consideration is that breast care nurses may document key issues relating to patient care in their own records but may not adopt the standard descriptors. Alternatively it may be recognition of the sensitivities associated with managing the need for privacy and documentation of information related to sexuality which adds to this omission. Whatever factor, or combination of factors, are at play the interesting feature remains the different reported levels of use of “altered body image” as compared with “expressing sexuality”.

Respondents were asked how often they offered to discuss sexuality issues with breast cancer patients and their partners over a six month period (question 132) and 58.5% (n=58) responded with less than ten. This low estimate may reflect a number of issues. It is recognised that there is considerable variation in caseload however it is unlikely

that any breast care nurse encounters less than ten patients per month (Allinson 1998). The question asks the respondent to conflate estimates of patient-nurse and nurse-partner encounters which may have produced a lower result than if the information had been requested in two separate questions. Lastly this could be an accurate picture of the range of breast care activity across the country. However when question 132 is contrasted with questions 142 to 145 eliciting information relating to meeting needs of lesbian or homosexual breast cancer patients other issues may be at play.

Figures 4.9, 4.10, and 4.11, represent the responses and non responses to questions 142 to 145 that relate to sexuality issues and the needs of lesbian or homosexual patients. Question 142 asked respondents to indicate if they did, or did not, discuss sexuality issues when involved in the care of patients who are known to be lesbian or homosexual (see figure 4.9). Of the sixty seven respondents who chose to answer the question 62.7% (n=42) indicated an affirmative response.

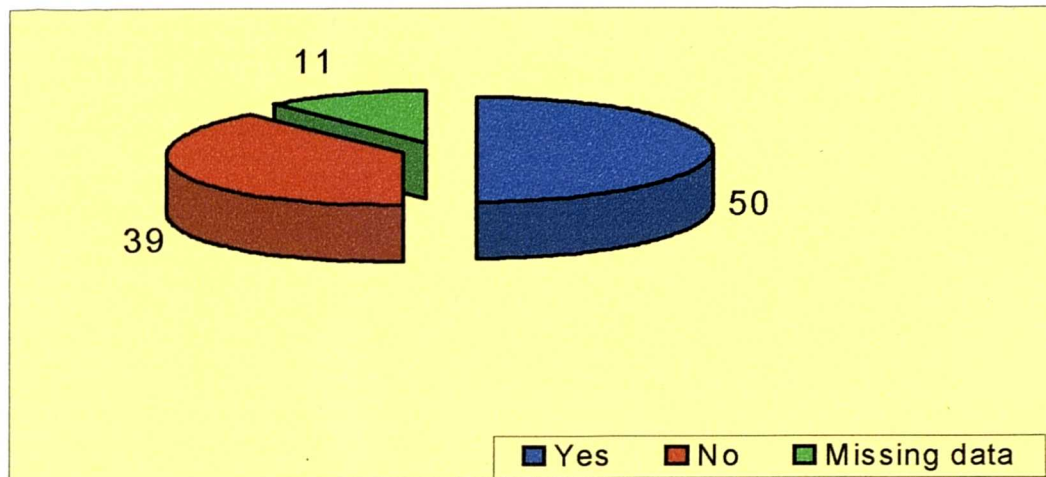
Figure 4.9 Pie chart illustrating whether respondents (n=67) discuss sexuality concerns with lesbian or homosexual breast cancer patients



When participants were asked (question 143) if they had ever cared for a lesbian or homosexual patient of the eighty six nurses who responded, fifty indicated they had not cared for a lesbian or homosexual patient. Some of the responses to question 142 can be

explained by informants responding as if to hypothetical rather than real world experience (see figure 4.10).

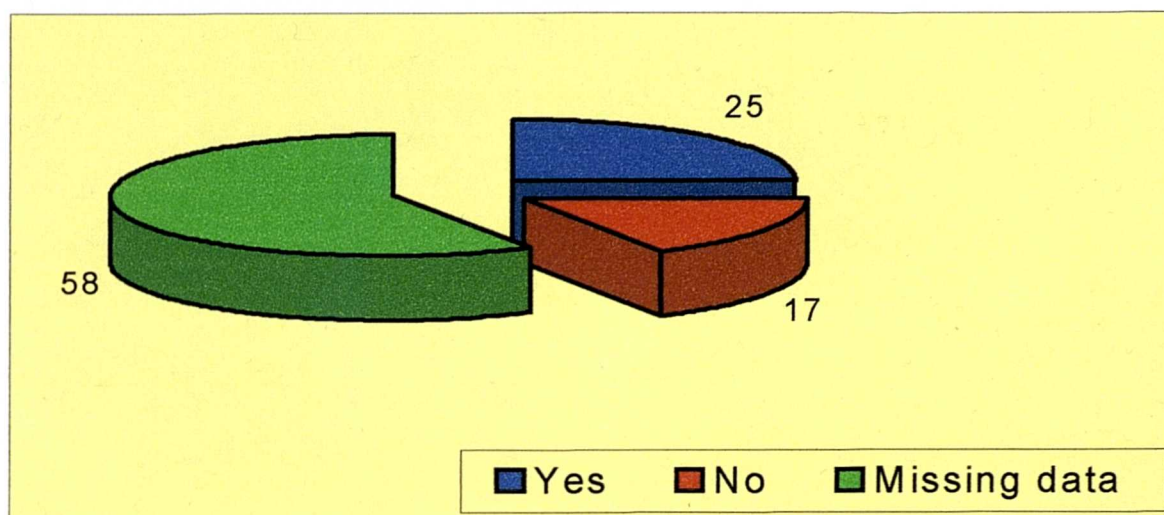
Figure 4.10 Pie chart showing distribution of respondents (n=89) who knowingly cared for a lesbian or homosexual client with cancer



Question 144 enquired if the respondent, when discussing sexuality issues with lesbian or homosexual patients, extends those discussions to include the patient's partner (see figure 4.11). Forty two respondents answered this question with 58% (n=25) indicating they would involve partners in these discussions. An explanation is that partner involvement in care may be determined to an extent by the breast care nurse's ability to access to a patient's partner rather than insecurity with lesbian or homosexual clients. However compared with the situation described in question 132, relating to heterosexual patient's and their partner's involvement in discussion relating to sexuality if access is the prohibiting factor then a similar trend would be expected. This question was structured slightly differently to the equivalent question relating to partners' of lesbian and homosexual clients and therefore direct comparison is problematic. Nevertheless sixty six breast care nurses reported discussing sexuality issues with at least five patients and their partners, and twenty four breast care nurses reported a number greater than twenty heterosexual couples in the last six months. From the results it would appear there is at least some reticence among the respondents who have been involved with

known lesbian and homosexual clients to address sexuality issues. This omission may be explained, if only tentatively, by supposed homophobia among health care professionals (Wilton 1996).

Figure 4.11 Pie chart showing distribution of respondents who discuss sexuality concerns with partners of lesbian or homosexual patients (n=42)



Question 145 asked those respondents who were unwilling to discuss sexuality issues with lesbian and homosexual patients and/or their partner whether they would refer them to someone who would. Twenty eight individuals answered this question and only three indicated they would refer the woman's partner to someone else. This may well relate to absence of alternative health care professionals within health care organisations rather than unwillingness to refer to others.

Discussion

This phase of the study set out to measure the levels of knowledge and attitudes to sexuality of a group of specialist nurses working predominantly with women with breast cancer. An element of that process was to examine the relationship between knowledge, attitudes, demographic characteristics and espoused practice behaviour in relation to

sexuality. The underlying premise was that the reported morbidity associated with breast cancer and its management would result in 'sexuality work' as an aspect of the nurse-patient interaction. What this part of the study has shown, probably unsurprisingly, is that 'sexuality work' is far more complicated than a knowledge + attitudes = behaviour equation.

The respondents in this study were predominantly mature women, over thirty years of age, with varying years experience of working with cancer and breast cancer patients. They were all registered general nurses; a small but significant minority held a second registered qualification. They were predominantly employed in posts graded within the NHS at Grade G or above. In hierarchical terms they were employed in the higher clinical grades which probably is commensurate with the perceived expertise and knowledge needed to perform this specialist role.

The first consideration is whether the respondents were adequately prepared to fulfill their roles. A majority of participants (77.1%) held the ENB A11, which is the appropriate professional course to underpin the role. Also 66% of participants had or were currently undertaking study of communication skills and/or counselling. Nevertheless a minority had no professional education or training to undertake their role. If there is an association between education and training and effective performance this could be seen as problematic. Breast care nursing as a unique specialism only emerged in the late 1970s and the major proliferation in breast care nursing posts followed the publication of Forrester Report (Forrester 1986). Therefore the education provision appeared after nurses had taken up posts rather than was developmental to a nurse's preparation for the role. Breast care nurses were the main protagonists in demanding specific education provision, through the Royal College of Nursing Breast Care Nursing Society, and led educational developments in the mid to late 1980s at the Royal Marsden Hospital, London, Christie Hospital, Manchester, and in West Yorkshire with the West Yorkshire College of Health. So the profile of these respondents may be an accurate profile illustrating the historical development of this group of nurse specialists.

Clinical nurse specialists such as breast care nurses have been positioned in recent policy documents (Department of Health 1999, 2000a) with education to at least first degree level and working toward a masters award in a discipline appropriate to the specialist field. The profile of participants in this study would suggest that there remains a considerable gap between ideal professional standards and the reality in NHS Trusts. The association between age and academic profile does not suggest that younger women are or have been motivated to take up academic study in greater numbers than the older participants. Although no comparisons can be made with other sub sections of nursing the finding that over fifty per cent (50%) had undertaken academic study could be seen as positive. Tait (1994) in her study demonstrated a relationship between job satisfaction and education and training but went on to suggest that post registration education should be focussed on increasing the critical mass of the motivated rather than directed to those “though compassionate carers, are nor necessarily motivated to optimise their role” (p9). Although in a health care industry committed to evidencing and ensuring effective research based practice ill prepared expensive practitioners may be leaving themselves open to scrutiny.

Despite the number of participants with no formal undergraduate or postgraduate academic education this sample of breast care nurses achieved a marginally higher sexuality knowledge score than any other comparable nursing group investigated in the reviewed literature. This may just be that this group of women is ‘older and wiser’ than the previously tested cohorts and comparison with a cohort with a similar demographic profile may produce a more meaningful result. The results of the SKAT attitude test suggests that the breast care nurses hold more liberal attitudes to abortion and sex myths. Scale scores in the SKAT instrument are ordinal measures and the scale scores order groups in higher than or lower than relationships on the dimensions. In effect the numerical value is irrelevant (Davis, et al. 1988).

The findings relating to attitudes to heterosexual relationships and masturbation are possibly more illuminating about this group of nurses when examined against frequency

of interventions associated with “expressing sexuality” and clinical interaction in the form of discussing issues relating to sexuality with heterosexual, lesbian and homosexual patients and their partners. Here the ‘conservative’ attitudinal score may be a measure of willingness and ability to engage in effective discussions with this section of the population.

What remains unanswered is whether this possible link between conservative attitudes is in fact acted out in the realities of practice. From the evidence that emerged in this survey breast care nurses do not come into much contact with lesbian women with breast cancer. What is more probable is that the breast care nurses do come into contact with lesbian women but a woman’s sexual orientation is not known. This may mean in practice women are assumed to be heterosexual. If so, resulting messages to lesbian and bisexual women may be at best confusing and at worst not conducive to disclosure. Alternatively if the lesbian client is explicit about their sexual preferences interactions associated with expressing sexuality may be omitted or managed less than sensitively. It has been suggested (Platzer and James 1997) that lesbian women may find it difficult to be open about their sexual orientation and relationships with health care professionals and this may go some way to explain these results. Another interpretation may be the dominant ideology of heterosexism (Walpin 1997) in clinical practice, research and educational preparation in medicine. This is possibly pervasive in breast cancer thereby rendering the lesbian patient invisible; the possibility of multi-layered construction of a ‘blind spot’. These issues will be examined in greater depth in Chapter Six.

Tait (1994) proposed that breast care nurses saw their main focus as providing “a holistic, emotionally supportive model of direct care for patients” (p5). This model she went on to describe as having a number of dimensions which included: “valuing patients, connecting with them, empowering them, ‘doing for’ them and finding meaning with them for both patient and nurse” (p5). Whilst in no way wishing to criticise these laudable qualities of the breast care nurse – patient relationship this study suggests that it may be problematic to claim these if a proportion of patient encounters are less than open. It would seem that valuing, connecting with, and empowering, are all

activities which demand a transparency which would currently seem absent in the results obtained in the practice element of this survey. An interesting feature of Tait's list of dimensions is the inclusion of "doing for". It could be construed that the high reported levels of intervention associated with 'alteration in body image' in this study are connected to this dimension. Arguably the altered body image aspect of care can be seen as 'doing for' in terms of prosthetic fitting and advice on dress and minimising disfigurement. Whereas discussing sexuality cannot be so easily managed and may have a longer trajectory in terms of resolution assuming resolution is possible. Breast care nursing has been described as resembling a: "potentially recurring crisis intervention model with the onus mainly on the patient to contact the nurse following the initial crisis" (Tait 1994: 4). The trajectory of difficulties associated with sexuality and the nature of the problems may not fit well with a patient initiated response when they are in crisis. These are all issues examined in chapters five, six and seven.

Summary

The key findings were that the breast care nurse participants have a marginally higher knowledge score than previously tested nurses. Breast care nurses who participated in the survey have a mixed profile in terms of education and training to underpin their role. The attitudinal set of the participant breast care nurses was not uniform. Two alternative explanations can be given: one, that the informants did not hold homogeneous views, and two, that the items within the scale are non relational. The latter interpretation may be more accurate in the light of the factor analyses undertaken. The majority of breast care nurses (96%) agreed that discussing sexuality aids recovery although less felt comfortable initiating those discussions or were more comfortable if the patients or their partners initiate discussion of sexuality issues. The missing data in terms of the number of informants who chose not to answer questions about lesbian or homosexual patients and their partners was intriguing. Further, those that who did complete the items were divided in terms of whether they would or not discuss sexuality in clinical encounters with lesbian and homosexual patients. Finally interventions associated with altered body image were reportedly more commonly undertaken than those associated with sexuality.

This survey has resulted in more questions and the relationship between knowledge, attitudes, and behaviour remains largely hidden. A number of issues remain unanswered or uncertain in some part due to the possibly doubtful reliability and validity of the selected instruments. Those limitations apart there are some striking findings, which emerged from this survey that provide a platform from which other layers of this complex aspect of clinical interaction can be examined. The next chapter presents examines some of those layers and presents an account of the delivery of breast cancer care in the English NHS from the perspective of breast care nurses and women with breast cancer.

CHAPTER 5

THE DELIVERY OF BREAST CANCER CARE

Introduction

In chapter two I discussed how government policy since the Forrest Report (1986) has fashioned the development of breast care services in the National Health Service. I pointed out how the current delivery of breast cancer services is on the one hand heralded as good practice whilst on the other being pilloried in the media, and sometimes by government, for poor results in comparison with other industrial Western nations. This chapter will set out the context of breast cancer care as seen through the eyes of breast care nurses and women who use the service. The emphasis will be upon the treatment trajectory from the point when the women recollect becoming aware of something amiss, through treatment, to follow up when the women become individuals who have had rather than have breast cancer. This would have been affirmed, or otherwise, in routine outpatient consultation with a specialist surgeon (Allen 1998). This trajectory for both the women and the breast care nurses in this study appeared to be characterised by an intense but short-lived period of activity associated with diagnosis and initial surgery. This is followed by a period of surveillance undertaken by the breast care nurses, with varying degrees of engagement, whilst women were preparing for and undergoing further treatments such as chemotherapy or radiotherapy. The period ends with a leave taking when the women become just some of the vast numbers who attend outpatient departments for follow-up monitoring. This point in the trajectory was described by as “winding up the story” (BCN 4) or “it is not really a signing off but it’s a sort of pulling out” (BCN 23). I will interweave both the women’s and breast care nurses’ accounts in order to illustrate the experience of cancer treatment. Documentary sources will be used to contrast these experiences with the policy of a uniform level of service provision as indicated in clinical guidance (NHS Executive, 1997), BASO guidelines (1998) and the recently published consultation document outlining standards for cancer services (NHS Executive 2000a). In addition, breast care nursing professional guidance (Royal College of Nursing 1994) will be used. This chapter therefore sets out to provide the background against which the closer scrutiny of the work of breast care nurses offered in later chapters can be understood.

In the breast awareness literature women are encouraged regularly but not ‘ritualistically²⁴’ to check their breasts so that they are familiar with colour, texture, and contour, in order that they will recognise abnormalities and report them without delay (Bailey, 2000). A feature, although not one shared by all informants, was that the significance of the lump was tempered by other influences. There was variation in the way women claimed that they responded to suspicious lumps that were subsequently found to be breast cancer.

Failure to recognise the potential seriousness was a situation reported by Liz arguably confounded by prior experience of a benign breast lump:

“I found the lump when I was in the shower just washing and I thought “ummm this is a bit funny”. But I thought, you know, I’d had something before and it was benign so I didn’t do anything about it straightaway. I think I left it for a couple of weeks. I didn’t panic you know at all because the last one had been benign so I wasn’t worried really. But when it was still there a couple of weeks later I thought I’d go to the Doctor so I went.”

(Liz)

Similarly Helen, one of the participants in Focus Group 2 delayed reporting symptoms:

“I waited six weeks because my mum was ill at the time and we had a lot on with my mum and then once that got sorted out I went.I think I was distracted because my mum was poorly and I was more concerned about her, but I knew I would have to go. Whether that six week would make any difference I don’t know, but I wouldn’t have thought it would.”

(Helen: FG2)

Nevertheless, for most of the women in the focus groups response was immediate. Moreover, some of the women could remember the exact day of the week they found the lump, possibly emphasising the significance of their finding and marking the day as something which changed their lives. For example Pat, Mary and Marie, three women in Focus Group 1 when asked how quickly they sought medical attention when they found the lump responded:

²⁴ An unfortunate epithet attached to breast self-examination by the retiring Chief Medical Officer at the Department of Health in 1991.

Pat: Straight away the day after
Marie: The morning after
Mary: It was a Sunday when I found mine and I went on the Monday.
(FG1)

Similarly Brenda, one woman in Focus Group 2 remembered the exact day but also noted the significance and likely implications of her discovery:

“It was Friday because I’d two sisters who’d had it (cancer) just knew straight away what it was. I think that was Friday night...”
(Brenda: FG2)

In common with White et al (1998) most of the women in the focus groups voiced having strong suspicions that they knew what their lump meant and recognised in advance of diagnostic certainty that they had cancer. This is of course a claim offered in retrospect to its confirmation by medical diagnosis.

Since the Calman-Hine report (Department of Health 1995) in order for women to access specialist health care (a local designated breast unit) within the National Health Service they need to be referred following a consultation by their general practitioners. General practitioners are now advised to refer women for whom they have concerns about the seriousness of the presenting symptoms directly to the breast unit and neither carry out nor request diagnostic tests at their own behest. The rationale for this is that mammography in isolation can be unreliable and may result in false reassurance for woman and general practitioner alike (Given-Wilson, et al. 1997). The women’s experience of navigating through general practitioners to the local breast care unit was not in all cases straightforward. For example Tess, one woman in her early 40’s in Focus Group 2 reported:

“Not with my doctor because she thought it was hormonal. She said “come back when you’ve had your period”, that was another 10 days. I’d left it about three weeks because we couldn’t feel anything and I just thought (pause) so I’d left it about three weeks and she said “oh leave it” so that was another 10 days and then she was on holiday. And finally when I actually went back I went back with an ear infection and another doctor had a look

and he said straight away “Oh I don’t like the look of that”. I said “Oh that’s what my husband said” and then I realised.”

(Tess: FG2)

Most of the participants found their general practitioners very aware of the potential seriousness of their symptoms and responded by providing urgent referral to the local breast unit. One participant in Focus Group 1 entered the system through private health care and reported delays:

“I work for (employer) actually that’s why I saw them (non-NHS well woman/screening provider). I was in a private scheme you see. So they found the lump. Then I had a mammogram. They said there was nothing with the mammogram but the doctor and the nurse said “Well I should check it out because if there’s a lump there there might be something”. So I went and had the ultrasound and I think it took two weeks altogether before I got the result.”

(Jean: FG1)

Whereas Carol, a different informant in Focus Group 1 had greater difficulties getting health care professionals to take her symptoms seriously:

“No, I just had one (mammography) and he said go home, don’t worry about it. So I did and then I saw changes in my nipple. So I went back again two years later and again the mammogram was clear, but then I eventually had a biopsy.”

(Carol: FG1)

The current advice is that there should be minimal delay between referral from general practitioner to first appointment in the breast unit and subsequent communication of diagnosis. Short term delay is said to increase anxiety and long term delay, defined as longer than six months, is reported to have an impact upon survival (Department of Health 1997d). Diagnosis should be determined by triple assessment as outlined in chapter two. Ideally results should be communicated the same day or shortly after the diagnostic tests have been undertaken. There was in fact wide variation in the time it took for individual women to proceed from diagnostic investigations to being told the diagnosis. As the responses in Focus Group 2 clearly demonstrate:

Susan: I waited a week

Brenda: I knew that day. She (Breast Care Nurse) phoned me up because it was coming up to a bank holiday and she (pause) I don't know just with talking and what else she said "I got the impression you would like to know "well just the mere fact that she phoned and as I say I knew anyway.."

Wendy: I had another two biopsies.....

Anne: Two weeks

Pam: Two days.

(FG2)

Although immediate (same day or one stop) diagnosis might be preferred by many women and recommended in guidance to minimise anxiety this service would not appear to be uniformly available across England (see appendix 7 for breakdown of service provision as reported by breast care nurse participants and appendix 6 for profile of breast care participants). The breast unit where the focus groups were undertaken does not routinely offer a one stop diagnostic service although it would appear from the responses that at least one woman obtained a same day result.

Managing "bad news"

From the interviews with the breast care nurses the two different approaches to managing diagnosis and ultimately breaking bad news were adopted within breast units. The first of these is "one stop", the preferred option in guidance (BASO 1998), is where triple assessment is undertaken and after a short period (usually two to five hours) the diagnosis is communicated to the patient. In some units a multidisciplinary appraisal of the results occurs at a meeting prior to the announcement to the patient and treatment option(s) are discussed and the preferred treatment plan was decided by the team. A second approach adopted in other units, tests are undertaken at an initial out patient attendance, a multidisciplinary meeting is normally held in the intervening period, and the "bad news" is delivered at a subsequent out patient appointment. With this approach the preferred treatment option will have been decided in the multidisciplinary meeting prior to the bad news consultation with the woman.

The approach adopted to communicate diagnosis is said to influence how women cope with treatment and rehabilitation (White et al 1998). In the interviews with all participants this event was discussed. Frequently, as advised in guidance, information was sent to women in advance of a diagnostic outpatient appointment suggesting they bring someone with them. This additional person, usually partner or friend, was often invited into the consultation. The patients receiving bad news were usually attending a general breast clinic where large numbers of women are attending for appointments and not all would have or had breast cancer. To be the harbinger of bad news was seen by most, but not all the breast care nurses, as the role prerogative of medicine. In some cases this was irrespective of the breast care nurse's assessment of the particular doctor's skill in undertaking the task:

"It is always the doctor. I, we don't converse in that interview (bad news). That is their's. We are in the background and we take them (women) aside and then we take them to the consulting room."

(BCN 22).

The majority of women attending the out patient department will be there for the purpose of review following treatment or for communication of histology results and discussion of further treatment after initial surgery. The sensitive management of women who were to receive bad news, in and among women with competing needs, was discussed by the breast care nurses as requiring managing. The following account describes the management of women through a busy out patient session in a designated breast clinic in a teaching hospital:

"Now we have several rooms running down the back corridor so we have got eight rooms that we can use. We are seeing on average 70 to 80 patients in a clinic setting, so we have to give the impression that everybody is special. And we want to give that impression. And there are ways of doing that by very small gestures, getting people in, making them feel secure, asking them to undress, putting on a gown, and trying not to keep that waiting time there too long. But the clinic nurse will leave them then, come out and then hopefully doctor will go in soon after when he, or she, has had time to look at the case notes and the referral letter. So we try to and cut down that period of time actually. When we go into that room, they will be sat there just on the edge of the couch, or on a chair wherever they want to be. It is possible that a medical student may go in and take a history to start with but they have strict instructions that they must only be with a lady five minutes."

(BCN 5)

This account illustrates the logistical demands exerted by the sheer volume of patients moving through a system. Staff seemed to try, and were organised in such a way, as to attempt to ensure patient's interests were served. The perception of length of waiting time was minimised by keeping the women busy and on the move through the system. In addition, competing interests such as, in this institution, the need to ensure that medical students access to patients in order to ensure that educational priorities are also achieved. This particular outpatients department had been designed to ensure that attendees were moved from a small waiting area to another closer to the suite of consulting rooms until they finally were invited to enter for the consultation where the outcome of the investigations would be confirmed.

In another different breast unit where the "one stop" diagnostic service was offered the logistical problems of uncertainty of outcome made logistical management a very immediate problem:

"Particularly if it is a busy day and you have two results come through together. Sometimes we actually ask you to wait and put you down a couple of spaces and then by that time I have moved the person on. Now often this system works really well because people's reactions are so different. So it is not often that we get so that we are really doing some nasty rationing but every now and then. The problem with any one stop clinic is that you may have all beginners or you actually end up with six malignant results. In which case it is a crude sort of triage system like the people who burst into tears or faint get more time than the people who look as though they are still holding together."

(BCN 2)

The breaking "bad news" scene

In advice pitched particularly toward a medical audience Faulkner (1998) suggests that patients frequently are aware of the seriousness of their situation and therefore news is not broken it is merely confirmed. She suggests that the patient's perception of the seriousness should be sought and if "the person knows or suspects the truth" (p130) then a warning shot or exploration of understanding should follow. In this study no observations of clinical encounters where bad news was communicated were undertaken

and the accounts of these events are based on hearsay from patients and breast care nurses. The accounts nevertheless suggest that the diagnostic bad news interview have a planned and almost theatrical quality. It appears that the scene is carefully stage managed to deliver an already scripted interaction, between doctor and patient with predetermined and practised roles, entrances and exits. The patient is thus the only participant (and their friend/partner if in attendance) who does not know her lines in advance. An additional uncertainty for the permanent cast is the absence of knowledge concerning how the patient will perform. The stage management may well ensure the script is adhered to and direct the action. Breast care nurse 1 who works in district general hospital breast unit describes the scene into which a woman, with or without someone in attendance, routinely enters to hear her fears confirmed:

“Well there is the consultant, the secretary is always in because he dictates everything, the clinic nurse and myself (Breast Care Nurse). The clinic nurse and myself always stand behind the patient and the secretary is in the corner.”

(BCN 1)

In contrast in a different setting, during another reportedly rehearsed event, on this occasion the surgeon with breast care nurse in attendance engages in a further clinical examination. This laying on of hands suggests the human mastery involved in medical clinical judgement irrespective of the reliability of technology:

“Often he’ll examine the breast again, so they’ll be undressed, He’ll make sure they’re sat up on the couch hold their hand and tell them this has come back the cancer or he’ll say it’s cancer and he’ll talk through what that means.”

(BCN 3)

In addition in this scenario not only does the surgeon have his script and staging rehearsed but has his leading lady, the patient, the woman, semi-naked.

Breast Care Nurse 9 works with two different breast surgeons, in an inner city district general hospital breast unit, who have slightly different approaches to breaking bad news but was able to give an account of both scripts:

“One of them tends to say “Well we have the results and I am sorry to say that it is cancer....” whereas the other one tends to say “You came up to see me because you had a problem etc and the tests show you have cancer.....” So basically they are fairly similar. They are easy to work with as they both seem to work along the same lines. Just slight little difference in how they present information but I would say it is fairly similar.”

(BCN 9)

A number of the breast care nurses interviewed offered views on the capability of particular surgeons to break bad news:

“He is quite good really when he does it. But I suppose he wrote the script. Strangely enough I rarely interrupt because he is good at it there is no need really.”

(BCN 4)

In this account she goes on to describe a scenario when the patient appeared not to be following the surgeon’s script:

“One afternoon this woman was sat there looking completely and totally lost and it was obvious to me that something was wrong. He was carrying on with his script and she had totally lost the plot and he hadn’t noticed although he’s good at that. But on the occasions that kind of thing happens then I interrupt. He is good at shutting up and letting me do that but it isn’t often he does not get it right.”

(BCN 4)

Faulkner (1998) suggests that a level of shock is the inevitable consequence of bad news and therefore time is necessary before concerns or feelings can be explored. This account offered by Breast Care Nurse 8 describes a well meaning but possibly over zealous commitment by a surgeon for information giving:

“She over tells them and in fact we have got her on a (name of a communication course) because she makes it very hard for herself I think. Because she is so good and she wants to do everything for the patient, making it better for the patient she gives them the news she does tend to use the word tumour – which we are working on her – she uses the word tumour but then they don’t get a break. The patient is you can see them literally holding on while she then goes on about surgery and about the follow up treatment. I feel she needs to quit whilst she is ahead really. Break the bad news and then let me have some time with them just to release all that emotion. As soon as I take them away just a touch and out comes a question “Does that mean I have got cancer?” They have remembered nothing”

(BCN 8)

Breast Care Nurse 14 describes a setting where there are two very different approaches: one in which the breast care nurses deliver the news, and one which follows a medically led approach:

“There are two different ways if working with the two different consultants. One of them likes us to break the news and go through the various treatment options which we have discussed with him²⁵ beforehand, and then he will come in and go through it all again. The other consultant likes us to be there while he breaks the bad news and then goes through it afterwards with the patient.”

(BCN 14)

Whereas in one unit contrary to the BASO guidelines (1998) the breast care nurse reported not being part of the bad news scenario:

“It is not normal here for the breast care nurses to be in the room when the consultant or doctor gives the diagnosis. I think it is down to personalities and also the workload. I mean I have known it isn’t usual but I have known situations where ten women are given a diagnosis of breast cancer. Well it’s just impossible to organise all that. If I happen to be there it is a stroke of luck but if (clinical associate) knows she is going to give somebody bad news she will come and get me.”

(BCN 18)

Whereas in the focus group interviews there was a notable absence of talk about the how, where, and who by, of the bad news event. The one story:

“You’re that shocked you don’t know what he’s talking about. You’re not listening really are you.”

(Linda: FG1)

Whereas for Liz how she was told or rather how the scene was set on which the drama of the news was presented was remembered with an enduring clarity.

“I wasn’t worried. I just wasn’t worried. I don’t think I’d time to think about it. I went into the examination room and suddenly all these people. I thought why are all these people here? Normally it’s just the consultant and his nurse and suddenly there was about four people (pause) and this woman who I’d seen before who was the breast care sister and I suddenly thought there’s something going on here (pause). And what happened next? I think, I think, that was it, really they’d already decided

²⁵ At diagnostic meeting with the multidisciplinary team

that it was (cancer) and then I got whizzed into the Breast Care Sister's office."

(Liz).

A recurring, but not universal, feature in the narratives is the presence of the breast care nurse at bad news scenes. She originally appears to be cast as an observer listening, almost as an extra or as having a minor part, until the scene becomes emotional or until the medical contribution is over and the action needs to move on. Crudely, the breast care nurse's role in terms of the patient at that supposedly critical moment is to be available for spontaneous reassurance if the scene deviates too far from the script. It is as if their role is to be available for emotional containment and possibly to protect the teller of the news from the impact of that emotion. It seems incumbent on the breast care nurse to remove the women (and attendant other) to another setting or to facilitate the exit "stage left" of the doctor. In addition, another meaning ascribed to the role is that described by Liz who reported that it was seeing the breast care nurse that made her realise the seriousness of what was happening. This was affirmed in the interview with Breast Care Nurse 8 who works in a metropolitan teaching hospital breast unit:

"It has come to light talking to the patients that they actually know they are going to get bad news when they see me going into the consulting room. So patients who have not been to clinic before – I don't know how it works but they know when they see me going in they know that it is bad news"

(BCN 8)

From these accounts it would seem that although the breast care nurses contribution to the narrative in the breaking bad news scene is minor²⁶, they contribute in a variety of ways to the scene and moving the action onwards. Their presence would thus seem to have significant symbolic importance. In chapter 6 the importance of listening and observing as contributing to knowing the patient will be examined in greater depth.

²⁶ Exceptions BCN 11, 14, 17 and 26 who are informants in some cases

Women's responses to diagnosis

White et al (1998:20) reported that women's responses were very strong and language such as "devastated disbelief, horror, petrified" were used by their participants. This has resonance with a number of the auto/biographical accounts such as Butler and Rosenblum (1994:10): "I shut my eyes and saw absolute black, no lines of red and purple, pure black. My agitation lifted me off the table and I started walking around the examination room in small steps, working off the tension. I thought I might put my fist through the wall". This is repeated albeit in more temperate language in Moch's (1995:13) analysis of twenty women's breast cancer stories: "The initial shock was the worst. What bothered me was not so much the cancer but what was going to happen to my life". Some of the women in the focus groups voiced varied responses to diagnosis and surgery. Some participants were thankful and willing to have a speedy progression through from diagnosis to surgery almost bypassing possible support or information from breast care nurses:

"I could either wait till the following Friday or they could do it in the morning "So I said well I might as well instead of sitting around worrying about it" I said "just get it over and done with". It was a shock but I thought I might as well have it done."

(Pam: FG2)

Whereas another woman reported a different response: wanting to control events in contrast to the other account which was more suggestive of a willingness to give up control of events in order to move beyond talking about to beginning treatment.

"I had to fight for it (not to have a rapid admission). He (consultant) was going on holiday and he said "Well you'll have to wait five weeks" he said "I don't want you to wait five weeks". I said "I'm not coming in Monday" and he said, "Well I don't really like that" and he ummed and arrghed and I just stuck to my guns I just wouldn't give in. I had to prepare psychologically. I had to be strong physically and psychologically and I'd also read that if you'd had the operation so many days after you'd ovulated you had a better chance of (pause) your recovery was quicker and I'd worked it out. I knew it was going to be Monday and in the end it was another week because I wouldn't have it. I knew I was going to have a mastectomy, it wasn't that I was thinking whether I was going to have it or not. I just wanted to have it planned."

(Tess: FG2)

Taking the analogy of the bad news scene as a theatrical event her desire to assert control could be rooted in a will to have her leading lady status recognised. In reality the script demands that the woman remains compliant with the medical objectification of the tumour as the 'star of the show'.

First meeting: assessment

The starting point of the breast care nurse-patient relationship in any formal sense commences after the doctor has exited 'stage door left' or the woman has been "gathered up" and taken to another room. This relationship starts with establishing what the woman (and their partner/friend) understands. For some of the nurses, as in the account given by Breast Care Nurse 6, this is because of medical misinformation:

"Well with the one (consultant) who does the triple assessment because he's so "this is a naughty lump" or he says "This is a tumour". First thing I say is do you understand that you've got breast cancer. Sometimes they have and sometimes they go "oh my God I've got breast cancer he said I've got a tumour". That's the first thing and then I do well ummm it really depends on the woman. Obviously if she's too fired up I bring in their partner and leave them alone and when they are compos mentus I go through what's been said."

(BCN 6)

Whereas for others the establishment of mutual knowledge becomes a pre-emptive strategy in order to begin collating information about the woman:

"I ask them to tell me what they have just been told and I ask them that question for two reasons. One is to see where they are starting from what they remember being told but the other one is so that I can check out that the information that they have been given is actually accurate because most times it isn't or maybe options haven't been discussed with them. So I tend to check out at the start what's been said."

(BCN 18)

For some of the breast care nurses this session has a large information agenda, particularly for those breast care nurses where this meeting is the only opportunity for them to work with women prior to admission for surgery. Whereas for other breast care

nurses the service was organised according to the woman, should she wish to be seen at home, or to revisit the hospital to discuss treatment options, the meaning of cancer or other issues within the context of breast cancer. From the breast care nurses' accounts these home visits were viewed as the 'gold standard' level of breast care nursing. Those nurses who were unable to offer home visits in the period between diagnosis and surgery were often apologetic and in some cases blamed resources and managerialism for this perceived reduction in service quality. The impact of managerialism was twofold: firstly, the managerial scrutiny of activity in relation to budget streams sometimes curtailing hospital based nurses activities associated with community outreach; and secondly, prioritising breast care nurse activity to input that is monitored in breast unit accreditation processes.

Those breast care nurses who in effect had to make the most of this encounter because it was perhaps the only face-to-face encounter gave accounts similar to Breast Care Nurse 2:

"So I have got a quite sort of heavy psychosocial objectives of what I want to find out about this person. I also want to try and make sure that whatever it is that can be done, in terms of treatment, goes along with what that person feels they would like done, and sometimes that is about being given choice, but sometimes it is not about being given a choice it's about being told what will happen.....I go in with a quite heavy agenda. Now somewhere in that there has to be a kind of space bubble for her stuff, and I try and put that in as soon as possible, because so often what her stuff is, a lot of mine will be covered and then I only have bits to ask. Otherwise it feels a bit like an official agenda."

(BCN 2)

For some breast care nurses who undertake home visits the first interaction was more concerned with providing care and support:

"I suppose in a way in the clinic situation, and obviously the patient is very shocked, they don't really they can't really think about much at that time. So I suppose we sort of get them out of the clinic as soon as reasonably possible but having said that sometimes you are in the room for half an hour it just depends. But what we would do at that point is arrange to see the lady at home prior to admission because normally the last thing the surgeon tells her is the fact that there is an admission date."

(BCN 29)

In contrast the home visits appeared to have a range of purposes: information giving, eliciting concerns, choice of treatment if options are on offer and initial assessment. The agenda for home visits was most frequently described as driven by the women; nevertheless the breast care nurses appeared to have a menu of subjects they wished to cover in the interaction. For example:

AT: At the home visit what do you talk about?

BCN13: Really it's about their attitude to cancer often and the fears. The first fear that we all get is the fear of dying. So I tend to talk through that, and then the treatment options, and I try to reassure them as such that treatments are much better now than they were two years ago or three years ago. And say "you must never compare yourself with someone else" and you really try, you would try and reassure them at that stage that they are in good hands, and that they are getting the best treatment.

(BCN 13)

Decision making

As presented in chapter two, in the UK and elsewhere, there was until twenty years ago in the United Kingdom and elsewhere little option for women in terms of treatment for primary breast cancer. Although the extremity of the surgery may have depended on surgeon preference the treatment outcome for the majority of women was amputation of the breast. Following the weight of evidence that emerged in the 1970s and 1980s, the trend increasingly moved towards wide local excision with additional treatment (radiotherapy, chemotherapy or endocrine manipulation) where limited surgical intervention would not alter the likely outcome. Moreover, rates of mastectomy were an issue that emerged as a quality indicator in some of the interviews with breast care nurses.

Concomitant with optionality in treatment comes decision making. I have argued in chapter two that much of literature relating to decision making has focussed on the willingness, and fitness, of women to participate in decision making. Decision making in the context of breast cancer refers to specific treatment options, surgical approaches

including breast reconstruction, and in some cases whether the woman wishes to be treated with the options available from conventional Western medicine. The main focus of much of the early research was on the psychological burden of decision making on women. With hindsight this could be seen as paternalistic, with the requirement for overwhelming evidence of patient capability especially where women are concerned, before allowing them to make or participate in decisions (Ashcroft, et al. 1985; Morris and Royale 1987; Morris and Royle 1988). More recently research, predicated on the assumption that involvement of patients is fundamentally correct, has focussed on strategies to facilitate involvement of women in decision making in breast cancer (Beaver, et al. 1996). In the standards produced by the Royal College of Nursing (1994:4) topic 2 defines the role of the breast care nurse in relation to treatment choice as: “ All patients with breast cancer are aware of the treatment options available. They will have the opportunity to discuss their situation with a breast care nurse, and make an informed choice with the nurse acting as advocate if necessary”. That standard suggests that breast care nurses have a very significant role in ensuring women are provided with the information on which to make decisions and where necessary “advocate” for the woman. Unless the standard represents a wish list rather than real practice, it would seem reasonable to assume that breast care nurses believe they have the authority and the ability to identify and communicate a woman’s wishes thereby ensuring the woman’s decision is acted on and they receive their preferred treatment.

Treatment choice and how that was facilitated within the clinical context was a strand that emerged in the breast care nurses accounts. As Breast Care Nurse 23 outlined, much in keeping with the RCN standards, her priority was to ensure the woman makes an informed choice concerning treatment:

“My agenda is to ensure that they understand what is going on and I suppose in a word it’s informed consent, which I find very difficult. Because I go giving them a crash course in breast cancer really you know der di der di der di der and then I want to go. It’s not as cold as that but that’s you know, I come away thinking “oh my goodness she is going to cry, so upset about the possibility of having lymphoedema and stuff”. Now some people are ready for that level of truth but some people are not ready for that so you have to pitch it where they are at.”

(BCN 23)

Moreover the post diagnosis session whether undertaken in the hospital or in the woman's home is an opportunity to determine a woman's wishes for treatment although in the BASO guidelines this is couched more in terms of "the opportunity to have questions answered and be given information" (BASO 1998:7).

Nevertheless, other issues emerged which have some bearing on the fitness of women to participate in decision making and contextualise the tensions implicit in patient involvement. The term fitness is used to emphasise how other factors might influence potential to be fit and may function as limits to an equal relationship between patient and health care providers in terms of decision making. Firstly, speed may impact upon capability to decide as one woman recalled:

"Well I saw him (consultant) on the Tuesday and I was (admitted) on the Friday. It was frightening."

(Mary: FG1)

Moreover with the current emphasis in government policy on services that offer speedy response from symptom to initial treatment this may impact upon available space for information giving to occur. Quality indicators (NHS Executive 2000a) set the minimum standard at two or less outpatient visits for diagnostic purposes for less than ten per cent of all new breast patients irrespective of whether malignancy is confirmed. In addition, more than ninety per cent of women should be admitted for initial surgery within a fortnight of diagnosis (BASO 1998).

Secondly, the manner in which choices are presented may influence how an individual responds to information:

"To a large degree (consultant's name) will guide them as to what is the best decision to be made. If it²⁷ doesn't really matter if it really isn't a problem well then I (BCN) will take them and go through options because sometimes (consultant) will offer a wide local excision when the patient wants a mastectomy."

(BCN 8)

²⁷ Where clinically there are treatment options which would more than likely produce similar results in terms of likely prognostic outcome

In this account there are a number of competing issues at work. The consultant “guides” the woman to the “best decision” and in this case, “best” is based on scientific (medical) indications. If there is, based on the science, choice, the consultant has a “preferred option” that unless questioned by the breast care nurse will be (implicitly the only one) offered. The woman’s preference is something that the breast care nurse “knows” but does not appear to voice within the formal clinical encounter of consultant – patient – breast care nurse. This knowledge is elicited outside of, and separate from, the doctor – patient consultation and known only to the breast care nurse and woman. The breast care nurse presumably communicates that knowledge to the doctor, and/or multidisciplinary team, so that the woman receives the treatment she wants. The communication of a woman’s wishes usually occurs at the multidisciplinary breast meeting “and it is mandatory that these nurses²⁸ attend” (BASO 1998:8).

However in many of the units described by breast care nurses in this study particularly in those where a one stop service operates the multidisciplinary meeting is held prior to diagnostic information being given to the woman and before the breast cancer nurse can elicit her wishes. As described in this account from Breast Care Nurse 18:

“Every woman is discussed at that meeting before she is told that she has breast cancer so everybody has input into that meeting. You know if the oncologist feels that she may be a candidate for primary radiotherapy rather than surgery you know. So the decision is made at that meeting as to what advice will be given to them. Women, who to control the disease don’t need a mastectomy, will often be told by a surgeon: “You don’t need to lose your breast. We just need to take some breast tissue away”. But I will actually discuss with them so they do have an option to have the breast removed. The majority of them don’t (have mastectomy), but some of them do, and some of them even before I say that will say to me “I have got cancer of the breast and I want it off”. So then we talk through the issues. But although the surgeons will not actually offer the woman a choice, I will then discuss with the woman that she has that choice and the surgeon is quite happy to discuss it with them. So just because, in all fairness to them (surgeons), because they don’t always offer the choice it doesn’t mean that they are not. They will comply with a woman’s choice.”

(BCN 18)

²⁸ Breast care nurses

This account is again expressive as it illustrates, within the context of the diagnosis of a life threatening disease, an authoritative voice presenting a preferred option. The woman then, more than likely in a distressed state, is taken aside to discuss options. This discussion is undertaken with another health care professional, who they may have only just met, who in addition may well be perceived as having a different, possibly lower, authority or status and unsurprisingly most women accept the option presented by the surgeon.

A third influence exerted on decision making may be an effect of the scrutiny currently on cancer care in general, and breast cancer in particular. This puts emphasis on the volume of specific surgical procedures and the criterion upon which judgment about the quality of medical care is based. This is seen in this account offered by Breast Care Nurse 15 talking of the breast unit where she works:

“Well at the moment there is a bit of controversy about the mastectomy rate here. The reason being our consultant changed in the last three years and the previous consultant had the lowest mastectomy rate when you look at the stats(istics) from around the area (sub-regional cancer registry). We have suddenly got the highest mastectomy rates in the last year and the majority of the cases have either been patient choice or the decision, the final decision, has been made by the oncologist and I feel that the patient should be offered a mastectomy. The surgeon, as I say at the multidisciplinary meeting, but he, I know will say “She (referring to the breast care nurse) is going to say that this lady needs a mastectomy”. Because he doesn’t like doing them, but normally he takes the advice from the oncologists. Once they have got the pathology results, and certainly the patients with multiple DCIS (ductal carcinoma in situ), or margins unclear, margins or unclear certainly of millimetres, and s/he will say “I’m following the guidelines”. Because on questioning²⁹ somebody says: “Well why is your hospital rate higher? I can’t believe you’re following them”.

(BCN 15)

The public scrutiny may well not only exert an influence upon how results are translated into preferred treatment plans but also on how options are presented to women.

²⁹ Scrutiny occurs at various levels through clinical audit, and at visits as part of the accreditation process for cancer unit status.

Fourthly, a determining factor, or at least an aspect of decision making for some women, may well rest on the availability of reconstructive surgery as part of the whole package of primary surgical intervention. Breast units are charged with giving advice about reconstructive surgery and if not locally available should have “a recognised line of referral to a breast or plastic surgeon with expertise in breast reconstruction” (BASO 1998:6).

Although all units in this study claimed to offer reconstruction there was considerable variation in how availability was defined and this appeared to influence how information was communicated to patients:

“We don’t usually do reconstruction at time of surgery as we have to get a plastic surgeon in from (name of another NHS Trust) and it’s more difficult to get a day when two surgeons can work together. He has offered to do the mastectomy (plastic surgeon) but the breast surgeons won’t let him do the reconstruction they say they can’t do them. So they offer it (reconstruction) to the young ones twenty eight year olds other than that it’s only tentatively mentioned but it’s not mentioned at that stage (diagnosis) anyway.”

(BCN 6)

Lastly, the basis of decision making for women may be founded on a different agenda from that which constructs medical advice. As Breast Care Nurse 22 pointed out :

“I think the fact that we are in a rural district will make a difference they just want to get the surgery over and done as: “ I (patient) have got the farm to look after, the kids, this is going on that is going on, the children are in horse trials etc just do this.”

(BCN 22)

From these accounts decision making is far more complicated than the rhetoric implicit in standards emanating from government, and professional bodies would suggest. The narratives suggest that decision making is a complex and difficult process. Not only is it dependent upon the woman being given information and having acquired knowledge but it is also one that is potentially influenced by the authority and status of the informant. Moreover, the ability of the woman to be an equal partner, or even participate, in decision making may be made all the more problematic by the shock of diagnosis, and

the distress that precipitates. I do not wish to suggest that those influences should exclude women from the decision making process but I use them to illustrate how they may work to restrict or even obviate a woman's capacity to perform. A further intricacy of the decision making process is the assumption on the part of breast care nurses that they are advocates for the women they counsel (Tait, 1996; Stewart 2000).

Ward visiting

The responsibilities of the breast care nurse whilst a woman is an in-patient are described in the BASO guidelines as: "The nurse should be available to see patients pre and post operatively on the ward where such matters as arm exercises and operative complications worrying the patient can be discussed with any personal problems. Temporary prosthesis may be fitted by the nurse before discharge and booklets given regarding treatment, hospital support groups, etc" (BASO 1998:7).

The Royal College of Nursing guidelines make no specific recommendations about the nature and scope of the breast care nurse's role while a woman is in hospital having initial diagnostic or primary treatment surgery. Language used to describe the ward located work is in itself illuminative. The breast care nurses describe themselves as "popping in", or "up", to the ward, "visiting", "saying hello" which seems to portray the nature of their status in the ward environment as that of a visitor.

There was variation among the participant breast care nurses about frequency and amount of time spent visiting women on the wards however, there was some commonality relating to purpose and function. The ward was seen as the natural territory of the nursing staff who undertake the main body of their work there. It is not the domain of the breast care nurse. A number of the wards described to which the women undergoing breast surgery were admitted also accommodated other 'types' of patients. Women undergoing treatment for gynaecological conditions were often mentioned as being housed alongside patients with breast cancer. Breast care nurse 3 describes typically the nature of her work:

AT: And what happens in those daily visits? What do you talk about?

BCN 3: Superficial things because it's an open ward and it's not the right format for talking about things on the ward. I never feel it's the right format and they're often busy on the ward you have the drains³⁰ or whatever and they'll have made friends with the woman opposite. So it turns more into a group chat than anything. One you just talk about the surgery how they are coping with it what the (wound) drains are what's going to happen.

A number of the breast care nurses discussed how they had no wish to diminish the skills of ward-based staff. As Breast Care Nurse 29 discusses:

“Obviously they are being cared for by the ward nurses and you wouldn't want to presume that you were the only person who could talk to them but I like to see them pre op and they seem to appreciate that, you know, to see a familiar face. Just to see if they are settled into the ward and if they have got any last questions. And then post operatively I mean there are issues like looking at the wound etc so it is still important to be around.”

(BCN 29)

Nurse specialism as discussed in chapter two has often been criticised for deskilling the generalist nurse and territorialising aspects of care such as psychosocial support for particular client groups. The breast care nurses' accounts were littered with concerns about territory both in relation to other nurses and other professions, particularly medicine. This may well reflect the current debates associated with health care delivery and demarcations between and across health care workers and professionals in the National Health Service. The issue of defining breast care nursing and territorial demarcation will be developed in chapter seven.

Post surgery, “definitive diagnosis” and preparation for future treatment

Following discharge from hospital following surgery for primary breast cancer most women were invited to attend a follow-up outpatient appointment where their histology results³¹ are confirmed; this was referred to as definitive diagnosis by the breast care nurses. From the descriptions offered this appointment appeared to involve a clinical

³⁰ Wound drains

examination of the woman by the surgeon to inspect the wound. This was followed by information concerning histological findings from the surgery and discussion of further treatment. The information given typically adopted this pattern:

“They will talk about the grade of a cancer they will talk about how big it is and then will talk about the patient seeing the oncologist.”

(BCN 18)

In units where this information was given in the outpatient department the breast care nurse was usually, but not always, present when this information was given to the woman.

In a few centres the planning of further treatment was discussed following confirmation of the definitive diagnosis while the patient was still hospitalised. In two breast units the information concerning definitive status was supplied to women by the breast care nurse during a home visit and presented within the context of information about further treatment:

“Ours are told at home by (other BCN) or myself and then they come to the surgeons. Having been told at home what might be said to them they are not sat for an hour and a half stewed up feeling sick waiting for definitive answers. (When) they go, they know exactly what is going to be said. They have three to four days to think about it and they’ve got questions. So they go in informed and know what to ask.”

(BCN 22)

The breast care nurses saw a large part of their input around surgery was to prepare women for further treatment. Part of this forewarning appeared to include information about the content of the post surgery outpatient appointment so that the women “know what to ask”. That is the women were, potentially, more prepared to engage with the doctor(s) and participate actively by questioning.

As described in chapter two there are three main routes through the adjuvant management of breast cancer: Chemotherapy, radiotherapy and endocrine therapy. There is a paucity of guidance (Royal College of Nursing 1994; BASO 1998) connected

³¹³¹ Extent of differentiation, receptor-status, lymph node status, and margin clearance producing a more

with the role of the breast care nurse associated with the prolonged period in the woman's journey through adjuvant treatment for breast cancer. This omission may relate to the organisation of cancer services particularly in the case of radiotherapy³² and the increasing sub specialisation of nursing (and medical) roles within cancer care. Only three of the breast care nurses interviewed were involved actively in the administration of chemotherapy to women. None of the breast care nurses were based in a cancer centre and therefore they were not involved in close monitoring of women undergoing radiotherapy, although a number were part of a breast unit within the same NHS Trust as a cancer centre. Most of the breast care nurses claimed to hold a 'watching brief' during the six to eight weeks of radiotherapy, six to nine months of chemotherapy, and dual modality treatment for those women who had both. All medical surveillance during the period of adjuvant treatment should since the Calman-Hine report (Department of Health 1995) be undertaken by an oncologist in the designated breast unit supported by a clinical nurse specialist³³.

Adjuvant treatment: "just having radiotherapy" (BCN 1)

The period of radiotherapy appeared, from the interviews with breast care nurses, to be outside their domain except in special circumstances – almost a case of being out of sight geographically and therefore out of mind:

"When they go off for radiotherapy what I say is, will they contact me as soon as their treatment has finished and I will go and see them."

(BCN 21)

Two different explanations were offered for the minimal contact by the breast care nurses. One, a very honest response suggesting that the problems women experience during radiotherapy were less dramatic and "less medically interesting" as described by

definitive picture of stage of disease (see Chapter Two)

³² Radiotherapy is provided at cancer centres; although the designated breast unit may be situated in a NHS Trust which also is a designated cancer centre. Most women who undergo radiotherapy have to attend for treatment at a geographical location different from that where they received their surgery or where they attend for out patient follow up.

³³ The particular variant of nurse specialist is not specified. From the interviews this was an area of conflict in a small number of units where a cancer nurse specialist was employed in addition to breast care nurses.

Breast Care Nurse 2 who works in a teaching hospital based breast unit. The other more frequently offered explanation for the loss of contact was related to the women having:

“Enough on their plates travelling backwards and forwards to (the name of cancer centre) and they are pretty tired.”

(BCN 21).

In the interviews with women with breast cancer, much of the discussion of the experience of having radiotherapy related to transport difficulties and the impact of road works, rather than the actual experience of having the treatment. As described by Mary:

“It is over and done with in a matter of seconds you’d taken all that time to travel there and you knew you’d got a long journey back.”

(Mary: FG1)

The women described the experience as tiring, demanding, and they remembered having feelings of being isolated.

“That was a lonely time. That was a very lonely, that was very lonely. I thought it was a very lonely experience.”

(Liz)

In comparison to radiotherapy, the experience of chemotherapy took both longer in time and also seemed to be perceived as more demanding for many of the women. What was apparent was the different regimes produced different levels of symptom distress.

Moreover, response and rebound from the chemotherapy produced different treatment trajectories for individual women. This is clearly illustrated in this exchange from Focus Group 2.

AT: You have the chemotherapy here? How’s it been?

Brenda: Fine

Helen: Horrible

Susan: Touch wood, I’ve been fine with mine. I’ve just had a bit of indigestion and a sore mouth. I kept my hair. I’ve been quite lucky.

Pam: I’ve found it’s been quite all right

Anne: I have too, I think I got off lightly compared with some. I’ve met others having their treatment and they’ve had more side effects than me. I mean there’s different treatments isn’t there? They affect people differently but I think I got off lightly.

Helen: Well I just don’t like it. I don’t like the tablets or anything. I mean my stomach churns. I really don’t like them. I feel sick for a week and then I force myself to go out after a week. I don’t go out for a

week I stay in bed for two days. I have a bucket in the car, in the living room, everywhere you go there's buckets, because I feel for a week like I'm going to be sick all the time.

(FG2)

Costain Schou and Hewison (1999) describe in their study that followed cancer patients, many of whom had breast cancer, through treatment. With a certain elegance, they use the metaphor of the "treatment calendar" which patients navigate. They suggest that patients step out from a personal calendar and follow one constructed by individual responses to treatment. Helen (FG2) effectively describes that experience of being on a treatment calendar and underscores the tension with her real world which this creates for her. This tension was also evident in Carol's account from Focus Group 1 who then made a decision to withdraw from the calendar set by treatment and return to what she described as "normality":

"I had six months off work. I was climbing the walls. I wanted to get to normality and if I'd had another three months of chemo I'd finance to think about, I'd gone down to half pay. I'd also my own family to think about and I felt personally to get back, to as I say, normality was the best tonic for me ever and I haven't looked back and I don't regret it. That doesn't mean (pause) That was for me."

(Carol: FG1)

The symptom distress caused by chemotherapy for the women in both focus groups was rated firstly the nausea, vomiting and taste changes and secondly hair loss. In addition a number of the women who had completed chemotherapy reported residual more long standing effects particularly non specific bone pain. The role that the breast care nurses described during this period was one of surveillance to monitor how women 'coped' and that remained compliant with treatment. The next section outlines that surveillance process.

Monitoring

None of the policy documents examined (Department of Health 1997c;1997d; NHS Executive 2000a; 2000d) or standards developed from professional organisations (Royal

College of Nursing 1994; BASO 1998) provide a template for the ‘ideal’ breast care nursing contribution. Tait's (1994) study undertaken for Cancer Relief Macmillan provides some insight albeit now superseded by initiatives emanating from the Calman-Hine report (Department of Health 1995). Nevertheless, Tait argued at that time that the role of the breast care nurse had developed *from a context where there was little* consensus concerning optimum treatment. Today there is probably far greater agreement concerning optimum medical care and breast care nursing has become a constituent aspect of multidisciplinary specialist care provision for this client group. In this period of health care delivery characterised by the rhetoric of rationality and exemplified by allegiance to evidence based practice, it would seem a safe assumption that a respected, and often used example of particularly effective nurse specialism, would practise with some cohesion and consensus. Subsequent to the initial phase of intensive input, there was no discernible similarity in the way services provided by the twenty nine breast care nurses were organised. Some units (breast care nurses) had protocols for monitoring³⁴ patients, usually in the home, for the first year from diagnosis. This was separate from attendance at out patients (BCN 11 and 14, 13). Some followed up patients at regular intervals until treatment was complete by visiting at home (BCN4, 15, 19, 21, 28, 29); this was not a formal policy but an approach adopted as it seemed a “good idea”. Others saw the opportunities afforded by women attending outpatients for medical follow-up³⁵ (surgical or oncology and/or joint breast clinic) as somewhere where they could monitor women (BCN 2, 5, 6, 8,9, 12, 13, 17, 18, 20, 23, 24, 26, and 27). Some breast care nurses offered a form of telephone surveillance (BCN 2, 5, 12, 13, 22, 25) where they telephoned women at points during chemotherapy or radiotherapy treatments. Some breast care nurses offered drop-in clinics that allowed women with difficulties to self refer (BCN 9, 23, 25, 27,). Others followed up patients at regular intervals until treatment was complete by visiting at home (BCN1, 3,4, 8, 15, 19, 21, 28, 29). A self-referral service, usually telephone based, which might initiate a hospital or home encounter or on the telephone interaction was the approach, offered by Breast Care

³⁴ The term monitoring has been used here to best describe the purpose of contact between breast care nurse and woman. This monitoring in terms of content, purpose, structure, recording, will be examined in greater detail in chapter 6.

Nurses 25 and 27. In contrast Breast Care Nurses 17 and 23 offered a needs based service dependent on their assessment of what individual women required, or were considered, to require although other factors such as geography appeared to influence availability of home visiting.

Irrespective of the organisational structure for continuity of support, and/or the positive and negative ramifications of operating one type of approach over another, a number of tensions were discussed as influential in determining the type of monitoring offered. One tension related to the relationship between the breast unit and cancer centre and ownership or responsibility for individual women. This movement between organisations appeared to present difficulties in relation to ensuring continuity of monitoring:

“This is the main difficulty I have in my role my contact is completely gone once they go to the (cancer centre) because I don’t feel I can disturb them. They do have a breast care nurse at (Cancer centre) but she is carrying her own caseload. They have chemo nurses in the chemo unit but from one to one like I had with them before, then nobody and you build up rapport and you build up everything and then you’ve lost it all. They can come back to me and still contact me. They can still come and see me and I love spending a day at the (cancer centre) so that I can catch up with those ladies that are having chemo.”

(BCN 22)

Irrespective of the approach used to monitor women the main, but far from sole, purpose of monitoring appeared to involve keeping an eye on women in order to assess whether or not they are coping. Although it was difficult to establish on what basis coping was defined, or if it held a common meaning among the breast care nurses:

“In the beginning in the very early days it was very much how do I cope with and psychologically how am I going to cope. And three months down the line they appear to be coping much better in all aspects really and at six months most of them are doing OK but that’s often when you find the ones who aren’t. There are just one or two that’s not coping with the implications of cancer and it tends to be the implications of cancer I find rather than

³⁵ This medical follow-up might be in surgical clinic, oncology clinic, or both depending on the breast care nurses’ attendance.

anything else and that colours them all and they start looking at relationships.”

(BCN 14)

Whereas Breast Care Nurse 15 saw the purpose of monitoring, in her case achieved through home visiting, as:

“(The) support visit (is) really a support visit. Support as in looking at symptoms, how they are actually coping not just themselves but sort of family issues as well you know how it has interrupted their lifestyle , advice, it’s there for support and advice because you know if you are suddenly not feeling yourselfit’s getting round the sort of areas of sexuality and those kind of things the weight gain, that they get just doing nothing possibly libido loads of those kind of issues and children, exams, having problems with the family it is those sort of things that they have no one else to talk to.”

(BCN 15)

This support is cogent with the “treatment calendar” metaphor adopted to describe the feelings engendered by prolonged treatment in Costain Schou and Hewison’s study (1999). The support offered by the breast care nurse could be seen as assisting women to keep two calendars, manage two parallel diaries. The treatment calendar contingent on medical priorities and a social calendar containing the womens’ real world priorities. The women in the focus groups appeared to value the availability of this support. One woman remembered a particular incident:

Never in a rush to get off. Plenty of time to talk about anything. I can’t fault her (breast care nurse). I’ve had no qualms at all, you never felt as if “Ohh should I ring her” because you know she won’t mind if you rang about anything and she’s gone out of her way to like when I had a softie³⁶ at first and when I put weight on it was I said “This softie’s a bit small”. “I’ll bring you one tomorrow and if you’re not in I’ll post it through the letter box” she said. It was there next day She put herself out.

(Mary: FG1)

This sense of being available for each woman was affirmed by other participants:

Pat: Yes because we knew her she was a friend

³⁶ Soft cotton covered pillow like breast shaped prosthesis supplied usually on discharge following mastectomy

Marie: Because she was there at the beginning and she was there all the way through really

Carol: If anything they could have done with more help

(FG1)

And by Liz:

“(Name of Breast Care Nurse) came to see me a couple of times. Just to talk things over. Just to see me. See how I was and I was alright (pause).”

(Liz)

From these accounts it would appear that the monitoring was not viewed as invasive. Nevertheless the everyday quality of the language used to describe the support both offered and received could be seen as downgrading the expertise and skill needed to provide that support because it is described in terms far more suggestive of a non-professional relationship even friendship. This claim is not unique to breast care nurses and is one reported in relation to a range of health care professionals (Hunt 1991). Hunt suggested, from her study examining the use of talk in the work of palliative care nurses, that ‘informality and friendliness’ has a purpose in that it: “seems motivated by desires to break down traditional, authoritarian, professional-client barriers, thus creating equitable encounters and partnerships” (Hunt 1991: 936). These motivations appear to be entirely reasonable when extrapolated to the context of breast cancer care where women in a very short space of time face diagnosis, threats to mortality, undergo surgery and possibly other treatments, and are invited to participate in decision making. Any strategy which eases the burden of trajectories seems supportable particularly if motivated by values such as equity and partnership. Moreover if suggesting friendliness promotes a relaxed atmosphere this may in fact facilitate the achievement of partnership in the nurse-patient relationship. However if friendliness is a disguise, however unconscious, for exploitation, then it is a more suspect strategy. The use of friendliness as a mode of communication to encourage disclosure appeared within the data to be related to “knowing the woman”. This concept of knowing, and friendliness as a strategy to elicit “knowing”, will be developed in subsequent chapters; nevertheless, there is a difference between exhibiting friendliness in interactions between nurse and patient and being a “friend” as suggested in the account offered in Focus Group 1. This

may be just a manifestation of language usage and “friend” is meant merely as a label used to describe the unusual or unpredicted behaviour – a level of personal service - over and above that expected of a health professional.

Prosthesis fitting

Women who have undergone mastectomy were normally invited to attend a prosthetic fitting approximately six to eight weeks following surgery or two weeks after the completion of a course of radiotherapy (Parker 1996). Provision of prosthetics although not mentioned in the BASO guidelines, appears as a topic in its own right in the RCN Guidelines. This possibly reflects the perceived importance within the specialty of breast care nursing and its irrelevance to medical agendas in the UK. The standard (Royal College of Nursing 1994) suggests that following breast surgery a woman should receive a permanent breast prosthesis of her choice if she wishes and that this service should be undertaken “by a sympathetic female breast care nurse or fitter in a private suitably equipped room” (p13). This statement is noteworthy as the same criterion, “sympathetic female”, would seem not to apply to other health care workers who the woman with breast cancer may encounter. From the participant breast care nurses in this study this activity was usually undertaken on a pre-booked basis with the breast care nurse. In some units delivery of the prosthetic service was the responsibility of surgical appliance officer [fitter](n=5), in others that of a ‘specially trained’ nurse(s) (n=3), and in one unit a ‘specially trained’ health care assistant. This devolved responsibility will be discussed in chapter seven along with a number of other features of the interviews relating to shifting role boundaries. The time allocated varied from breast care nurse to breast care nurse with thirty minutes to one hour being the usual length of appointments. In one unit fifteen minutes was allocated to each patient. Women were encouraged, by some breast care nurses, to bring someone with them to the appointment if they so wished. Those breast care nurses that continued to undertake the bulk of prosthetic work appeared to gain considerable satisfaction from the work:

“I think it is a lovely clinic to do. I really get a lot out of it. It’s not an easy clinic just it’s nice to get it right it is quite rewarding giving them some shape back.”

(BCN 1).

Similarly from Breast Care Nurse 25:

“.. and then they normally leave and I just love the way they walk out so differently you know “Oh my shape is back and this is great” and I get a lot of satisfaction from that.”

(BCN 25)

The goal of successful prosthetic fitting appeared to be “to make them say wow” (BCN 8) and to participate in improving a woman’s wellbeing: “I just love the way they walk out so differently” (BCN 25). In addition for some but not all of the breast care nurses this interaction was the location for assessment associated with body image issues:

“But quite a lot of my assessment as to how they are coping with the loss of a breast is when I’m doing the prosthetic fitting about four to six weeks after.”

(BCN 5)

The striking feature of the narratives concerning prosthetic fitting was the volume and minute description offered by the breast care nurses about this aspect of their work. This was not mirrored in the focus group interviews with patients as there was very little mention of the prosthetic fitting event per se but some discussion about living with prostheses, and sharing of tips and stories often tinged with black humour:

Mary: Sometimes if I’m gardening and I’ll bend over and I find I’ve got a bosom down here that’s flopped out (points at ground). We once went to a dance as well oh that was embarrassing. We went to do the hoe down and we were jigging round and it was the first dance we’d been to since I’d had this operation (mastectomy) and it came out I’d lost it

Marie: Round the dance floor ? (Laughter from other participants)

Mary : I had a tight skirt on and my blouse was tucked in so I couldn’t have actually lost it but it was really embarrassing. It must have just moved. So I was careful after that when we did all the fancy steps (more laughter from Mary and other participants)

(FG1)

In Focus Group 2 Susan disclosed:

“You eventually get used to it. Sometime I used to take mine out and leave it lying around and me son said “Oh Mum you’ve left your bosom lying around again”. He’s a big lad. He’s 18.”

(Susan: FG2)

The difference between the two accounts is that one of the breast care nurses privileges the primacy of the nurse–patient relationship and the positive feedback which the nurse appears to receive as part of the event sometimes irrespective of her satisfaction with the chosen outcome. As illustrated in this account:

“Like today I’m fitting a lady with a prosthesis, to me it was appalling. It would never have fit her at all. It was much too small and her bra was wrong but she was happy with that and she went out saying that was “fantastic” and I went back into the office and said I hope nobody knows I fit that because it was dreadful. Because to me it just never fit but she was happy with it. So I want people to look right and good when they go out but at the end of the day they’ve got to be happy with what they’ve got.”

(BCN 3)

In contrast the stories offered by the woman participants of the focus groups locate the prosthesis as an integral aspect of their social lives.

Audre Lorde offers in her autobiography a thought provoking (Lorde 1985) insight into health professional notions of appropriate behaviour post-mastectomy and suggests that the promotion of prostheses is an avoidance strategy promulgated to allow women not to face the loss of a breast. She offers a description of an interaction with a nurse in evidence:

“I was already dressed to go home when the head nurse came into my room to say goodbye. “Why doesn’t she have a form³⁷ on?” She asked Frances, who by this time was acknowledged to be my partner.
“She doesn’t want to wear it,” Frances explained.
“Oh you’re just not persistent enough” the head nurse replied, and then simply turned to me with a let’s-have-no-nonsense-now look, and I was simply too tired. It wasn’t worth the effort to resist her. I knew I didn’t look any better.”

(Lorde 1985:37)

³⁷ Term used in USA for prosthesis

Other studies which have elicited views on satisfaction with service provision (White, et al. 1998) or examined breast narratives in women's breast cancer stories (Langellier and Sullivan 1998) have rarely mentioned issues associated with prosthetics. When these are mentioned they relate to the failings of the equipment (lingerie or prosthesis). The RCN standard stresses that prosthetics should only be fitted if the woman actually desires restoration of contour. The message emanating from the limited professional literature is that "restoring a woman's breast contour after surgery is a very important part of her endeavours to adjust to diagnosis and her altered body image" (RCN 1994:48). The research literature is less convincing in terms of satisfaction with prosthesis (Hart, et al. 1997), sustained use (Tanner, et al. 1983), or that psychological outcomes are enhanced (Reaby, et al. 1994; Reaby and Hort 1995; Reaby 1998). What would be worrying is if prosthetic fitting is an opportunity for breast care nurses to feel good and women merely go along with the pretence that wearing a "realistic breast form" (Parker 1996:148) "is an essential part of aiding rehabilitation" (Parker 1996:149)

Prosthetic fitting is an aspect of the breast care nurses' role that has been taken on as part of the colonisation of territory previously undertaken by appliance fitters and sometimes company representatives. Parker (1996) in agreement with many of the breast care nurses in this study argues it as an important aspect of the work. Yet it has become one area of work that was indicated as an aspect of breast care nurses' work appropriate for devolving to other health care workers (nurses, health care assistants, and appliance officers). This is discussed in chapter seven.

From "having" to "had" breast cancer:

"we move them out of that box into another" (BCN 10)

After the intense support offered around diagnosis and the monitoring associated with chemotherapy and radiotherapy there appeared in the interviews to be a point where women were considered by the breast care nurses and themselves to have changed their patient status from having cancer to had cancer. This shift was marked by a redirection in the focus of care delivery from treatment for cure to surveillance for recurrence. Yet

for the women and breast care nurses this was a juncture where concerns shifted as Breast Care Nurse 20 discussed:

“And there’s the point when they have got to stop thinking of themselves as a woman with breast cancer to being a woman who is probably cured or possibly cured and has to get on with the rest of her life. Yes because everybody else around them starts to do that and they are left totally isolated.”

(BCN 20)

This reported diminution of support has been noted in other work (Veronesi, et al. 1999) and claimed to be influenced by appearances of illness. This juncture in service terms appeared to be handled differently by breast care nurses. Some breast care nurses used the outpatient system to observe women moving on from the breast cancer experience and getting on with their lives. This was quite starkly described by one breast care nurse as:

“About six months down the line I’ll put them³⁸ in the other drawer and then you still see them in clinic. But generally I wouldn’t ring them. I’d put it back to them and say “if you need me you’ve got my card, You know where we are always ring “ but I wouldn’t be ringing somebody unless they had problems after six months.”

(BCN 3)

The aspect of service provision, discharge, unlike the period surrounding diagnosis and preparation for treatment appeared to raise a number of issues for some of the breast care nurses (BCNs 11, 14, 16, 20, 21, 22, 25, 28, 29) The issues are best described as disquiet related to missing womens’ needs and perceptions of availability of support. The uncertainty associated with concerns about failing to identify problems was raised by Breast Care Nurse 20:

“Something in me tells me that at the point (3 months post treatment) you might then be able to pick up long term issues. But I have not managed to do it yet.”

(BCN 20)

Whereas Breast Care Nurse 25 reported an audit undertaken which identified that some women would like to talk to a breast care nurse after treatment this resulted in:

³⁸ The patient’s records kept by the breast care nurse

“.....a post treatment phone call in (the) care package, so we always make a note when the treatment’s going to finish and we phone them. As that is often the time that they want the support because they are feeling very abandoned and quite concerned. Because it’s “Oh what am I going to do now the treatment is finished”.

(BCN 25)

So, it is suggested by some of the breast care nurses that post treatment period is one which some women find difficult. In order for the breast care nurse to monitor that level of distress and assess “they have managed to a get a grasp back on their life, that their confidence has come back” (BCN28) a debriefing is undertaken. In addition to this event functioning as “pulling out” (BCN 10) it is claimed to be valuable as it: “It is important to see them maybe just once to establish the fact that we are still here.” (BCN 29).

Follow up outpatient appointments are another point when patients can be monitored although as many of the breast care nurses reported these are often busy settings with a range of patients at very different points on the cancer journey and often with competing needs. The complexities associated with ensuring those women who will receive their diagnosis have the appropriate personnel available at the bad news event appears in itself a feat of logistical management. In addition there are other women who might be deemed “needy” for attention from the breast care nurse i.e. those having confirmation of recurrence or advancement of their disease. One breast care nurse described her availability in outpatients for the large bulk of women and particularly those who were beyond active primary or initial adjuvant treatment as “hit and miss” (BCN 23). And although reported that she was aware that she might be failing to identify difficulties women were experiencing, she indicated the level of interaction for most women attending follow up outpatients was minimal:

“What happens in clinic now the long term follow ups go round the corner as it were to the senior reg(istrar) and the SHO (senior house officer) and so you see them sitting in the corridor and say: “Hi”, yes as you skateboard out to see somebody else.”

(BCN 23)

Follow up outpatient surveillance was an area that emerged from the interview that enjoyed a topicality with many of the breast care nurses. A recent study undertaken to examine women's experience of their follow up attendance (Allen 1998) found that although outpatient appointments functioned to reassure, women recognised that there were competing priorities for the attention of medical and other staff. This had the consequence that the non-problematic "had cancer" woman, had a brief and rather unsatisfactory interaction with doctors and virtually no contact with breast care nurses. This experience, when contextualised by evidence that suggests that women whose disease recurs self-diagnose without the advantage of a skilled clinical examination or investigations questions the value of this activity (Schpira 1991). The territory of outpatient follow up is an aspect of service delivery, from the interviews, that was claimed to be ripe for colonisation by nurses. This will be developed further in chapter seven.

Conclusion

This chapter sought to unveil the backcloth against which women with breast cancer experience health care services from the perspective of both patients and breast care nurses. Costain Schou and Hewison (1999) present a persuasive analysis proposing the demands of active treatment impose a "treatment calendar" which centres on a medically driven trajectory and the individuals response to medical interventions. This in the case of cancer has the consequence, for many patients, of making them feel more unwell than when they presented with initial symptoms. Using the "treatment calendar" analogy I illustrated the conflicts or tensions that can be exerted on the "personal calendar" of an individual. This was graphically apparent in the account offered by one woman (FG1) which delayed her presentation with a breast lump to her general practitioner. This was also reinforced by the decision of another woman to cease treatment because of the demands of the "treatment calendar" on her social world. The breast care nurse would appear to have a role assisting women to comply with the demands of the "treatment calendar". Breast care nurses reportedly achieve this through listening and observing how women respond. By informing women of the consequences

of the “treatment calendar” based on the assumption that forewarned is forearmed. By eliciting information about a woman’s social world through home visits to determine her wishes if there is opportunity for choice and possibly her potential to comply. By encouraging disclosure and investment in a relationship, a very time limited relationship, using the strategy of being friendly. Moreover I would suggest by helping women to ‘normalise’ any disfigurement through the use of prosthesis.

In addition breast care nurses, just as the women appeared to do, operate in an environment characterised by competing agendas. What became striking in the interviews was the breast care nurses role in managing the treatment calendar for both women and other participants such as surgeons and other involved health care professionals. This managing is perhaps best illustrated in the roles played out in the bad news encounter with its dramaturgical overtones. What has as yet not been fully developed is the close analysis of how listening, observing, informing, speaking for, managing, all activities reportedly undertaken by breast care nurses work to ameliorate the experience of breast cancer. Further how knowing women, directs the work of breast care nurses and is operationalised within the client encounter. In order to present that close analysis the specific work the breast care nurse participants offered as the nature and scope of their work associated with sexuality and body image care will be used to examine the concept of knowing women in the next chapter. Shifting territorial concerns and the boundaries of breast care nursing practice will be presented subsequently in chapter seven.

CHAPTER 6

KNOWING THE AUTHENTIC WOMAN: AWARENESS CONTEXTS, MORAL JOURNEYS AND (IN)VISIBILITY

Introduction

The preceding chapter delineated the structural framework of breast cancer care as currently delivered in the English National Health Service. I suggested that one of the concepts integral to breast care nursing was “knowing”. Knowing appeared to be an ongoing and accumulative process throughout the primary treatment trajectory.

Knowing appeared to be achieved through regular and ideally sustained contact by the breast care nurse with the woman. Nevertheless there was a range of contact patterns described by the breast care nurses. Strategies used to elicit knowing included observing (as in the delivery of diagnosis), listening to, and informing (translating medical information into everyday or consumable language) the woman. Friendliness was a quality considered by breast care nurses and patients as characteristic of these interactions. The purpose of the interactions was one, to uncover knowledge of the woman in order to assess her fitness for coping with the demands of treatment and two, judge the levels of social support available to her and offer professional support in order that the challenges imposed by treatment were achieved. In some organisations this was a targeted rather than a universal service. Entangled in that process of gleaning knowledge was an ongoing surveillance in terms of response to treatment that concomitantly revised knowing. Knowing was viewed by the breast care nurses as best elicited in the social setting of a woman’s daily life rather than the alien(ating) environment of the clinic or hospital. The connection between knowing gained in domestic surroundings seemed to be linked to an assumption that an authentic woman was waiting to be uncovered and the purpose of breast care nursing was supporting that presumed authenticity.

This chapter will focus largely on the data which emerged about sexuality and body image talk and provides a closer analysis of the narratives related to “knowing women”. These will be examined to locate knowing as underscoring the practice of breast care nursing. The work of Glaser and Strauss will be used to situate knowing theoretically and offer a revision of awareness context theory (Glaser and Strauss 1965).

Barney Glaser and Anselm Strauss (1965) examined the level of understanding held by patients about their awareness of their impending death. They developed a schema to describe four levels of awareness that emerged from their intensive fieldwork in two health care settings in the USA during the early 1960s. The prevailing practice at that time was for doctors to provide little information to the patient about their impending death. This was claimed to be in the best interest of patients as it was thought to protect through ignorance thereby reducing exposure to undue burden and obviating existential distress. Nurses, in common with most health professionals who came in contact with dying patients were complicit in withholding information. There remains considerable debate as to whether the complicity of nurses was voluntary or reflected the hierarchical position of nurses in relation to the hegemony of medicine. A common practice was to inform relatives of the patient's condition. Contemporary UK practice has reputedly moved to the opposing position i.e. that patients should be told their diagnosis and prognosis and this right overrides any desire of relatives or health care professionals to protect the patient from undue distress. In simple terms, the imperative is to uphold a patient's 'right' to information because it is now believed that honesty is the best basis for clinical practice. A key role for health care professionals is that of supporting relatives toward an understanding that truthfulness is the best approach upon which preparation for death be based. This shift has been influenced by many authoritative figures such as Kubler-Ross (1970, 1975) and Glaser and Strauss (1965), the influence of the hospice movement, and the developing speciality of palliative care and expertise associated with pain and symptom management. This changed position is also manifest in the literature, which possibly reflects the professional preoccupation, associated with communication skills and specifically the breaking of bad news, (Wilkinson, 1993; Maguire, et al. 1996; Ptacek and Eberhardt 1996; Faulkner 1998). Whether the realities of truth-telling and open awareness are enacted in all contemporary settings where individuals die remains to be seen.

Glaser and Strauss' (1965) starting point was to examine the dying individual's understanding of their status. They sought to examine how patients achieved awareness of their status and how they communicated their knowledge of their status through

interaction to others. This work was part of a larger project attempting to contribute to “the problem of how to conceptualize and account for ‘social interaction’”(Glaser and Strauss 1965:9) and became ground breaking on two levels. Firstly in relation to illuminating the complexity of acquiring knowledge that the outcome of an episode of illness will be death and secondly in terms of the development of research method known as grounded theory (Glaser and Strauss 1967). Central to the exegesis is the concept of awareness context, which is defined as “the context within which these people interact while taking cognisance of it. Plainly, that context is complex, and it may change over time, especially as the patient’s condition worsens and as explicit and implicit messages on his condition get through to him” (Glaser and Strauss 1965:10). Glaser and Strauss proposed four levels of awareness. Complete awareness is when all parties (patient, relatives and health care professionals) share understanding in an open and frank way and this is clearly demonstrated in interaction. Mutual pretence awareness, is where both patient and health care professionals know the disease trajectory includes certain death yet both parties pretend that this is not the case and choose to interact as if the individual’s condition will improve. Suspicion awareness is where the individual suspects that they are dying but the health care staff maintain a firm position of non confirmation of diagnosis which Glaser and Strauss (1965: 47) liken “metaphorically to a fencing match”, and closed awareness where the patient is unaware of their prognosis and all parties are intent on maintaining that state of ignorance.

To extrapolate that to the context of breast cancer care from the accounts offered in the preceding chapter suggests that on the surface the current practice is one of complete awareness. That is all parties share understanding of the diagnosis and prognosis and moreover encourage awareness. In addition there appears to be allegiance to the rhetoric of patient – health care professional partnership based on assumptions of casting the patient as consumer and therefore having rights to information with the onus on health care professionals as providers to ensure that they choose the best option on offer. Rather like a shop with a range of products that have the same fundamental purpose, the role of the health care team is to enable the consumer, through information giving, to

purchase the best product for their situation. Some doubt has been shed on the substance of that rhetoric particularly in the presentation of data associated with accounts of patient participation in decision making. Nevertheless, in many of the versions offered, breast care nurses cast themselves as defenders of women when they speak for the absent woman during the decision making process occurring in multidisciplinary meetings. This they describe as advocacy, and provides the mandate for the role acquired through the breast care nurse's superior knowledge of the woman. This allows the breast care nurse to speak for the woman in order to influence the treatment option(s) presented. The majority of the women who participated in the focus group interviews appeared to adopt a more passive or recipient role preferring the doctors to "get on with it" (FG1). Whereas Liz reported being actively engaged and gave an explanation for her involvement in decision making:

"And they assumed that I'd be making the choice. I'd be making the decisions. I might have, I might have been less than she (BCN) thought. I think that was the difference. I might be imagining that, but I don't think I was imagining that. It's true of everywhere you go if you're supposedly middle class, reasonably educated; you get treated really differently."

(Liz)

From the literature concerning health care professionals and communication it would seem that the rhetoric and ideology presented particularly in that with a mono-professional target readership is different from the realities and messiness of day to day practice. The term rhetoric is used here to refer to writing or wordcraft with intent to persuade. It is, according to McCloskey (1998) a verbal or written idea which involves invention, that is "the finding of arguments, arrangement and style" (p10). The intention in this chapter is to examine knowing within domestic contexts, the moral journey associated with breast reconstruction, and the (in)visibility of lesbian and bisexual women in breast cancer care. The work described associated with body image and sexuality concerns of women experiencing breast cancer will be used to examine the rhetorical premises underscoring breast care nurse-woman interactions and the limitations of current awareness.

Knowing in domesticity: “getting to know you”

For many of the breast care nurses the first encounter with a woman is at diagnosis. In a few centres breast care nurses reported being present in clinic (particularly in one stop clinics) and were available to meet women and provide information about the diagnostic process. This did not appear to be a universal service. For many breast care nurses, and confirmed by the women recollecting events, the appearance of the breast care nurse into the clinic room when diagnosis was announced indicated to women the seriousness of the news: the breast care nurse thereby symbolic of bad news. The breast care nurses suggested that the intention was to demonstrate their availability to manage untoward expressions of emotional response to the news, begin an assessment of the woman, and have knowledge of the information the woman has been provided with by the doctor. This knowledge was seen as an aspect of initial assessment that became integrated into knowing which formed the basis for subsequent nursing interventions. The breast care nurses perform the traditional role of ‘handmaidens’ symbolised by their availability for care and support: ‘mopping up after’ medical colleagues have presented the news of a cancer diagnosis.

In nursing practice, assessment traditionally is undertaken at the beginning of nurse-patient relationship, forms part of the ritual of admission³⁹ procedures and is the first step of the nursing process⁴⁰. Assessment as a basis for the work of the majority of the breast care nurses seemed to be a far less structured or formalised process except when undertaken in association with the collection of medical information or when referral to a different discipline was seen as necessary.

“So the only time we will do anything remotely formal is when we begin to think we are actually with a person beyond us, in which case I will run through a heavy set of questions because if I think I am going to have to write a referral letter. I want the referral letter to sound not too woolly “and by the way I think they need to be referred”. I want to be able to say she has

³⁹ Admission used here as a ‘catch all’ term to suggest an access point to nursing care whether that be onto a caseload in primary care, out patient or as an in patient in hospital.

⁴⁰ The system most frequently used to structure nursing care and used as the basis for nursing documentation

got early morning waking, she's got you know. I don't run up standardly (and do this) look I wouldn't put these patients through that."

(BCN 2)

However, the more usual form of assessment undertaken by the breast care nurses was characteristically a gradual unfolding process with addition and revision occurring in response to interaction with the woman and in some cases her social network. The assessment process was therefore an accumulation of a number of encounters and seemed to have little formality. This account describes a first encounter with a woman immediately following the announcement of diagnosis:

"We go into the other room and give them ten minutes to have a drink and then say, "right what do you understand about the last few hours". And it is from there really you need to pick up vibes. You know have they had too much? Are you giving them too much information or do they want more? And it's at that point I begin to make my assessment."

(BCN 15)

The limits of that as an interaction for assessing are identified and this breast care nurse then explains the ongoing nature of the assessment process.

"It's only when you start seeing them in their own homes I would say you really get to know what's going on, and around the treatments, and how they are feeling about that, and what support they are getting at home. Whether they are actually getting the right kind of support or whatever. And so it is only on a regular visit that you realise and quite often you get people that don't mention things until you have been going six months and suddenly they come out with some kind of problem. I think you have got to know how far you can go without pushing. It depends on the person whether they are open, or whether they keep things close to their chest, or whatever so it is an ongoing assessment."

(BCN 15)

From this account various interpretations can be applied. This breast care nurse appears to assume that the authentic person, the 'who' the individual woman is, can be best determined in the woman's domestic environment. That justification for sustained visiting is that the breast care nurse will elicit concerns through disclosure. Moreover it is inappropriate for a framework or model to be imposed upon the interaction in order to force disclosure, as the woman should lead the pace. Within the confines of the treatment trajectory the relationship is not time limited as ultimately she will talk and

her concerns will be laid out for the breast care nurse. This is perhaps what was encapsulated in the comment concerning the end of initial treatment that the relationship remains unfinished and assessment is never complete but always open to revision:

“A woman rang yesterday, she had a mastectomy eight years ago, and I had to say “Just remind me again?”. And that was fine. So it is not really a signing off but it is - us sort of pulling out.”

(BCN 23).

The narrative offered by Breast Care Nurse 15 contains powerful rhetorics. These include an assumption of person-centred non-confrontational talk based interaction as beneficial, it affirms importance of ‘support’ and professional support manifested through prolonged visiting as therapeutic, and that who a person is, is more authentically represented within a domestic setting. This has the potential to be read otherwise by the recipient of this attention. The women may perceive the breast care nurse as someone with authority, that the persistence with talking (information giving) and listening, reinforced by visiting in the home must have a utility and therefore must be beneficial. Irrespective of whether the woman perceives the attention to be an invasion of privacy she may well recognise her compliance may produce a better ultimate outcome i.e. the breast care nurse leaves or the attention is less sustained. She chooses to provide the breast care nurse with a ‘gift’ of disclosure to demonstrate compliance and indicate complicity with the professional rhetoric. This linkage of domesticity and authenticity as the test of reality (the real woman) may be presumptive and in fact the domestic setting may enable the woman to construct an artifice in which to act out a subversion of knowing. This extrapolated to awareness contexts theory suggests that location within the domestic facilitates open awareness whereas the location may in reality enable a woman to have greater control should she so wish to subvert awareness. The significance of home-based encounters as the superior location for authenticity is clear in this account but its superiority for knowing is recognisably associated with prior occupational specialisation:

“Because I come from the community⁴¹. Maybe that has something to do with it. And I know I cannot give holistic care to a patient and her family in clinic because you can’t do an assessment properly. You don’t see all the

⁴¹ Prior to becoming a breast care nurse worked in the community as a district nurse.

other stuff that is going on around you. You don't see the kids waltzing in, going in and out, saying: "Mum where's my bats". Or husband sat in a corner sulking you know. You don't see any of that in the clinic because they get tarted up and they come and say they are all right. You can't assess family care, sexuality, body image. You know that is my big thing and there is no way that you can assess that in a clinic unless someone breaks down, and that doesn't happen often. By making an assessment every time you see them. I mean you are assessing all the time for depression and if you are doing that you are trying to find the causes of depression or anxiety."

(BCN 28)

The superior status of domestically acquired authentic accounts of knowing was acknowledged by those breast care nurses who entered the speciality with previous community experience as district nurses or health visitors. A noticeable feature of those breast care nurses (BCN 6, 13, 14, 18, 22, and 28) who came with that prior experience used it to suggest it gave a stamp of authority to their view. It would be naïve to assume, and I have no evidence that the breast care nurses in this study have assumed, that domesticity is devoid of complexity. The advantage for the woman may be that it enables her to be better placed to control the clinical encounter. Nevertheless home visiting has the potential to be perceived as an invasion of personal space; a bringing into the home the reality of the situation that the woman may wish to compartmentalise as separate. Or it could be construed as having a merely social function particularly if friendliness or everydayness (Hunt 1991) characterise the breast care nurses tone and content of presentation within the interaction then the therapeutic potential may be diluted or not engaged. This balancing act between social aspects and therapeutic needs was raised by a number of the breast care nurses and is reflected in this comment:

"I play it very much about what the patient needs actually. I have learned in the last five and a half years that there are only a certain amount of cups of tea you can have in a day."

(BCN 21)

And another breast care nurse commented that when interaction remained stuck at the level of everydayness and "nice curtains, lovely coffee" (BCN 12) was the main content then the breast care nurses time was wasted. This issue of what is perceived by breast care nurses, as having utility will be further examined in chapter seven.

A feature of home visits was the potential for other people, family members, partners, and friends, to be present. Some of the breast care nurses actively encouraged other people to be present or did not discourage people from staying in the room. One breast care nurse saw family participation as indicative of 'good' support. Further absence of partners or family might indicate to breast care nurse the 'truth' about quality of social support particularly if there was inconsistency between the women's account of support and what was observed by the breast care nurse.

"I always encourage women to have somebody with them and I always find it interesting as to whether they have got somebody with them or not. And if they have who that person is. Sometimes women will tell. I mean the woman I have just seen now⁴² she just always tells me how supportive her husband is but I have never met him yet. And that tells me quite a lot. And then sometimes you go and there is a room full. You know there is sometimes even the dog is there. It's brilliant."

(BCN 29)

In this account not being able to observe or meet a woman's source of social support was problematised with presence of family considered to be an affirmation of commitment to support. This assumption that there is a 'right' kind of support, other than that provided by the breast care nurse, even in the absence of insight of how that might be defined remains unclear from this narrative, moreover resonates with assumptions of 'social judgement' (Johnson and Webb 1995). Whereas others breast care nurses preferred to meet women alone as suggested by Breast Care Nurse 8:

"Well with experience I have learnt now that it is better just me and the lady. Because I have been in some horrendous situation where there have been me and the whole family and the dogs and the husband saying "No I think this is important". And I remember one awful, awful time. It was an older lady who had her sister sat next to her and her husband. It was quite extraordinary her husband was in the corner making – it was so bizarre really – making a cup of tea and going backwards and forwards. I think from that I sort of decided it was better if I do see. I will obviously give the opportunity to speak to whoever would like to be there. But I think it is important that I do have time with the lady in the home."

(BCN 8).

⁴² Just before the interview she saw a patient in the hospital department.

In this account the presence of others was perceived by the breast care nurse as exerting an influence on establishing a relationship with the patient thereby preventing achievement of the breast care nurse's goal of knowing the woman. The relatives were interpreted as acting as a barrier to the breast care nurse. From these paradoxical accounts two opposing assertions are offered as better to assess or know the woman in her social situation and judge quality of support. One is predicated on the assumption that authenticity is derived through interaction with a woman surrounded by her social network, as described by Breast Care Nurse 28. As this provides insight of the woman in relation to her significant relationships, in action or, as naturalistically enacted. It assumes that if a woman represents herself in a certain way in her interactions this is representational of an authentic self. This takes no credence of the possibility that a scene may be played to its audience. Whereas, the preferred approach of Breast Care Nurse 8 may well facilitate a perception of closer involvement with the woman. Nevertheless the account of social support will always be in retrospect and having undergone reflection, possibly reinterpretation, even been mythologised and sanitised, into a format perceived by the woman as consumable by the breast care nurse and offered as, and accepted (or not), as representative of reality.

A framework for talk

When asked, a minority of the breast care nurses (BCN 6, 7 and 23) reported routinely using a formal framework for assessing psychological distress outside clinical trials or claimed to adopt a formal counselling contract with women (BCN 6, 7, and 24) who they had identified as having more substantial 'problems'. For example Breast Care Nurse 6 and colleague used the Hospital Anxiety and Depression (HAD) inventory⁴³ with all patients on admission for surgery, at the initial home visit. If a woman presented with a high score the breast care nurse would formally contract a woman to six sessions of counselling and/or would refer the woman to a clinical psychologist. Whereas for

⁴³ HAD is a brief assessment of anxiety and depression consisting of 14 items. Scores of 11 and greater are considered 'definite' cases of depression (Bowling 1991)

other breast care nurses assessment of psychological distress was reportedly ‘intuitively’ determined or based on an unformalised framework derived from experience:

“I guess we don’t use any tools to help us so at the moment it is through continuous assessment so it is by the questions we ask and the answers we hear.”

(BCN 20)

Although most of the breast care nurses refrained from suggesting that they used formal assessment strategies allegiance to one particular approach for eliciting knowing was discussed by the majority of the breast care nurses. Maguire’s work appeared to be influential for the breast care nurses on two counts: first, for providing the evidence to underpin the specialism of breast care nursing (Maguire, et al. 1980a). Second, through the auspices of the Cancer Research Campaign Psychological Medicine Group, in Manchester, providing training which was reported by a number of the breast care nurses to have informed their individual approaches to communication with women. This approach is based on teaching health care professionals, through experiential learning with ‘simulated’ patients, to listen for cues or concerns expressed by patients. It teaches, through the use of open directive questioning, strategies for the exploration of the psychological dimensions of the patient’s experiences and opportunities to clarify psychological concerns. This influential training has been shown to enhance communication skills in the short term although some doubts, despite its influential appeal, as to the longevity of this type of skill acquisition have been raised. It appears as an approach to have some limitations in terms of sustained value (Maguire, et al. 1996). This suggests that communication skill acquisition may have a limited value unless supplemented by regular refreshment. Other critiques of this behaviourist approach to communication skill acquisition include a failure to recognise that a skill acquired in ‘laboratory’ conditions however well simulated may not be the same as that required in clinical encounters. Moreover it fails to take account of the impact the context in which communication skills are enacted may have.

A number of the breast care nurses said that their training using this approach had been partial (BCN 18, 20). Others felt it had been adapted from that used as a basis for most

of the literature promoting the benefits of this approach (BCN 5, 7, 8, 9, 11, 16, 23, 24, 25, 26, and 29). That is not to say that the breast care nurses do not have excellent communication skills and can elicit concerns and act upon them appropriately. The two main challenges to effective communication in health care are said to be lack of training and fears about the adverse consequences of delving into patients' concerns. Health professionals are said to use what has been euphemistically described as 'blocking techniques' (Wilkinson 1991; Booth, et al. 1996). These are reported to be most strikingly adopted when associated with concerns related to the psychosocial demands of mastectomy on intimate relationships. This notion of 'blocking' will be developed in relation to sexual orientation and discussions associated with sexuality later in this chapter.

Others (BCN 18 and 25) claimed affiliation to Carl Rogers' person centred approach:

"I liked Carl Rogers' I liked his interest in patients or people's ability to feel themselves. I liked that and I liked the idea I would be more of a facilitator. I suppose just helping people to find the key to open the door to go home ability rather than telling people to do. I find it's non-directive I am quite happy to go along with the patients. To go where they want to go but I am quite happy to go along there."

(BCN 25)

Other nurses used 'counselling models' of undisclosed provenance or claimed to be naturally good communicators.

To summarise from the breast care nurses' accounts assessment is an ongoing process constantly open to revision but best undertaken in the domestic situation. The agenda was claimed to be led by the woman and based on three underlying assumptions. These were: one, that it is good to talk, two, eventually disclosure of problems will occur, and three the breast care nurse, with minimal use of objective measures of response to experience of breast cancer, will be able to elicit concerns. Once that knowing process has been established the breast care nurse can intervene with more listening, talking/listening therapy or refer the woman to a different health care professional if the

service⁴⁴ is available. If she refers the woman to another health care professional this will involve undertaking a formal evaluation, probably using an objective measure(s), so as to frame the referral letter within the disciplinary discourse appropriate for its target recipient. The communication approaches used are characterised by friendliness, influenced by a concerns based approach, and believed best accomplished in the privacy of domesticity. Through these activities the breast care nurse will come to know the woman as if “we have become related” (BCN 21).

Record keeping

In most cases the breast care nurse in an edited or annotated format recorded the knowing accumulated from interaction with women. All the breast care nurses indicated that they made a record of their interaction with women that only appeared to be used, and accessed, by the individual breast care nurse or other members of the breast care nursing team. Both the content and purpose of the records appeared to be locally determined. For Breast Care Nurse 3 the function of the record was: “I try to put things down that might be useful if somebody else read it” but she then went on to suggest “but it could mean more to me than it would mean to somebody else”. This breast care nurse works in a team of two. Disclosures concerning relationships particularly relating to content of a “deeply intimate” (BCN 5) nature were claimed to be omitted as it was suggested that some types of information gleaned in the course of their work with women was “probably just between the patient and yourself. So it’s not really for anybody else to read. I think it wouldn’t concern anybody else” (BCN 3). This omission was affirmed by other breast care nurses and justified “I tend to keep the private and confidential things out” (BCN 9). Although as Breast Care Nurse 29 discussed what was recorded and chosen to be omitted or sanitised by the breast care nurse before entering in records was an area of uncertainty:

“There is a big issue about documentation and we keep our own records⁴⁵ and nobody else is interested in them. But if anything happened I suppose

⁴⁴ Since Calman-Hine clinical psychology and/or psychiatric support is a necessity within the package described for accreditation. How this support has been translated into availability appeared to vary.

⁴⁵ Part of a team of three breast care nurses

somebody would. They might well say we want to see your record so it is quite tricky really. You know there can be a lot of issues buried in the past that you know the patient does think that you are somebody that they can tell. There might have been previous sexual abuse or rape although nobody has told me anything like that.”

(BCN 29)

Statements indicating a problem had been discussed might be entered in records although the substantive detail would normally be excluded. The purpose of the record was said to act as “an aide memoire” (BCN 2) and to record priorities (BCN 2, 7, 14, 29). It was also a legal record (BCN 11 and 14), used for audit purposes, and as record of number of contacts in the case of complaints (BCN 11, 29), and to record details of referrals (BCN 2, 7, 8, 9). In addition some of the breast care nurses indicated that on occasion they recorded information in medical records:

“Sometimes it is appropriate to write in medical records, sometimes if you having huge problems, but it would be in summary form that could mean anything probably”

(BCN 5)

What was considered to be a priority varied from what could be broadly classed as social issues such as difficulties with childminding, financial problems, absence of obvious social support (i.e. widows living alone) to psychological problems such as body image problems, or severe anxiety. There seemed to be no clear definition of what constituted a problem or what were the most frequently occurring menu of problems or how the nurses gauged the severity or importance of a problem. There was a sense for some breast care nurses that helping women through treatment often by assisting the woman in accessing social care (benefit advice, facilitating access to social workers, sorting out a treatment regimen that fitted child care) was the daily focus of the work for women. This was most striking in the interviews with Breast Care Nurses 15 and 24, as Breast Care Nurse 24 described:

“I think the greatest talent I have because of the different amount of patients I have here. Apart from the fact you know I have got so many languages, so many nationalities. So for me it is one of the greatest challenges from the point of view that each day is going to be completely different. There isn’t you know a typical breast care nurse there isn’t a typical breast care patient

and I don't go to that coffee morning thing with a pink ribbon. I am more into what I can do to help that particular patient. That's supply and demand on a one to one. Some of them don't have the bus fare to come here or don't have someone to look after the kids."

(BCN 24)

This breast care nurse (BCN 24) works in a large metropolitan inner city district hospital breast unit serving a large very mixed multicultural population.

So far in this chapter I have offered an account of knowing as a core concept to define the work that breast care nurses undertake with women (and their significant others). The intention was to offer knowing as a keystone but then illustrate the uncertainty of knowing, the mirage of what might be presented and interpreted may not be in reality be the case, to emphasise that situatedness may influence a breast care nurse's capability to know. Knowing is not a one way process but one in which the women actively engages in order to make a representation of themselves. Further, I believe I have cast some doubt on the certainty expressed within the rhetoric of the narratives of the linkage of authenticity and domesticity. In the remaining part of this chapter the concept of knowing will be further analysed in relation to an aspect of the breast cancer experience which has been recognised as problematic: namely sexuality and body image.

Sex talk

In chapter two, I discussed the nature and scope of problems, which have been reported to be associated with breast cancer. In chapter four, I addressed the literature relating to health care professionals', and nurses in particular, attitudes and knowledge associated with the sexuality and body image concerns of their patients. In this study a survey of breast care nurses was undertaken and the results were presented in chapter four. Those results summarised indicated that the breast care nurse participants had a marginally higher sexuality knowledge score than most previously tested nurse cohorts using the same instrument. The breast care nurses held a mixed profile in terms of the education and training undertaken to underpin their role. The attitudinal set of the participant breast care nurses was far from uniform. Two possible explanations were offered: one.

that the assumption that the homogeneity of participants by virtue of their role as breast care nurses was erroneous, and two, that the items within the scales may well not be relational. The majority of the breast care nurses (96%) agreed that discussing sexuality aids recovery although they stated they felt less comfortable when initiating those discussions and that they were more comfortable when the patients, or their partners, initiated discussion of sexuality issues. Interventions associated with altered body image are reportedly more commonly undertaken than those associated with sexuality. In this section some of the questions raised by the findings presented in chapter four will be considered.

Altered body image and sexuality

The rationale given by the Royal College of Nursing Breast Care Nursing Society to justify the standard for altered self-image care by breast care nurses is: “careful and sympathetic understanding assists the patient with an altered self-image to adjust to an acceptable reality and so restore confidence and self-esteem” (Royal College of Nursing 1994:6). The criterion offered to judge success of a breast care nurse’s intervention, or a woman’s adaptation, or both, is that a woman adapts to her altered state. She functions to her satisfaction within her lifestyle, and resumes a physical relationship “when she is ready” (p6). Chapter five examined issues associated with decision making and reconstruction along with the nature of breast care nurse interventions associated with prosthetic fitting. These were presented by breast care nurses in this study as part of the armoury available as options in body image and sexuality care. Earlier, this chapter dealt with the unfolding process of knowing as central to breast care nursing. It is my intention in this section to examine the strategies the breast care nurses used in their work with women associated with body image and sexuality. The terms body image and sexuality were used with regularity in the interviews with informants. Although frequently used in conjunction in accounts there appeared to be a distinction between activities and understanding associated with body image work that was different from those used to address sexuality. The former having practical or physical actions associated, a repertoire of activities, that could be undertaken, or drawn from, and

‘adaptation’ would happen. It was as if body image was something that could be accomplished.

“I mean, body image is something that I feel strongly about and so I am keen to incorporate that in one of the home visits.”

(BCN 21).

A number of issues emerge in relation the conceptualisation of body image work by the breast care nurses. Firstly there was an enthusiasm associated with body image work that may well relate to the physical involvement necessitated by prosthesis fitting which provided a sense of accomplishment. Secondly there was a sense that body image work was easier than dealing with sexuality concerns.

“The body image bit I think is easier in some ways than the sexuality bit because you can help a woman do practical things to affect her image. Yes, you can also, even down to helping her take on board the new ‘her’. Being, dealing with a scar or the loss of a breast you can encourage to look at herself, touch herself, work on the cognitions of how she sees and views herself, which would have a knock on effect on how she feels. But I think there are more practical issues about body image. The more practical things you can do to help.”

(BCN 20)

The breast care nurse sees this work as “easier” and that easiness comes from having something to do or on offer that may impact, and hopefully enhance, a woman’s altered physical image. Although not stated in this account, but discussed in chapter five, there are strategies such as fitting a prosthesis that can normalise appearance to the onlooker. Implicit is a belief that the strategies work and that camouflage from others, the ability to “pass” as having two intact breasts, has benefits in terms of social presentation and representation. Goffman explains: “because of the great rewards of being considered normal, almost all persons who are in a position to pass⁴⁶ will do so on some occasion by intent” (1968:95). Whilst camouflage conceals the extent of physical loss, and prevents others in many social settings from having an awareness of the woman’s loss, it in no way conceals the disfigurement from the woman. In effect single breastedness, for those women who underwent mastectomy, is a permanent reality which, reinforces both

⁴⁶ “Pass” means to go unnoticed

physical difference and potentially asserts the unpredictability of the woman's body (Crouch and McKenzie 2000). A number of the women who participated in Focus Group 1 experienced constant reminders of alteration that brought the reality of changed anatomy to consciousness:

- Mary: The main thing I found difficult to come to terms with was actually looking at my body. You know when you get out. Drying yourself after a bath. In fact it still feels strange to not (cut off)
- Pat: I don't look
- Carol: It's not a pretty sight is it?
- Mary: We have a bathroom mirror opposite the bath and when I stand up (pause). Sometimes when I just catch sight of myself and I think "Oh yes, you know that is me and it will always be me now"
- (FG1)

In addition the impact of the altered physical appearance in terms of the responses of others particularly in association with sexual intimacy was discussed:

- Mary: It depends what type of partner you've got as well I think, how you cope.
- Helen: It must be difficult. I think as well your partner doesn't have doubts. It's you that has the doubts about they're going to be with you, if you know, it's you that's insecure. You don't want them to see you at first. They wouldn't mind seeing you. It's you that is conscious of it and people say "Oh my marriage has never been the same since". But it might not necessarily be the husband's fault, it might be their problem with it. Because I still do feel a bit.
- Pat: I'm not bothered
- Mary: Self conscious and you don't feel as desirable do you. You don't feel as if they fancy you anymore.
- Jean: You're not the same are you?
- Marie: There's a lot of men react differently to what's happened.
- Jean: I suppose there's a lot of men that can't cope with it can they?
- Marie: No

(FG1)

In both these segments from the interview with women in Focus Group 1 the ever-present nature of changed anatomy is communicated. Another noticeable feature is the absence of the word breast in the conversation. Both the actual breast, and the word breast is absent yet the word breast was used repeatedly in context of the disease and treatment. This was a feature of Langelier and Sullivan's (1998) study that sought to explore the meaning of breast loss to women. Breast loss to the women in the focus

groups appeared to have a greater significance than just the loss of a body part. It includes aspects of who the women believed themselves to have become having undergone this change: “You’re not the same are you?” (Jean: FG1). In the first exchange the absence was characterised by a sense of surprise, a nudging into consciousness, the jolt forced by the captured image in the mirror to bring the altered reality back in focus. As another woman commented:

“Sometimes I look at myself and I just think “God who’s that? I’m in somebody else’s body”

(Susan: FG2)

Goffman suggests that there is a distinction between the visibility of a ‘stigma’, in this case single breastedness, and knowledge of it – ‘known about-ness’. Goffman distinguishes between the discredited, those whose stigma is known, and the discreditable where it remains unknown but with the potential to become known. Cannon (1988) found in her study that women who had undergone mastectomy felt discredited irrespective of whether their single breastedness was known to others. Her participants talked of having feelings that everyone was looking at them but over time came to recognise that not to be the case. Moreover some of the women in her study came to anticipate when disclosure of single breastedness was important in order to prepare others. Whereas other participants chose to avoid situations where their single breastedness would be noticeable in order to prevent their exposure. In Goffman’s terms they obviated the potential for becoming unnecessarily discredited and maintained their capacity to ‘pass’ as normal. Women with breast cancer can be doubly discredited firstly by the disease (Sontag 1979) and secondly by the consequences of treatment: full or partial removal of the breast, scarring, radiotherapy damage, hair loss and weight change from chemotherapy and endocrine manipulation. Stacey (1997) suggests that ‘passing’ is a preferable option for many people with a cancer diagnosis and concealment of the facets of the illness, treatment, and distress is an additional burden to the individual with cancer. She proposes that “the cultural imperatives of secrecy and disguise are a constant reminder of living with a stigmatised illness” (Stacey 1997: 67).

As Mary (from Focus Group 1) confirmed:

“I started going swimming and must admit I make sure I get in a cubicle to get changed. I go with my Brownies and I went on holiday this year. You’re wondering a bit about it (prosthesis). We were in the Jacuzzi and all these kids and I was thinking “I hope nothing pops out”. But my daughter did the same. If you were less than 14 you had to have an adult with them. I was the only staff that went with them. So they had me going in the steam room and the sauna and my daughter was saying, “I hope nothing happens to that bosom of yours”.

(FG1:Mary)

In this account it is not only the woman who voiced fears of being discredited but also her daughter. The potential for exposure was possibly made riskier by the public venue and being in the company of young people. What is interesting in this account is that it is a tale of successful ‘passing’ in a situation with a high probability (risk) of exposure. It is as if the woman chose to test herself, by risking detection, and the observational powers of others potentially to discredit. Another feature that emerged in Focus Group 2 related to the women having made their diagnoses public therefore exposing themselves to the implications of having been discredited found themselves not appearing ill enough:

Susan: Sometimes I get so cross just to prove
Helen: They’re sort of disappointed that you don’t look poorly enough.
Pam: Yes. You should be dying
Helen: You have this dreadful disease and you look wonderful
Brenda: I know exactly what you mean
Helen: It looks like disappointment
Anne: I found that close friends and that were more upset than I was.
And they’re saying “Look take it easy, I’m not looking at your
face, I’m looking at your eyes and your eyes say you are doing too
much”. And this and that and the other.

(FG2)

Stacey (1997) proposes that books, and I would suggest oral stories, tell us through their narratives something of the experience or rather their reality of the experience. These stories may be presented as ‘facts’ as in medical texts, the research evidence (Department of Health, 1997c), and even the guides written by doctors for general readership (Baum 1988; Baum, et al. 1994; Buckman 2000). There are the stories presented by those, and of those, who conquered the disease through heroic struggle and lived and often underwent a transformatory experience (Wadler 1994; Segrave 1995),

and those stories which tell the reader about the battles which fail and the lost opportunities, the pointlessly foreshortened lives, the limits, or poor quality, of medical practice (Lorde, 1985; Batt, 1994; Butler and Rosenbaum 1994; Dunckner and Wilson 1996; Diamond 1998; Picardie 1998). An impact of these cancer narratives may be for the individual undergoing diagnosis, treatment, recovery, survivorship, as the women who participated in the focus groups were, is that they establish expectations of behaviour for those who discredit. Being “normal”, in “as before”, is not the expected behaviour; manifesting illness as stigmata is preferable, so others can respond by supporting their “courage” and in some cases contribute to well being. Whereas the stories that emerged from this study were more frequently accounts of women trying to marry the entity of the disease, Costain-Schou and Hewison’s “treatment calendar”, with their personal lives and their responsibilities in terms of the needs of others. This is seen in the woman who presented late because of responsibilities for an ageing relative (FG1). The woman who stopped treatment because it was having too great an impact on family life (FG2). The women who worked in paid employment throughout treatment and on the surface appeared to encounter less side effects of treatments than those portrayed in the narratives (Liz, Janet, FG1 and FG2) and numerous cases presented in the breast care nurse interviews.

“We just talk and listen to them, we listen to them talking about it.”
(BCN 26)

A standard approach advocated as a springboard for opening discussions about sexuality and body image outlined in textbooks for nurses (Webb 1985; Denton 1996) is the use of open questions. These are intended to elicit insight into the individual’s role identity within relationship(s), their feelings about their sexual identity, their understanding of the impact treatment might have on them, and the consideration, if any, they may have given to how they might adapt to the change(s). From the accounts given by the breast care nurses asking women about their relationships with partners was often used as a ‘shot across the bows’ approach to initiate a response which then could be used as a basis to open up discussions. Breast Care Nurse 14 in this commentary offered a description of her approach here used in the context of pre-operative discussions:

“I would often ask about the partner and say “You know how has he reacted to this?” and “Have you been able to discuss it with him?” And that opens the floodgate usually and it’s not been a problem for me to delve into it.”
(BCN 14)

Similarly Breast Care Nurse 29 talks of using what she describes as “fairly direct questioning” to initiate discussions:

“There are certain questions which you can ask. Which to some people are obvious whereas others they are not, you know. For instance, you know “Do you think having had the mastectomy has changed the way you feel about yourself as a woman?” Now some people will say “What do you mean?” So just fairly direct questioning really.”
(BCN 29)

Whereas Breast Care Nurse 16 uses the guise of information to provide an inroad, a way into discussion of sensitive issues associated with sexuality, but implied that this would be pursued more frequently if the woman was undergoing a mastectomy where bodily integrity was threatened. Giving information was seen by this nurse to be a strategy for obtaining permission to discuss intimate issues. Permission is the first step of a widely advocated approach for health care professionals to address sexuality with patients called PLISSIT. This mnemonic represents the four parts of the model: Permission, Limited Information, Selective Stimulation, and Intensive Therapy (Annon 1974). Annon (1974) suggested that giving a patient permission will enable discussions of cancer and its treatment. These will be discussed within the context of an individual’s prior sexual experiences. Allegiance to this model was claimed by some of the breast care nurses particularly in terms of the first two stages: permission and limited information.

“One of the ways in and I don’t know if this is sneaky or not but many of the ways in is that when giving information about Tamoxifen. Vaginal dryness is a real side effect and it feels like a nice comfortable way for you to ask permission you know: “Can I talk about this?”. And from there I would often move on to if, say, the woman was having a mastectomy try to find a way in.”
(BCN 16)

Giving permission is said to provide an authoritative signal to a woman thereby indicating that to engage in sexual activity is permissible after diagnosis of breast

cancer. Moreover that the breast care nurse is willing to talk about concerns (Webb 1985) should the woman wish to. Nevertheless giving information may not necessarily encourage response. Moreover if that information is embedded within a series of possible side effects, or pieces of information, there may be more immediate or hierarchically ordered concerns for which the woman may seek reassurance. This may very well override anxieties associated with sexuality. However, this breast care nurse implies that it provides her with a “comfortable” entry point for further discussions. A feature of the commentary is the use of the word “sneaky” suggesting almost catching the woman unawares in order to achieve entry into this domain. In addition maintaining the breast care nurse’s comfort was also a consideration. For Breast Care Nurse 18 the patient and her partner’s comfort were claimed to be the paramount motivation for initiating talk in the domestic environment. This connection between home and sexuality may also relate to the context where sexual activity may occur.

“Usually if I do a home visit it’s then. I think possibly both partners of whatever sex they feel more comfortable because they are on their own territory because I am visiting them. They are in control. You know they are not visiting me in a clinical environment.”

(BCN 18)

This breast care nurse then links the discomfort she experiences associated with ‘sex talk’ with invasion of privacy into aspects of people’s lives. This could be connected to what Stacey (1997: 64) describes as “the cultural imperatives of secrecy and disguise” which she claims are an immutable reminder for those living with a condition that it is perceived as stigmatising. Privacy, argues Savage (1990) is particularly constrained within institutional life. Some aspects of the private and personal appear to be forfeit whereas for others disclosure is required and in some cases publicly discussed (bowel function). Paradoxically, privacy is also used as a justification by nurses for not addressing sensitive issues (Topping 1996). Whereas in the context of breast care nursing the word privacy is used to describe concerns associated with accessing information or knowledge that is outside the traditional confines of nursing interrogation. Secondly its use suggests recognition of the responsibilities associated with knowing and the management of knowledge within a system where confidentiality has the potential to be leaky. In this account the breast care nurse chooses to discuss

concerns associated with intimacy in a setting over which she claims to have little control and recognises as potentially intrusive, yet she persists despite her own discomfort:

“But it isn’t an easy thing to introduce into the conversation and I feel it is a little bit like talking about finances. How much money have you got coming in and how much savings have you got? You know when you are filling out a Macmillan grant form. You feel , I feel, as if I am being a bit nosy and they might not want you to ask these questions.”

(BCN 18)

It is argued that if a health care professional is uncomfortable they are less likely to address a subject such as sexuality (Payne 1976). Should they persist it is suggested they are more likely to be obstructed in their endeavour or the attempt will lack due sensitivity (Topping 1996). This has the potential to cause offence or be misconstrued. No breast care nurses reported knowingly having caused offence to patients when addressing concerns in this area, however Breast Care Nurse 8 did offer an account of an interaction with a distressed woman. This event occurred during a pre operative home visit to a woman planned to undergo mastectomy. The woman’s sister and husband were present in addition to the breast care nurse.

“I asked the lady because she was so very distressed. She was crying and crying and crying. And I said “What’s worse? What is it? What’s worse for you the cancer or the loss of a breast?”. And she was probably about 75. And she said: “The loss of a breast”. And it was just, that moment it released it all what she was feeling. It was quite a powerful moment. But her sister was so cross with me for upsetting the sister. That the sister actually complained about me. She said “I don’t want you coming to the house again. I don’t want you upsetting her”.”

(BCN 8)

From this account it is unclear whether it was the open discussion about breast cancer, or whether it was the subject focus, i.e. breast loss and the body image implications of surgery, which caused offence to the relative. It does, however, raise issues about sovereignty of information and interaction. In effect, should patients’ autonomy be respected over beneficent concerns of their relatives (Benson and Britten 1996). If the breast care nurse in eliciting the substance of the woman’s concern identified its basis and that was deemed helpful by the woman her autonomy to have that feeling validated

takes precedence (for the breast care nurse) over her sister's desire to protect from distress. Alternatively the woman may not have wanted to have the knowledge of the basis of her concerns to be revealed or shared with her sister. She may have wished to deny the problem or leave it unvoiced. In Goffman's terms, although the woman was about to be "discredited" by the imminent mastectomy she may have chosen not to have the meaning, the significance of that to her, be known to those who could "discredit" her. Alternatively the woman may have chosen, consciously or otherwise, to adopt a stance of denial which has come to be recognised as a "valid coping mechanism for those who are unable or not yet ready to adapt to the reality" of a life threatening disease (Faulkner 1998:130). Without having access to the interpretation of events from the viewpoints of all participants it is impossible to do other than offer conjectures as to the possible meanings implicit within responses. This scenario does nevertheless raise a number of issues concerning permission to inquire, interpreting response to permission, who has authority to limit interaction, all of which will ultimately impact upon the quality of "knowing" as an integral aspect of the patient- breast care nurse relationship.

On blocking and being blocked

An area which receives considerable attention in the literature relating to communication skills of health care professional is the use of blocking behaviours (Wilkinson 1991; Maguire, et al. 1996; Booth, et al. 1999). These authors claim that nurses use these blocking behaviours, and the consequence for patients is that they are reportedly prevented (blocked) from talking about their problems. Various reasons have been offered including lack of communication skills, not using extant skills, fear of the consequences of unleashing emotion particularly if the nurse is realistic about the limitations of existing skills, and personal anxieties associated with subject matter of the area they may facilitate disclosure. Various behaviours have been described including normalising or stereotyped comments, premature reassurance, inappropriate advice, closed questioning or use of multiple questions, requesting an explanation, disapproving or disagreeing although approving and agreeing have also been identified, defending, changing the subject, moving the focus, "jolly along and personal chit-chat"

(Wilkinson 1991: 679). The subject of sexuality is an area fraught with sensitivities and arguably demands skill in order to facilitate openness in a way that is neutrally loaded and commands a sense of safety for all participants (Topping 1996). As indicated earlier a standard approach adopted by the breast care nurses to open discussions about sexuality concerns is to question the woman about her relationship(s):

BCN 27: I usually ask them if they are actually having a physical relationship with their partner.

AT: Do you get blocked?

BCN 27: I try and approach it in a different way and if I get blocked again I leave it

(BCN 27)

A number of the breast care nurses reported that 'shots across the bows' whether via questions concerning relationships, or in association to other activities, or possibly explained by other factors sometimes failed to open discussions in this domain.

"In fact that was one of the reasons we wanted to take over fitting because we felt it was a good opportunity to actually meet the lady and identify any problems because they weren't being picked up before. On the whole unless I am blocking them. Maybe I am not asking the right questions but it is not a session where I pick up a lot."

(BCN 8)

In this account the breast care nurse offers a statement concerning her performance "unless I am blocking them" which suggests insight into her performance of communication skills. As she surmises the absence of response from woman may be due to a variety of reasons, for example: not asking the right questions or indeed the location ' may be wrong. Whereas other breast care nurses use that event in order to initiate discussions in this area:

"It's a very sensitive hour because that sometimes can be the dawning of "God I've got to live with plastic now for the rest of my life stuck to me bra". But for many people they see it very positively..... It usually takes about an hour and as I say we cover lots of issues as well whilst doing this. Sometimes it is a very jokey, happy type of atmosphere. I am completely led by the patient and you know some of them refer to it as a sex aid. You know "If I don't fancy sex tonight I will just tell him to play with this". So it's how they want to play then obviously that's how I play it as well but some people can be quite tearful. "I don't like looking at my scar". "I've not got

undressed in front of my husband since this happened". Those sort of issues. Can come out at that time."

(BCN 5)

Another breast care nurse suggested that discussions about sexuality issues were rare in her interactions with women and indicated some surprise when a woman sought her out to explore issues:

"Women don't talk very often to me. Not very often because I wonder sometimes whether they (men) leave their wives alone because of what they have been through. I think, I remember one woman and she had a mastectomy and when I went to see her at home this was before I started actually offering a visit to people who had surgery. And I went to see her about two weeks after she had gone home and when I got there we went in the kitchen to make a cup of tea and she shut the door. And I remember being extremely amazed at this woman and I shouldn't be. You'll be mortified when I tell you but this woman all she wanted to talk about was sex."

(BCN 9)

A different breast care nurse claimed rarely to discuss relationships pre-operatively despite the possible consequences of body image in terms of treatment choice or the recognition later in the interview of the importance in knowing about availability of social support.

AT: Do you ever ask about their relationship and their partner?

BCN 11: I would say definitely not. (at pre-op home visit).

(BCN 11)

Whereas others recognised personal discomfort in this area and if they were 'blocked' chose not to pursue discussions:

"I have got to feel right about it too. I do often say you know this can be difficult or embarrassing to them. I don't know where to go from there. I tend to think if they say "No I don't want to talk about this" I will probably leave it."

(BCN 16)

Another breast care nurse very pragmatically grounded her responses relating to enquiry about how she sought to open and develop discussion in this area:

“To be honest sometimes I can be just downright relieved you know because if you are not up to par yourself or if you are busy you can think “Oh right. I’ll leave that to later”. Sometimes I think you can feel all sorts of things. Sometimes you feel inadequate because as much as you know you are not all things to all people. You do try to be. Sometimes you feel frustrated if you are really trying hard and you are convinced that this is a real problem for this woman. You can feel angry, you know, especially, like, because some people just block you totally and you can feel angry.”

(BCN 20)

This account clearly emphasizes the burden of the work of breast care nurses and how this may influence whether this area is pursued in discussions and, when it is pursued and blocked by the woman, the impact that has on the breast care nurse. In the absence of direct observation of nurses interacting with women (and their partners) it is impossible to comment on the basis of estimating skill level of individual breast care nurses. Nevertheless when these comments are interpreted collectively they do raise questions about the limitations of the dominant approaches to skill acquisition to underpin practice. Breast Care Nurse 20 identified that patients can choose not to respond to cues or even “get the point” of the nurse’s concern. Irrespective of skill, if a woman chooses not to disclose, and decides to be a non-participant thereby blocking interaction, she is acting on her imperative. A woman has no obligation to play a part in an interaction or in the nurse’s pursuit of knowing. She can block thereby limiting knowing and only enable a partial knowing. However from some of the accounts it would appear that the nurse’s own comfort has greater influence in the one to one encounter and determines whether this topic is on the agenda for discussion. This is suggestive of a hierarchy of importance that exists, despite the evidential basis for problems in this domain, and some breast care nurses appear to choose to avoid and/or block thereby constructing their own partial knowing. As an addendum blocking may of course be a situated act and context specific. This is a point which will be discussed later in this chapter in relation to sexual orientation.

Sex and body image work

A number of the breast care nurses gave examples of their work with women related to particular difficulties individual patients and their partners sometimes encountered. These accounts presented by the breast care nurses were frequently prefaced by comments such as “I don’t know if I’m doing this right but..”⁴⁷ In the absence of any real knowing of what is best practice in this area they can only be judged in terms of anecdotal responses of benefit.

“I’ve got this wonderful article it’s a newspaper cutting and I am desperately trying to get hold of the painting of a woman who had a mastectomy and actually let her friend paint her and they published this picture of her having had surgery. And it’s wonderful because she is there and you know. And we gradually we use that and a lot of the psychological. We talk about it and talk “She doesn’t look like a freak”. “She doesn’t look ugly”. “She still looks attractive”. “She looks young and still looks” And so we sort of use that. And we use a bit of imagery and visualisation to sort of work them through it.

(BCN 17)

“And sort of ask them how they see themselves after the operation you know. What do they, have they looked in the mirror and that sort of thing. What do they do and how important their breasts are to them. Which makes them look at me sort of as if I have fallen off the Christmas Tree. Are they functional. How do they feel about them. And sometimes they are just there you know they have their kids and they are just functional. And it’s something to stuff in a holder and that’s it.”

(BCN 25)

In these two accounts different strategies are used to encourage women to confront the physicality of breast loss and translate the feelings associated with loss into language. It is as if an aspect of the work is to facilitate the woman to present her sentiments in a narrative different⁴⁸ from, but in addition to, that offered by medical discourse of the “crash course in breast cancer” (BCN 24) associated with information giving around treatment decisions. Another strategy offered was using information to enhance, in this

⁴⁷ This prefacing of examples may have had something to do with my perceived ‘authority’ in the area (see Chapter One)

⁴⁸ Could the breast care nurses be using these “listening/talking” sessions to facilitate weaving of boundaries (interfacing) medical treatment agendas to illness narratives?

case, quality of life. In this account the breast care nurse acts as educator in order to offer options or possibilities within a woman's sexual relationship.

"I have a lady who had bone cancer and really wanted to continue the intimacy of sexual contact with her husband but was finding it painful. So we had a long discussion about this. And although we were talking about different positions, and why and how, she couldn't really see it. And we were getting lost so I remembered some leaflets I had from (Name of organisation) and there was one on positions and so I got one and we went through it. Had a laugh and went through the positions to see if they were painful for her, or not, and some were OK and some weren't. So she went home armed with these leaflets. And she came back and she said it had been one of the best sessions she and her husband ever had. They never laughed so much.I do find leaflets very useful for, especially situations like that when people are not normally used to being adventurous or using other positions. It's not that necessary they feel you know they just need a bit of painting by numbers sort of guide. It just takes some of the pressure off and they can concentrate more on how they are feeling doing what they are doing.

(BCN 27)

Another aspect of talking and listening interaction was related to disclosures concerning aspects of personal life, past and present, which have the potential to discredit while at the same time increase knowing. The act of disclosing is in itself presented as a valuable strategy suggesting the catharsis of telling somehow has an implicit benefit – "a problem shared is a problem halved".

"I think that people tell me things in confidence. Things they talk to me about things that they never even speak to their husbands about. Or they wouldn't want their husbands to know. I was just thinking about one woman. We did talk a lot about their sexual relationship and not only her problems. Not being able to touch her breast anymore because she couldn't bear him because of the soreness or whatever. She just didn't feel like it and that was the big cause of their relationship. She felt very guilty. And she said "I felt awful telling you that because he would be horrified". She sort of categorised him as a bit of a prude and she never saw him undressed. She never saw him in the bath. Nobody saw him in the bath or undressed. He was very much a private person yet they had a very close relationship.

(BCN 11)

The strategies so far discussed have been talk based and have as their basis instructional or "listening to" and reframing concerns as strategies for alleviating problems. The next

section discusses reconstruction as a strategy for obviating distress and the breast care nurse's role in facilitating access to permanent cosmetic approaches to body integrity.

Breast reconstruction: the moral journey

The issues of how treatment choice were presented to women, and the breast care nurse's role in providing information to assist the woman in decision making, have been examined earlier (see chapter five). That analysis cast some doubt on the status of the woman as an equal partner in the decision making process. It was suggested in that analysis that health care professionals believed themselves to be participating in what they understood to be a shared decision making model although it was doubtful how women could voice their concerns and contribute in a meaningful way. The reality as portrayed in the interviews with breast care nurses, was a process organised with the woman in either a state of ignorance (the decision or 'advice' constructed prior to the woman having diagnosis confirmed) and in absentia (in a multi-disciplinary meeting). Her case was, to all intents and purposes, decided on medical 'facts' and the breast care nurse's "knowing" of her. This was subsequently presented to the woman in a way that had the potential to minimise her involvement. That conclusion can only be partial as it is based solely on accounts from breast care nurses and women's recollections. That said, little dissatisfaction or criticism of the level of involvement in decision making was evident in the interviews with women.

An aspect of the management of breast cancer, and an option that some women may wish to have offered to them, is reconstruction. The recently developed standards (NHS Executive 2000a) propose that the Breast Multidisciplinary Team (MDT) include a plastic surgeon as a member of the extended rather than core team. The guidelines for surgeons (BASO 1998: 5) indicate: "All patients should have the opportunity to receive advice on reconstructive breast surgery where appropriate". The position outlined in the standards of care for breast care nurses (Royal College of Nursing 1994) more forcefully proposes that at diagnosis the possibility of reconstruction should be discussed. In addition, women for whom reconstruction is an option should have the "knowledge,

support and a realistic expectation of the results of surgery” (Royal College of Nursing 1994:11). As illustrated in chapter five the way in which reconstruction is presented to women in some units may have a greater relationship to availability of a plastic surgeon than offering real choice to women.

In chapter two I discussed the range of surgical options that can produce a reconstructed profile for women. In this section the data relating to breast care nurses’ involvement in patient education and gatekeeping associated with breast reconstruction will be presented.

Zimmerman (1998) argues that there is a medicalisation process that defines breast reconstruction and works at three levels. Firstly, it pathologises a disease or bodily condition. Secondly, it involves the development of an organisational structure to treat; and thirdly through interaction it judges the decision to undergo surgery within a medical discourse. This is best illustrated in the use of the terms cosmetic and reconstructive. The former relates to surgery to enhance and the latter to reassemble after iatrogenic disfigurement. The language used to pathologise body image change brought about by breast amputation can be seen in the explanation offered to describe the behavioural responses engendered in women by mastectomy:

“Many women are dissatisfied with any prosthesis that they are offered, and they may attempt to avoid facing the painful reality of their loss by refusing to look at the chest wall or allowing their partners to do so. Some go to the lengths of covering mirrors, dressing and undressing in the dark, and minimising the time they spend bathing. These activities reflect an **avoidant style of coping**⁴⁹. It is hardly surprising that these women tend to have lasting depression and loss of interest in sexuality.”

(Maguire and Parkes 1998a: 1986).

This account clearly sets behaviour as pathology. Considering the impact mastectomy can have on women it would be reasonable to assume that any strategies that might reduce the impact of the cure in order to improve the quality of survival would be actively supported. As long ago as 1985, (Schain, et al. 1985) strong evidence was established in the United States in support of immediate rather than delayed

reconstruction following mastectomy for cancer in order to reduce some of that psychological burden. This was additionally supported through federal legislation ensuring that women in some states in the USA were required under law to receive information relating to reconstruction. The response to improvements in surgical technique and greater range of technology to underpin reconstructive surgery has been less enthusiastic in the UK and uptake of reconstruction by woman has been less marked. Schain et al (1984) suggests that women who seek information about reconstruction fall into three categories. Those who ultimately have reconstruction, those who on the basis of an informed decisions choose not to undergo surgery, and those who remain undecided, vacillate, between wanting and resisting surgery (Schain, et al. 1984). The breast care nurses who participated in this study reported involvement with women who could be fitted into those categories:

“They may have asked us before; they may have asked us if we’re fitting them with prosthesis or something. They may ask our opinion. They may ring up and ask. So we put them in touch with someone who has had it done. That seems to be the best way. A lot of people ask but not a lot have it done.”

(BCN 3)

In a number of units reconstruction at the point mastectomy was presented as the best treatment option.

“It is given up front with the options of do you want a wide excision or do you want a mastectomy with an immediate reconstruction, or do you know the possibilities of. (Pause) Really quite a dilemma in choosing what they want to do, and I do sometimes think with the patients that we have dealt with, they have been in a dilemma more about having an immediate reconstruction than actually deciding what should a wide excision offer versus a mastectomy. It’s been the reconstruction side of the dilemma. Should I have it? Should I wait? Because you know it is different and it has to be said that it is more painful afterwards and we tell them this. We say you know and there could be complications in having this particularly with the implant than having a straightforward mastectomy, and then waiting until whatever. Until you have got over all the treatment out of the way. Or until you are in a better frame of mind to decide for yourself whether this is what you want to have. And I also think people decide for the wrong reasons.”

(BCN 15)

⁴⁹ Emboldening added by AT to emphasise nature of language used by original author

However even though reconstruction may have been offered, as in the account by Breast Care Nurse 15, close analysis of the detail of the offer suggests the use of a number of statements that could act to dissuade. “It is more painful afterwards and we tell them that”, the complications are presented as if immediate reconstruction is a more complex operative procedure and concomitant with complexity comes surgical risk. Delayed reconstruction is presented as having less risk of complications. This account is completed with a statement that women reach a decision to undergo immediate reconstruction “for the wrong reasons”. There is no criticism intended in relation to the importance of informed decision making based on ‘reasonable’ cognisance.

Nevertheless if understanding is linked with persuasion to encourage a particular decision then claims to enable patient autonomy are suspect. This narrative of right and wrong reasons appeared in a number of interviews and judging the rights and wrongs of a woman’s motivations for reconstruction appeared to be an aspect of the breast care nurse’s role moreover it allows her to function as an informal gatekeeper to referral systems. For example:

“I am lucky in that the plastic surgeon (will take an urgent referral) if I am really worried about somebody and I have worked through all the body image stuff to make sure we have got the right reasons. Because some people I think have reconstruction for the wrong reasons. You have got to find out what they are but if I am really concerned about somebody and I feel it is very important for them to get back to normality.”

(BCN 28)

There was a clear recognition of the need to gain insight into a woman’s motivations prior to referral for reconstruction and that appeared to involve establishing the woman’s partner’s involvement in decision-making and support for reconstruction.

There appeared to be an unstated requirement for partners to express the “right reasons” by showing solidarity and concern with the woman’s desire for surgery.

“I would ask about the relationship with their partner and how was it going and what did their partner feel about them having a reconstruction. Had they discussed this? Was she doing it for him or her? Get them to explore that relationship and those whom I was happy with would say, “Yes he loves me as I am but he doesn’t really want me to have a reconstruction but he knows it matters to me. Because I want to wear a plunging neckline

so he will go along with it but he doesn't want me to go through anything else that might, that might mean surgery. "Yes, great" I will then get them to meet other women who have had it done."

(BCN 19)

It would appear that a 'wrong' reason is to crave reconstruction in order to please a partner or as an effort to shore up a failing relationship. In addition concerns were raised as to the appropriateness of the reasons for surgery when they appeared to involve putting the interest of others, especially partners', in advance of the woman's own. This is illustrated in the following commentary:

"I had a lady recently who decided she would have. Well she went away and thought about it and then rang up and said: "I have decided I am going to have this immediate because it would avoid me having to come back into hospital. Because I can't come back into hospital because I have got my husband coming home". The circumstances were a bit (pause). He has become a quadriplegic through neglect of (the) hospital (where he was) based and he is waiting to come home. And she, once she gets him home she can't be taking time out to come and do this. And when she goes in the garden in the summer she likes to wear tops that don't reveal it. And I just got the vibes she was doing this for the wrong reasons and felt that she needed more time."

(BCN 15)

In this account after another consultation with the surgeon this woman chose not to have immediate reconstruction:

"Because he sort of said to her "You know it isn't always straight forward and there might, you might have to come back in to have it readjusted or realigned"

(BCN 15)

Superficially this account suggests that the woman made a considered judgement of the risks and then judged not to pursue this option. An alternative reading, albeit based on hearsay, suggests that the choice was presented in a manner that could function to dissuade and this was in part stage-managed by the health care professional involved. Some of the breast care nurses saw reconstruction as problematic to women. They suggested that it raised hopes that were destined to be unmet. Although the woman returned from surgery with a two-breasted profile, the product was a breast shaped physical mound on the chest wall, which was not equivalent to the woman's original

breast. The breast care nurses suggested that women, irrespective of the quality of the pre-operative information provided, believed that the outcome of surgery would leave them with an appearance similar to that they had before. This related particularly to reconstruction undertaken concurrently with primary surgical treatment. When women were offered immediate reconstruction as a choice from a menu, the perception was that sometimes (often) a hurried possibly ill-considered decision was made by the woman when she opted for reconstruction. Case examples were provided to illustrate how women had inappropriately undergone immediate reconstruction and had found the consequences challenging:

“I have had a patient actually at (place of work) who had her surgery in February, She had a reconstructed breast and she hated this reconstructed breast she called it a stump. She absolutely hated it.”

(BCN 8)

This issue of unrealistic expectations was raised by Breast Care Nurse 17 who commented:

“No matter how many times, and how long you spend talking to them about what their expectations are, the reality of it all, and the cancer. I don’t think they ever take on board that it is never (going to) be this normal breast again so that it’s as bad as looking at a mastectomy scar for some of them because it’s not the right shape.”

(BCN 17)

In this account holding realistic views of having cancer appears to be perceived as important to the breast care nurses but what realistic means is one of the uncertainties of the disease. There is a moral message associated with the narrative, as if having breast cancer involves the woman in a necessary engagement with her loss (acceptance of being discredited) before the luxury of cosmetic surgery is earned. This narrative is suggestive of a moral journey associated with cancer that has to be travelled before a woman can consider regaining an intact body image. Moreover if she has completed her journey she will accept the limitations of reconstruction more readily. This was reinforced by Breast Care Nurse 19 who suggested and judged:

“I found women fell into two camps. Those that wanted it (reconstruction) for convenience of how it looked and those who wanted it who didn’t want to remember that they had cancer.”

(BCN 19)

It is as if it is inappropriate for a woman to want to wish to look good or forget, stow away, the cancer experience until the penance of treatment is accomplished. This resonates with the implied messages and ideology of a puritan ethic (Charmaz 1983) that women are required to work at breast cancer and achieve adaptation. The work for a woman with breast cancer is to face the reality of diagnosis and treatment, recognise their discredited status, and then they have earned access to ‘cosmetic’ recourse. Moreover a woman should demonstrate ‘good’ rationale and to a degree so must their partner, if they are to be supported.

A number of the breast care nurses presented heroic case examples of women who had taken the ‘right’ approach to reconstruction. In the first case reconstruction was offered as gift after ten years:

“Yes there is a lady in theatre as we speak who had her mastectomy 10 years ago and because the old surgeon left, who was very much of the old school it was never mentioned, reconstruction. She wanted a reconstruction so she was absolutely amazed when it was offered. You know “How do you feel about this?”, “Well I hate it”. “Well, what about if we could do something about it?” Again, “Yes please”.”

(BCN 8)

And a second example of a woman who had clinical reasons preventing her undergoing reconstructive surgery and she is presented heroically almost as a martyr:

“I had a lady sat in here four years after her mastectomy last week and her hope was that she would have a reconstruction at some point and the consultant said no because of her chest problem. She is a youngish woman but she has a common chest problem and she is being assessed for it. And they just said “No way. It’s too big an operation”. And her problem was such that - She was an important member of our support group, the treasurer actually, she had been coming all the time it has been running and she is getting very upset by the mastectomy. She said she was coming to talk about reconstruction and it was getting her down. And she said to me that her relationship with her husband was deteriorating and she feels very sad about that and she said she blames herself it’s not her husbands fault. She

says "He is good to me as he ever was and I know that he doesn't mind but I feel bad about myself, I don't like myself, I don't like to go out"."

(BCN 14)

These heroic narratives represent the navigational process through reconstruction that some women chart. Two very different stories were offered. One where the woman has accomplished her period of adaptation as in the case presented of a woman ten years after mastectomy. The second account presents a woman with "problems" which may have redress by reconstruction but "through no fault of her own", a physical limitation beyond her control, is excluded from the opportunity of *cosmesis*. Both, however, depict a moral journey for women on which they encounter professionals, including breast care nurses, who appear to have a role in interpreting women's motivations to ensure reconstruction is sought appropriately.

To date in this chapter the focus has been upon the work breast care nurses undertake with women. Much emphasis has been placed on the work associated with body image change and sexuality dimensions of the disease of breast cancer and its treatment. That 'work' is predominantly based upon talk and listening and engages the breast care nurse and woman in an activity which I have claimed is seen as central to the work of breast cancer care namely knowing. I have argued that within the breast care nurse litany is an assumption that knowing is best elicited in domestic surroundings as a more real authentic picture of a woman will be achieved. Whether knowing, as described by breast care nurses, is fully achieved. I have illustrated some of the limitations which may well be imposed on knowing and predicated those upon an analysis of the delivery of breast cancer care, the structures and processes, and considered knowing within the context of the care provided by breast care nurses. At the beginning of this chapter I indicated that context awareness theory would be examined in relation to knowing in breast cancer care nursing and I used the phrase "suspect awareness" to describe assumptions of actors in terms of the status of the knowing ultimately gleaned. In addition in the section examining the processes leading to decision making and access to reconstruction I have suggested that women are held to account in terms of the moral agency underpinning their wish for reconstruction. In this next section, prior to further elaboration of

knowing, the data that emerged associated with lesbian women will be examined. This material underscores the partiality of knowing within nurse-patient engagement.

(In)visibility and knowing: the case of lesbian women

.....now let's just say when I started this job 10 years ago a couple would have had to have jumped up and down and shouted we are gay with matching T-shirts for me to have noticed".... (BCN 19)

The results from the survey undertaken early in this study indicated breast care nurses appeared to hold more conservative attitudes than other comparable groups (Lewis and Bor 1994) in the domains labelled heterosexual relationships and masturbation. These domains are claimed by Lief and Reed (1972) the authors of the SKAT scale, to offer an indication of respondents' attitudes to homosexuality. In the items added to the survey instrument (question 32) to elicit responses relating to breast care nurses' experiences with lesbian patients, and their partners, low levels of response were obtained. Over half suggested that they did not address sexuality or body image issues with known lesbian and homosexual patients, and those that did, claimed not to address the same issues with their patients' partners. These responses were interpreted within the context of that analysis as features worthy of further examination.

My initial interpretation of the survey findings which informed the interviews with breast care nurses, and subsequently precipitated the search for lesbian informants, was as follows. The clinical context and the clinical encounters are founded upon an assumptive heterosexuality as norm. This explicit heterosexual 'gaze' disempowers challenge, disclosure, or accommodation of relationships outside that norm (Stanley and Wise 1985). Therefore the individual patient, or their partner, may because of the explicit heterosexual 'gaze' of health care consider it inappropriate to disclose their sexual orientation. A variety of reasons have been given in the literature. These include clinician insensitivity (Platzer and James 1997), endemic homophobia (Wilton 1996), sexual orientation being perceived irrelevant as clinical information by the patient, their partner, or health care professional in terms of the specific health care interventions, and/or breast cancer event. In the absence of an 'open awareness' (Glaser and Strauss

1965) coupled with the inhibitory effect of a heterosexual 'gaze' the breast care nurse may fail to move outside a heterosexual knowing or discourse with clients. Heterosexual 'gaze' may be manifest in a variety of ways i.e. the management and content of discussions around intimacy and relationships being handled insensitively or within interaction cues blocked thereby preventing disclosure. The potential result is an absence of knowledge of the breast care experience from a non-heterosexual position and an invisibility of lesbians within the population who develop breast cancer. This invisibility, if it does exist, is probably not unique to breast cancer care. Indeed, Wilton (1996) in a paper examining the needs of lesbian women within the context of midwifery practice argues that the omission is a feature of much of the work relating to women and health care citing Miles (1991) and Webb (1992) as typical examples. This omission is made, it is argued by Wilton, more telling by the feminist stance adopted by these authors. Wilton reasons that irrespective that the women in Webb's study of never married single women may not have been lesbian, to have failed to mention the possibility excludes and "will distort research findings and continue the marginalisation of up to a tenth of the population" (Wilton 1996:127). Wilton, in almost apologetic terms for singling out Webb, claims the work is representative of a generalised blind spot. I would argue a similar absence in the breast cancer literature. For example: a recent study by Budin (1998) examining the psychosocial adjustment to breast cancer of unmarried women. She collected demographic data on age, family structure, racial background, level of education, employment income, medical history and follow up treatment, without mentioning the possibility that the unmarried women might also be lesbian or bisexual or considering that this could impact upon social support or aspects of quality of life, the data is exclusive.

Wilton argues this neglect has an impact on the education of midwives and leaves sensitive and appropriate support to chance. Although there may well be a link between widespread invisibility and absence of knowledge and understanding to inform the practice of health care what has yet to be established is whether visibility, in the form of open awareness of sexual orientation, has any impact upon the experience of health care, breast cancer care, and more specifically the perceived utility of support from health

care professionals. It may well be the case (to extrapolate to breast cancer care) that visibility is irrelevant, even detrimental, to the lesbian woman undergoing treatment for breast cancer and/ or the breast care nurses they encounter during their treatment.

Nevertheless, the opportunity afforded by the qualitative interviews with breast care nurses to examine whether any of these issues were relevant was compelling. The interviews as described in chapter three took on the form of a conversation where the breast care nurses were asked to describe the breast care service they operated within using the trajectory of the patient journey as an anchor for discussion. If the explanations offered by the breast care nurses to describe their work centred on heterosexual relationships, or appeared to interpret relationships as if from a 'heterosexual gaze', I attempted to draw out knowledge of lesbian women among their clients. This part of this chapter presents the analysis of that data that illuminates aspects of the lesbian experience of breast cancer. In addition material emanating from interviews undertaken with Janet and Liz, two lesbian women who agreed to participate in the study, are used to offer an 'insider' perspective. Little personal information was sought from the participants of the focus groups but the breast care nurse who recruited the women believed all participants to be heterosexual.

Breast care nurses involved in this study had different sized caseloads but all reported limited, and in some cases an absence of experience with known lesbian or bisexual women undergoing treatment for breast cancer. This incongruity was discussed by one breast care nurse from a large urban cancer centre:

"However if it's true that ten per cent of the population is gay then they don't get breast cancer, right, so I don't think this can be true"

(BCN 2)

Whereas for another breast care nurse she had no doubt that she had never encountered lesbian women:

"As far as I know no I can't think of anybody who could be."

(BCN 3)

And for others they claimed not to have encountered situations when a woman disclosed her sexual orientation as lesbian:

“I have not come across many people that have actually said “Well actually I am gay”. I have not actually come across any.”

(BCN 27)

“Not that I know of, nothing that anybody has admitted.”

(BCN 21)

Despite this, a number of the breast care nurses indicated that they thought they might have encountered undisclosed lesbian clients. One participant discussed how, having not established the woman’s sexual orientation, she misread the situation but still remained uncertain as to whether her impression that the woman was lesbian was correct. Nor did she make an attempt to establish her hunch with an enquiry:

“Interestingly I don’t think I have had a gay woman I thought I did have and that’s just saying terrible things about me because of the relationship I don’t think it was because I had read it wrong to begin with but it might have been.”

(BCN 4)

Another breast care nurse recognised that the label ‘single’ was normally interpreted as the woman not having a permanent heterosexual intimate relationship but recognised that this could well mask a women’s sexual orientation.

“No I haven’t I have to say no I haven’t and I have not been involved in any I mean whether I have been involved with single women and I have not (asked) and they have not actually said”

(BCN 15)

Liz, one of the two lesbian women interviewed had been part of the caseload of Breast Care Nurse 3 and offered:

“..but of course I thought they were bound to know because I’m on my own and she (BCN 3) talked to me about that.”

(Liz)

From these comments the patient – nurse interaction appears to be fraught with uncertainty and ambiguity. If, as presented in the earlier section of this chapter, knowing is central to the work of the breast care nurse and complete awareness is the basis for

knowing why then does sexual orientation appear to fall outside knowing? Stanley and Wise (1990:33) suggest that: “lesbians are women who are continually jolted back out of ‘everyday routine’ into a grounded experience of ourselves as ‘different’. The event of a diagnosis of breast cancer is far from everyday to women but engagement with health care delivery is relatively commonplace in many women’s lives in the UK. This presents a question as to why lesbian women are largely invisible in relation to a disease and its treatment, which has associated with it problems relating to body image change, sexual functioning and sexuality. If, as has been presented, exploration of the personal and private aspects of a woman and her relationships form part of the everyday interaction associated with care and support offered by breast care nurses why does this fail to result in disclosure of sexual orientation? Given the claimed subject of the interaction this failure despite proactive questioning on the part of the nurse, or as an unsolicited disclosure during the interaction, is telling.

Using the commentary provided by Breast Care Nurse 3 and Liz, although I remain mindful of the limitations of a single example, a number of issues emerge. Firstly Liz suggests that she felt “no need” to discuss her sexuality with the breast care nurse:

“But in all this time I didn’t, I hadn’t discussed my sexuality at all. I didn’t feel the need to do so.”

(Liz)

But interestingly as she continues recollecting her interactions with the breast care nurse she suggests she would have been “surprised” if her orientation had been identified. She, then begins to consider whether the breast care nurse might have guessed her orientation. This was, according to Breast Care Nurse 3, not the case.

“So no I don’t remember any probing about my body image whether this was because she may have already have picked it up I don’t know. I would have been a bit surprised if she (BCN) had. But as I say if I’d needed to I would have mentioned it. I wouldn’t have had any problems saying something.”

(BCN 3)

The breast care nurse may not have chosen to pursue questioning related to sexuality and body image based on knowledge of the treatment choice and the less drastic effects

of lumpectomy in terms of surgical disfigurement⁵⁰. The rationalisation offered for avoiding, or not encouraging, disclosure of orientation is the individual's right to preserve their privacy.

"If they got to the point where they admit it or it became so apparent this was actually a full sexual partner then that's fine I would but it could be they wanted to preserve their privacy so I would just talk"

(BCN 19)

From this account it would appear that Breast Care Nurse 19 is suggesting that knowledge of orientation is irrelevant to the utility of the interaction. An admission is "fine" but "talk" would appear to have a value irrespective of some aspects of knowledge of the woman. An alternative strategy employed by some of the breast care nurses with women about whose sexual orientation they were confused, or doubtful, was to omit discussion altogether. As BCN 11 illustrates in this exchange:

AT Have you had any lesbian clients?

BCN11 I have had well I have had a couple of suspected because I have never asked

AT You have never asked and they have not said I am gay?

BCN11 No

AT: Have you met their partners?

BCN11 Yes

AT And still nothing has come up?

BCN11 No

AT And when you sort of in your agenda at that post op visit (Home visit) asked about their relationship you have not asked it? You haven't asked?

BCN11 No.

(BCN 11)

Another participant reports her own lack of exposure with this section of the population but offers a colleague's experiences which suggests that the practice of avoidance was the approach.

"I have not, no (encountered lesbian patients) I have not. My partner (other BCN in team) has and through talking to her she found it difficult to the extent that she did not address it (sexuality) at all."

(BCN 8)

⁵⁰ The term surgical disfigurement is used to emphasise the physical extent rather than potential impact upon a woman's attribution of meaning of extent.

Breast Care Nurse 18 recounts her experience of lesbian women and then goes on to explain how with 'suspected' lesbian clients, "the others", she did not discuss sexuality. The reason offered, that the woman was not undergoing mastectomy, was based on an assumption that other treatments for breast cancer do not carry the threat of concerns, disturbance, or functioning. This perception may reflect a view sympathetic to conservative management (lumpectomy with radiotherapy) as "an effective alternative to mastectomy, and one that leaves fewer emotional and physical scars" (Yalom 1998: 229). The current position emerging from the literature is far less firm in terms of establishing the significance of body image and sexuality concerns associated with breast cancer and its treatment (Meyerowitz 1981; Reapy, Hort, and Vandervord 1994; Langellier and Sullivan 1998).

BCN18 Yes there have only been two. There have obviously been others where I have wondered but they have never said and I haven't asked. But no we haven't had other than you know "I am lesbian and this is my partner" I just have not had discussions around sexuality and well no I didn't.

AT Or body image?

BCN18 No they didn't have mastectomies so they didn't they weren't saying to me I have got a problem with this around sexuality or body image

(BCN 18)

This was also what appears to have happened for Janet in her interactions with a breast care nurse:

"They were more concerned with physical things. We talked about diagnosis and Linda McCartney. Even though they knew (sexual identity), they didn't talk to me about it.

(Janet)

Some of the breast care nurses offered specific examples of encounters with lesbian women. The first account is notable by the style used to describe the woman that appears to suggest that the women did not match this breast care nurse's image of what constituted a lesbian woman:

"You know I just loved her as a patient and I remember she came to clinic and she was really dressed quite so. She had a soft white polo necked jumper and a claret coloured needle cord jacket and she looked really lovely."

(BCN 9)

This contrasts with another account drawn from patient contact where the woman was described as ‘manly’.

“A long time ago when I was naïve she was actually a (occupation) quite high up in the (organisation) and I found her a bit frightening. Not because she did anything to frighten me but it was a bit, (pause) and she linked with her partner. And I don’t know what the relationship; it could have just been they were two good friends. We have all these preconceptions about what what are lesbian friends, what a lesbian. And because the patient that I had was very manly probably because she had been in the (organisation) and worked with me, but walked like a man, and talked like a man. It was more obvious to me that she was in a lesbian relationship. It was silly really it was just how I felt that their relationship might be.”

(BCN 11)

A striking feature of the interview data narrating encounters with lesbian couples that appears different from the heterosexual stories is the strong presence of partners within clinical interaction. Neediness of partners in terms of emotional support, or expectation of talk and listening by partners in addition to the woman with breast cancer, is one description offered of lesbian relationships. Another feature described is the representation of partnership characterised within lesbian relationships as described by the breast care nurses. Whereas in the accounts of heterosexual relationships male partners are cast in roles divided along more traditional labour division lines that are promulgated from the first invitation to accompany the woman through diagnosis. The picture of male partners offered in accounts from the breast care nurses suggest ‘good men’ demonstrate their support, expressing to the breast care nurse that their partner’s (woman’s) life is more important than body image change, demonstrating their support by participating in household duties and family care. When male partners were reported as reacting inappropriately, by over reacting or ‘over protecting’, by excluding themselves as it appears to be “women’s talk” (BCN 19), or not quite knowing how to demonstrate their feelings to their partner they appeared to be viewed sympathetically by the breast care nurses. Some accounts were offered of heterosexual partners who were unsupportive, of women in troubled or difficult relationships, of women who end relationships during the course of treatment. Yet men appeared to be viewed with an almost a benign acceptance of male failure to do the ‘right thing’ as acceptable

behaviour. Moreover some breast care nurses sought to coach men on acceptable behaviour for example in the following account from Breast Care Nurse 28. In this account the woman chose to construct an interaction between the breast care nurse and her husband in her absence:

“(Husband’s name) is not a person to talk to sit down and talk, you know. He will do anything rather than sit down and talk so we had to manoeuvre it. And I arranged to go and see her at 4 o’clock when he would be up because he does nights and casually call in. And when I called in there is no sign (woman’s name). And then it dawned on me what (Woman’s name) had done because (husbands’s name) said “She is over at so and so’s over the way, I’ll go and get her”. And I said, “No, no don’t get her. Let’s us have a talk. I haven’t seen you for ages, I’d just like to see how you are”. How’s work, stuff, and be all casual and we did. We were able to get onto sexuality and it had been a problem. (Woman’s name) had had a second mastectomy, and bilateral oophorectomy, and she had then had a hysterectomy. And she was feeling very lost her femininity full stop. Didn’t seem to be a problem to (Husband’s name). But it was a problem to her and she needed some feedback from him and he wasn’t giving it. He didn’t know how to, bless him. So we were able to talk about that as well. (Woman’s name) had cleverly got herself out of the way. She turned up three-quarters of an hour later when we had done a lot of talking. It really worked well because once he started he was able to talk about all sorts of stuff about his feelings and her feelings and how he worried about her. And so by the time she had come back he was ready to declare his love in front of the whole world if he needed to. And how much he desired her, and the fact that she had her breast removed didn’t matter, and he didn’t want her to have a reconstruction, and she was beautiful and all this business.”

(BCN 28)

Emphasising that male partners were deemed important participants in the woman’s recovery but also alluded to and descriptions offered were strategies breast care nurses employed to instruct men on how to behave toward their partner and accounts of men who did not perform supportively. Whereas for the lesbian couples their relationships and roles within it were viewed less positively and given greater critical scrutiny:

“And I had one reason I found it difficult to cope with the couple anyway, because they were difficult to cope with the couple anyway, because they annoyed me. The patient was very distressed very emotional but I wasn’t allowed to go and seek help. So I don’t know what the living arrangements were. I don’t think they actually lived together all of the time but every time it came for an appointment they got together again. One was masculine. One was feminine and it was the friend who was the masculine sort of

domineering person and when we came when the situation was talking she wouldn't shut up, it really used to bug me that I would like to talk to this person. Every question she (friend) would answer and I used to get to this stage where "suit yourselves, go and sort yourselves out because I can't do with it". The other thing about that couple wasn't particularly a problem with the way they were but one didn't want treatment, any treatment at all. Well she didn't want conventional treatment she had the (name) injections I can't remember what they were called and she wanted to come back for longer and I did spend, I did support her but that is what she wanted."

(BCN 11)

And another breast care nurse offers:

"The greater fear was from the partner who thought it might happen to her was the biggest problem. The patient was fine it was the partner who was the mess. What if it happens to me? It does really frighten women. It (breast cancer) does happen to people that you care about know it just doesn't happen to other people. Yes she had a problem with that but didn't want to talk to me about it. Partners don't feel comfortable talking to me in depth for that reason. I think they see me as the patient's."

(BCN 12)

The importance of breasts as the most visible and therefore tangible symbol of womanhood in Western culture is often offered as reason for the abundance of research on women with breast cancer and arguably framed the research questions in this study. Langellier and Sullivan's (1998) phenomenological study sought to explore women's language about breast cancer experiences in order to illuminate the meaning of breasts within that experience. They noted that the women in their study were either reticent or unable to use language to explain the different shades of meanings associated with their breasts. They argue that there is "pressure to construct women's bodies as passive and fragmented objects – by both social and medical discourses- threaten to reduce women's bodies to breasts and to reduce breasts to objects for others to view and use" (1998:91). Although Langellier and Sullivan included sexual orientation in their description of participants, and the sample included three lesbian women out of twenty one, they make only one reference to data unique to a lesbian participant and

this relates to an aspect of women's breast narratives they term "the sexualised breast" (1998:88). Whereas breast talk associated with lesbian women offered by the breast care nurses could be read as relating to conceptualised notions of what constitutes "the gendered breast" and a breast that symbolises femininity:

"They (lesbians) might have sort of different body images. I mean we had a lady who is (a lesbian) and had a mastectomy and she opted to have the other side as well."

(BCN 26)

"It (being a lesbian) didn't make any difference to the way I treated her and also the fact that she had a mastectomy - bilateral mastectomy. And she was not continually bothered about wearing prosthesis she was quite happy with a flat chest all of these things built up a picture in my mind but I didn't ever bring it up as a subject."

(BCN 11)

In another account Breast Care Nurse 14 recounted a story which involved an encounter where the patient is described as trying to embarrass as a strategy, or abnormal response, to dissatisfaction with cosmetic appearance:

"I knew she was trying to embarrass me but I (BCN) deliberately didn't pick up on it." ".....but she had so many problems with this wound she thought. She'd had antibiotics and wasn't happy, wasn't happy, wasn't happy and then she had she was going for radiotherapy but she was the type. She sat in outpatients one day having been examined. The consultant had seen her with one of the junior doctors. She was angry and said it was because it (her breast) was pointing outwards a bit and everytime she did this (movement) it was irritating, and "it's really, really, annoying me" and he said "Well it is very very early days yet I honestly don't want to touch it yet I want to give it another three months and see if it will settle down". "Well I don't like my nipples and my husband, my ex-husband always said he didn't like touching my boobs". So this history is going on so we just accepted that and didn't question it any further. (Consultant surgeon) just said if the problem persists in three months we would think about it."

(BCN 14)

What is of particular note is the disclosure in this account of a previous heterosexual relationship, an admission of a 'problem' encountered in that relationship related to the woman's sexualised breast, an affirmation of the problem (subordination to male interpretation of the breast) and an agreement to re-visit the problem. Although that

agreement being at the level of “we would think about it”. The power in the relationship firmly resting with the ‘we’, the consultant.

In another account the breast care nurse expressed consternation that a woman wanted to discuss her breasts but without locating that talk within the context of her sexual relationship:

“She (lesbian woman) was somebody that had got implants prior to being diagnosed with breast cancer so obviously her breasts were an issue to her to start with so it was quite easy and obvious to talk about how important her breasts were to her but you know she never said to me never talked about it in terms of her partner.”

(BCN 29)

And in another account a complex picture of the patient is presented with detail about sexual orientation, extensive breast surgery, and information about the women’s choice not to wear a breast prosthesis. This information might act as cues or indicate problems associated with body image or sexuality yet the breast care nurse chose not to explore this with the patient.

“It (being a lesbian) didn’t make any difference to the way I treated her and also the fact that she had a mastectomy, bilateral mastectomy . And she was not continually bothered about wearing prosthesis she was quite happy with a flat chest all of these things built up a picture in my mind but I didn’t ever bring it up as a subject.”

(BCN 11)

And in another case:

“This woman didn’t have breast cancer she has other problems which has resulted in her having mastectomies.”

(BCN 20)

So far the material discussed has concentrated on breast care nurses’ stories about specific clients often where orientation is explicitly understood if not spoken. Some of the breast care nurses offered accounts of working with women and their partners when orientation remains unstated and unknown.

Kitzinger (1988) offers six possible conceptualisations of lesbians, which she argues construct prejudice. Firstly a radical feminist position where lesbianism is not a given but a choice available to all women and one which is particularly threatening to a heterosexual hegemonic order. The expectation of lesbian silence is seen as an example of oppression. Second, a liberal humanist position, which she argues is the rhetoric underlying most contemporary social science research in this area. This depicts lesbianism as natural, normal and a personal (therefore private) choice; a position which is politicised at the level of legal and social reform i.e. bringing it into the range of normal and allow people to do what they want in the privacy of their homes. A third position locates lesbianism as slightly distasteful sexual activity and unlikely to be satisfying and presents lesbians as different from heterosexual women:

“They can’t imagine what it must feel like to be a lesbian, they have never known any lesbians, they don’t know they could choose to be lesbians, and they wouldn’t know how to behave in the company of a lesbian.”

(Kitzinger 1988:170)

Kitzinger’s fourth description is that of lesbianism as part of the menu of sexual gratification. It is often chosen as trendy, when no alternative (male) is available, and sampled as part of sexual liberation. This can be seen in the widespread use of women with women portraying sexual acts in pornographic materials. The fifth account of lesbianism is that of unnatural state using science as justification, whereas a sixth position is one based on views that lesbianism is unnatural, but built on religious reasoning. From the narratives offered I would suggest that threads of this typography of lesbian prejudice are present.

Privacy

The right to privacy was a theme that was voiced with some regularity by the breast care nurses based on an assumption that being public as a lesbian would be stigmatising for the individual. Interestingly, this view was offered without consideration of what constitutes ‘public’ or recognition that it may only be ‘public’ within the context of the

client-nurse relationship. Also this breast care nurse alludes to the stigmatising, the discrediting, effects of knowing sexual orientation.

“I mean you do ask if they have a partner but they may not want to be open about it anyway. It may be something they want to keep private and they might feel they will get, I don’t know, that sort of stigma isn’t it?”

(BCN 26)

Another breast care nurse rhetorically questions herself within the interview as to why she has failed to elicit orientation and offers an rationalisation which fits within Kitzinger’s typology of lesbianism as permissible but private:

“I haven’t said is this your partner? Now why haven’t I said it? Am I afraid of causing offence to the woman having known she was married but I have said to myself I have promised myself the next time I speak to this woman I am going to say “Don’t take this wrong but is (Name) your partner. I have promised myself to ask that question. I think it will allow her to talk more freely about how she is feeling as a woman and her sexuality. She does talk about it already but there is something missing if that makes sense there is a wall there yes there is a wall”

(BCN 20)

This breast care nurse expresses some disquiet about working within a ‘closed awareness’ context and the limitations that not knowing orientation brings to that interaction. Whereas Breast Care Nurse 5 does not see ‘closed awareness’ as having an impact upon interaction:

AT Does that (knowing orientation) make the conversation about intimacy different in any way?

BCN5 Well I don’t think it does

AT It’s immaterial almost?

BCN5 Yes

As can be seen from the language she uses whilst claiming to leave open an “other than heterosexual” possibility:

“But when I use the words husbands and partners I have usually got that on my mind because we seem to have a few people that have had woman living with them.”

(BCN 5)

Another breast care nurse describes the nature of talk with ‘single’ women both lesbian and those considered heterosexual:

“What I’m not so sure about (is) the lesbian who is not in a stable relationship and I have a feeling that I don’t know her orientation, who she is. Because certainly the number of times in a very long career that a woman has talked openly of the loads of woman without partners will talk about how differently they think it may be new partners. They talk to me about how difficult. Now they cannot possibly proportionately be how many gay women I have ever dealt with. You know they can’t all be out there they must be in here as well and I think sometimes I once done a “OK I think I’ll call your bluff here” because I felt she has given me enough clues to allow. To make me feel I could say “ We had better make this clear what we are talking about here. Are we talking about would this person be your lover but that I think is unusual. But I think I have other times when I thought the general conversation about I don’t think I could find anybody now and I have been too frightened. Because if my guess was wrong. OK for some people your guess might be wrong and they might say “Oh no”, but if it was wrong that might be the end (of the patient-BCN relationship) and I have tried in my responses to make it pretty clear that I would not make an assumption about people.”

(BCN 2)

Whereas another expresses ‘disappointment’ that a couple could not be open with her about being lesbians when she believed that to be the case:

“I can think of a couple where it was so glaringly obvious that they were gay but they never actually told me that and I always felt that disappointment that they didn’t. I mean it was so obvious that they were gay and I thought well maybe they just don’t trust me enough to or maybe they thought well she will know and it is no big deal because it isn’t. I suppose why should they have to say we are gay because obviously it doesn’t make a difference.

(BCN 29)

Much of the rhetoric in modern cancer care would, at face value, appear to welcome openness and truth telling within health care professional and patient encounters. This has in Western health care been a trend since the 1960s. Glaser and Strauss’s first described ‘awareness contexts’⁵¹ Costain Schou and Hewison (1999) in their study exploring the experience of cancer from the perspective of patients suggest that awareness is far from a passive exchange of information but social interaction involving interpretation and practical work on the part of the patient. They suggest that from diagnosis onwards the patient is engaged in a flurry of activity associated with sorting,

discarding, distillation, and interpretation of information in order to make decisions within the context of their social reality. They suggest that: “Their (patients) definitions, interpretation and choices arise through their interaction with treatment professionals and other patients”. (Costain Schou and Hewison 1999:30).

BCN18 Yes there have only been two there have obviously been others where I have wondered but they have never said and I haven’t asked. But no we haven’t had other than you know “I am lesbian and this is my partner” I just have not had discussions around sexuality and well no I didn’t.

AT Or body image?

BCN18 No they didn’t have mastectomies so they didn’t they weren’t saying to me I have got a problem with this around sexuality or body image

BCN18 I would probably be just as reluctant to be open about sexuality as I was with straight women. I didn’t (discuss it) and for the same reasons. I don’t feel that I felt uncomfortable that they were gay. I think looking back I felt that actually they were very brave telling me that they were gay. It can’t have been an easy thing to do especially in a stressful situation and with a stranger. I just have not had discussions around sexuality and well no I didn’t.

In this exchange Breast Care Nurse 18 has made it clear than she is reticent to address issues around sexuality with patients in general and claims sexual orientation is irrelevant. In fact she goes on to express her lack of disquiet about sexual orientation disclosures but recognises bravery in being open. She then discusses how she read the client and reached a decision that they did not have problems. Again the issue of not having a mastectomy and therefore deciding that discussions were irrelevant reappeared in this context.

Breast Care Nurse 19, however, makes no claims to being comfortable with the knowledge that someone was a lesbian but then tries to explain the nature of discomfort.

BCN 19: I do remember feeling vaguely uncomfortable because I hadn’t had the exposure. But there is almost uncomfortable due to ignorance as opposed to uncomfortable because of a moral position

AT Oh absolutely yes

BCN 19 :I was so worried about not saying anything to offend them, yes.

⁵¹ Closed awareness, suspected awareness, mutual pretence awareness and open awareness.

AT That you could easily have been offensive because you.....?
BCN 19 :Yes. It's like going into a house in a foreign country and not knowing whether to take your shoes off or not or what to do not to offend. It was that level. Desperately trying to be kind and understanding.

(BCN 19)

Breast Care Nurse 23, talking about her exposure to known lesbian and homosexual clients, talks about being honest with the woman and her partner about her lack of knowledge but also talks of her disquiet about discussing "sexual issues" with this couple. She also talks about being uncomfortable but that discomfort seems to have resulted from the combination of personal ignorance of lesbian sexual behaviour and the explicit nature of the discussions.

"I've looked after one woman who had a lesbian partner in breast care and in stoma care one homosexual chap with a gay partner. But with the couple that I did I said look I don't know. I was fairly honest and I was fine about the surgery, chemotherapy and the rest and then we got talking about sexual issues. I mean a lot of it was the same as any woman do you know what I mean. You know like the guy had been saying about her nipple and her erogenous zone and all that stuff but if like they were asking me about chemotherapy and how it would affect their good relationship and I was honest my knowledge of lesbian sexual relationships is pretty nil and I was quite honest and said that. I was unsure so I was honest. I was very uncomfortable and I came out and thought "Gosh, I hope I haven't messed it up and lost them". I did feel that they won't come back to me but they did. Probably because I didn't know what I was talking about and I felt at a loss and possibly embarrassed. If I am really honest embarrassed because I didn't feel comfortable about what I was talking about. I don't feel that when I have a husband and wife or you know (heterosexual couple) that wouldn't worry me but I just felt embarrassed because of what they were saying and I felt I just felt embarrassed."

(BCN 23)

Whereas Breast Care Nurse 20 talks more comfortably about her work with lesbian women and with more familiarity about lesbian sexual behaviour:

"I think it is very important but only because I suppose in one way it is not important because the sexuality the sexual activities you know what I mean is the same. The relationship is the same as much as people don't think that it is. Once you are in a relationship it is. But it's like an acceptance. It's a shared knowledge. It's like knowing somebody's name. I suppose you are part of the in crowd you know. You are in there with that person they know

you accept. They accept you accept. It's a giving, sharing thing which helps you with everything else."

(BCN 20)

One area a number of the breast care nurses wished to discuss in relation to lesbian clients was real and potential responses of other members of the breast care team. Breast Care Nurse offered a recent incident where a medical colleague questioned the sexual orientation:

"One of the consultant surgeons asked me this morning about (Name of patient). Said we (Medical team) were all wondering is (name of patient) a lesbian? Then said "I would treat her the same anyway" and I thought "yes?" But if I was the patient I wouldn't be in that kind of hurry to say because I don't blame them (lesbian women) for keeping quiet a bit."

(BCN 2)

In this story the Breast Care Nurse 2 would seem to be suggesting that even if she knew she would not disclose the information to medical colleagues moreover she suggests that non-disclosure by a patient to their medical clinician was appropriate behaviour.

Whereas Breast Care Nurse 20 offers a slightly different interpretation of medical response, one in which she would not in the first instance be sensitive to the possibility that the patient might be a lesbian compounded with a general discomfort with sensitive issues:

"So I don't think society is accepting enough yet so it is too much of a confidentiality thing. Well my own personal opinion is that they (medical staff) don't cope with the whole situation very well anyway so I don't really think they would cope with that any less. I don't even know whether it would cross their minds that they are a couple or they would probably think it was the sister or something because they are busy dealing with you know (giving bad news i.e. negative clinical information) "I am going to tell you this and I am uncomfortable so I will deal with it fast as I can so I can get away from this"

(BCN 20)

An alternative viewpoint but with a similar outcome was one based on experience of lesbians as problems which led the staff to ignore that aspect of personhood so as to avoid difficulties.

“That (a particular lesbian couple) caused so many problems they (Medical staff) would just ignore a lesbian relationship.”

(BCN 8)

And Breast Care Nurse 22 suggests that it is better for women not to disclose in order to protect themselves from differential responses from the health care professional:

“It only maybe the issues within the people within the Team, the other professionals, they (lesbian woman) can sense when professionals you know cotton on what they are and they (professionals) don’t particularly like what they are. We (Patient-BCN) may talk about issues like that.”

(BCN 22)

Breast Care Nurse 19 talks about an area discussed in the literature about responses of the health care team to knowledge of a patient’s sexual orientation status:

AT Do you think the issues were any different?

BCN 19: Yes, because they would talk about how hard it was when they came into hospital they weren’t allowed to be in a side room or lie down together for instance. Or they felt the nurses were treating them in a different way. The doctors certainly treated them in a different way and some of the surgeons were quite rude or so and so and her dot, dot, dot, dot. But I would challenge them. It’s very sad that that was there. This person was seen as different or not entitled to such good treatment. I mean I would have challenged that. “Oh does it make a difference to the course of the disease ha ha ha How fascinating”.

(BCN 19)

In this last section I have presented privacy as conceptualised by breast care nurses as an aspect of the (in)visibility of lesbian women. The question posed earlier enquiring why discussions of the personal and private aspects of the person, an everyday aspect of breast care practice, fails to result in disclosure of sexual orientation remains in part unanswered. I have presented possible explanations from endemic heterosexism, breast care nurse discomfort with difference, the protection of invisibility and the benefits of complicity in not knowing to both the lesbian woman and the breast care nurse. Nevertheless if “knowing” is central to the work of breast care nurses it would appear the (in)visibility of lesbian woman brings the nature of knowing under scrutiny.

Secrecy, disclosure and knowing

Secrecy and non-disclosure associated with informing patients about the likelihood of impending death described by Glaser and Strauss (1965) as 'closed awareness' is said to be a position of the past. Field (1989) suggests that in reality it is 'expert' opinion that has shifted the emphasis to truthfulness as the appropriate basis for doctor-patient and nurse-patient relationships. A variety of reasons are offered for that shift including the practical care of people who are dying. Pain control and symptom management have become better understood and therefore more likely to be controlled. This in itself has produced a more positive aspect toward death particularly in terms of medical and nursing care. Moreover, this has in some ways given impetus to the development of the care and management of dying into a discrete medical speciality (palliative medicine) and provided a focus for the care of the dying and bereaved within the specialism of palliative care. Nevertheless not all people die in a painfree, symptomless state of existential peace despite the advances in care and support. Field (1989) suggests that many of the debates engendered by Glaser and Strauss' work about awareness has shifted concerns to how people should be told and subsequently cared for. So, although the shift from evasion to openness may have occurred the ambiguity remains in terms of how, by whom, and when. Breast cancer as illustrated in this and the preceding chapter is experienced in terms of the biomedical context in an environment sympathetic to open awareness. Nevertheless the construction of open awareness focuses upon a biomedical trajectory and agenda, as described by Costain Schou and Hewison's (1998) 'treatment calendar', and offers limited consideration to the social reality of the woman's breast cancer which happens beyond or outside health care delivery. Glaser and Strauss in their description of the range of contexts emphasise the roles participant actors engage in order to maintain or move from specific awareness contexts (state of awareness) to others. The characteristic fluidity within interaction is emphasised as is the interplay between patient, doctor, and nurse to engineer changes in awareness.

So can awareness contexts theory (Glaser and Strauss 1965) be applied to understand the scenario of breast cancer? Context awareness theory appears to be closely linked

with the contention that self-identity is socially constructed through interaction with others. Central to the process of constructed self-identity is the influence of interaction with others. As Kelly (1992: 394) suggests “identity establishes what and where a person is within the social structure”. Annandale (1998) argues that a shift in analytic thinking in interpretations of health and illness has moved from conceptualisation of individual agency in response to status position (i.e. class, gender, culture) to a concern with social actors who “actively sustain their social world in every moment in their interactions with other people” (Cornwell 1984:19). Public accounts, those accounts of self that are acceptable to others, have claimed to portray illness as morally problematic. And I would argue in this chapter that has been illustrated in the exploration of the awareness context for knowing located in domesticity, the moral journey of reconstruction, and the (in)visibility of lesbian women. The accounts provide description of the experience of breast cancer as a project predicated on the concept of “successful illness” (Frank 1997), that is illness “lived substantially outside the clinical purview: the role of patient does not encompass the identity of the ill person” (Frank 1997:136).

The main thrust of context awareness theory is the transference of information from medical or nursing staff to patients. Timmermans (1994) argues this fails to grapple with three problems. One, the emotional investment associated with awareness. Two, the increased importance in health care delivery placed on providing prognostic information in the care of dying patients, and I would argue diagnostic and other information in the case of treatment for primary breast cancer. Three, that more information does not necessarily result in increased awareness; the individual can listen but fail to hear. I would add to these three revisions postulated by Timmermans (1994), that there is mutual agency in awareness. This point will be developed in chapter eight.

Breast care nurses, appear to recognise the notion of an authentic identity of the woman, the identity of the ill person, is something other than that knowable within a context limited by a biomedical orientation on disease, symptoms, response to treatment. This is particular apparent in their perceptions of body image change and sexuality concerns

and the significance of domesticity as a preferred context for knowing. As Kelly postulates “many people’s perceptions of who and what they are, are linked with their ability of otherwise, to have and maintain sexual relationships” (Kelly 1992: 405). Yet there would appear to be limitations in the breast care nurses’ ability to know. These limitations appear to be imposed by notions of ‘right reasons’, heterosexuality, stigmatising effects of cancer and treatment, and to some degree by the woman (sometimes her partner) willingly participating in “friendly talk and listening” to facilitate the breast care nurses’ knowing. Whereas the goal may be honesty in reality the outcome is a constrained view of identity predicated on suspect awareness. This suspect awareness does however allow the breast care nurse to control knowing of the real identity of illness, its morality, by keeping the “Pandora’s box” (Frank 1997:146) of illness closed or only partially glimpsed.

CHAPTER 7

DRAWING BOUNDARIES: TERRITORY, COLONISATION AND DECOLONISATION

Introduction

Frequently, and particularly recently, the social status of nursing has been explained in the context of gender relations, positioning nursing in opposition to medicine both male dominated and masculine in its gaze. Medicine is said to conceptualise illness and ill health through reductionist problematisation in contrast to nursing which is claimed as holistic and exercises values such as caring and nurturing which are gendered female (Barker, et al. 1995). The idea of nursing as victim to a dominant medicine as an overarching explanation has an appeal to an oppressed group but has its limitations. According to Wicks (1998), that analysis has failed to grapple with nurses “capacity as knowledgeable actors” to shape and extend through agency the scope and territory of practice. Her extension of the argument pivots on an examination of the “complex interplay of structure and agency” (1998:171) that constitutes “modern nursing as a paid occupation for women with potential for the development of autonomy and skill in the field of healing” (1998:171). Wicks’ study examined the work of nurses and medical staff engaged in day to day labour on wards. The work of breast care nurses differs from that of ward based nurses. Firstly, it is predominantly talk based, and secondly the work is undertaken in a variety of settings: wards, women’s homes, and clinics. Many of the arguments claiming a privileged status for medicine over nursing fail to consider the contribution of nursing to health care outcomes, often delivered in conjunction with, but not separate from nor always led by, medicine. Nevertheless, possible tensions exerted as a consequence of gender and the delivery of the goal(s) of breast care nursing will be examined.

The Forrest Report (Forrest 1986:32) was the first formal⁵² recognition of the potential utility of “specialised nurses to inform and support the women”. In the previous two chapters, chapter five and six, the range of activities that breast care nurses undertake in both hospital and domestic settings were described. I claimed, in addition to the work associated with information giving that through knowing⁵³, an ongoing activity

⁵² Formal in the sense of appearance in a Department of Health report

⁵³ Despite the limitations upon knowing discussed in chapter 6

undertaken through sustained interaction with women, breast care nurses provide support. From the evidence emanating from the focus group interviews and Liz's account, this support is well received by women. Using a metaphor comparing aspects of interaction between the patient and health care professionals to drama, I suggested that breast care nurses undertook the stage management role moving women through the "treatment calendar". At various junctures in previous chapters territorial issues have been introduced but not fully developed; that is the central concern examined in this chapter.

Although the purpose of the Forrest report was to make recommendations to government in relation to the feasibility of a national breast cancer screening service, the value of breast care nursing was recognised. Breast care nurses were identified as key members of the "specialist surgical team" (1986:32). This team was proposed as the core unit for providing a quality service and although it has undergone some revision in terms of constituency, it remains at the centre of contemporary breast cancer care. The evidence for the endorsement of specialist nurses came, as discussed in chapter two. Briefly, it derives from studies concerned with establishing the efficacy of nurses trained in skills associated with the assessment of psychiatric ill health to accurately identify and subsequently to refer appropriately to specialist clinicians those women who were experiencing psychological morbidity associated with breast cancer (Maguire, et al. 1980a; Watson 1988). This, now regarded as ground breaking work, has been more recently supplemented with studies said to demonstrate the efficacy of breast care nurses in providing psychological support (McArdle, et al. 1996), the role of nurses in information giving (Cotton, et al. 1991; Suominen 1993), and an exploratory study of breast care nurses (Tait 1996). Tait recognised in her work the wide variation in nature, scope and expertise evident in the practice of the breast care nurses who participated in her study. This view has been added to more recently by an Australian study (White and Wilkes 1998:95) which, using delphi technique, defined the breast care nurse as a specialist nurse "who facilitates the education of, and provides practical and psychological support for, patients experiencing breast cancer diagnosis and their family". In common with Tait, and White and Wilkes, this study found disparity in

terms of the range and reported strategies for the work undertaken by breast care nurses. That said, despite variation a commonality across accounts offered by breast care nurses was the perceived importance of “knowing” the woman in order to optimise care.

The clinical service guidelines developed by the Department of Health to inform local health purchasing strongly promoted the contention that a number of benefits accrue from the breast care nurse’s contribution to breast cancer care particularly associated with information giving and psychosocial support (Department of Health 1997d). These benefits include: enhanced understanding, increased patient involvement in decision making, reduced anxiety, depression and somatic symptoms and increased self esteem and general health. This study does not seek to (re)establish whether these benefits were the result of breast care nurses’ contribution to care but illuminate the way breast care nurses worked with women during the breast cancer experience. In effect, it begins to chart the work that breast care nurses undertake giving authority throughout the analysis to individual accounts. What has become clear is that just to have focused on accounts describing interaction would have disassociated the work from the context in which the women’s lives are enacted and becomes a sterile endeavour. It would have neglected the broader and highly politicised nature of breast cancer care delivery and failed to recognise the agency of breast care nurses in framing agendas and colonising “unclaimed territory” (Tait 1994/5:7). This chapter discusses how breast care nursing re-defines itself as a discrete specialism in a dynamic relationship with context.

The acceptance of the recommendations of the Forrest Report in 1987 has been claimed as a highly effective use of evidence to present a sophisticated rhetoric in order to frame changes in cancer policy (Wright and Barber Mueller 1995). Many of the assumptions underpinning contemporary cancer policy were first presented in the Forrest report (Forrest 1986) and then reinforced in the Calman-Hine Report (Department of Health 1995). These include mass population screening for early detection, the development of small specialist teams to deliver quality care, that care should be multidisciplinary, uniformly delivered across the UK, and based on evidence based clinical guidelines. Investment and quality improvement in cancer care has become a major policy initiative

in the UK National Health Service since Calman-Hine (Department of Health 1995). This is evident in the appointment of a cancer “Tzar”⁵⁴, and publication of site specific guidelines, standards, and directives emanating from the Department of Health, and other government departments. In no way do I wish to criticise the importance of investment in cancer care particularly as resources have been claimed as the major reason for the poor performance of the UK compared with other European countries (Coombes 2000). Nor would I contradict the value of quality management and evidence to underpin treatment and care, as these contribute to health improvement. However, this minute attention to detail represents a radical departure from previous approaches to surveillance of cancer care delivery in the UK described by the current Minister for Health as: “many variations in the quality of care and treatment across the country, leaving cancer patients frustrated by a postcode lottery” (Department of Health 2000b:3).

The interventionist nature of state surveillance coupled with an implicit agenda of individual responsibilities is worthy of examination. Howson (1998;1999) in examining cervical cancer, in which there are a number of similarities with breast cancer, offers the “Foucault paradox” (Turner 1987: 217) as a paradigm to explain the relationship between state intervention in surveillance and an implicit agenda of individual responsibility. She suggests (Howson 1999) the welfare system in the UK is underpinned by the value of equality of opportunity to access provision. A concurrent value increasingly expressed through policy is the responsibility at an individual level for that resource. In effect the state provides but the individual has responsibilities to support as well as receive. That support includes a willingness to support financially through taxable work and a willingness to participate through self-surveillance, life style, and screening. The ‘Foucault paradox’ (Turner 1987: 217) suggests that the state exerts greater surveillance and regulation over an individual who in exchange has rights, entitlements, and responsibilities. An economist would probably argue there is no point throwing good money after profligate waste. These responsibilities can loosely be described as aspects of ‘citizenship’. Howson (1998) argues that the discourse

⁵⁴ National Cancer Director Professor Mike Richards

surrounding cervical cancer is predicated on an assumption that “women ought to be concerned with prevention, not only to secure their own health, but also in order to maintain their obligations to others” (p221). Much of the language surrounding breast cancer screening holds similar messages. The reader is probably thinking how can a link be made to delivery of care. I argue that Howson’s critique of the underlying philosophy underpinning cervical screening has broader application to health care policy.

Governmental direction as expressed through Calman-Hine to more recently The NHS Cancer Plan (Department of Health 2000b) expresses surveillance as concomitant with investment and emphasises the obligations of NHS staff to forego their “outdated practices” (p3) and provide service through the delivery of uniform, standardised evidence based, demonstrable care. In addition, participation in updating, delivery of evidence based care and individual responsibility for professional life long learning is a strong element contained within the modernising plans underpinned by clinical governance. This has been recently augmented by a pledge that by 2002 health care professionals must demonstrate competence in communication skills (Department of Health 2000b). Against that background I now seek to focus on the constitution of aspects of the work of breast care nurses and the territory they have claimed, colonised and revised in their short history.

Toward defining the territory of breast care nursing

Tait (1994/5:7) suggested breast care nursing was “poised between medical and scientific knowledge of the disease and the illness experience of their patients” and breast care nurses “have to mediate between medical practice and its distressing impact on their patients’ lives”. The key activities described in chapter five associated with giving information and in chapter six associated with knowing begin to sketch a territory that involved a process of colonisation. The Standards of Care produced by the RCN Breast Care Nursing Society (Royal College of Nursing 1994:1) went some way to define breast care nursing. They claimed to distinguish between “a breast care nurse and a nurse” and make explicit “the level of service consumers can expect”. The territory was defined at that time by nine topic areas: information, treatment choice, altered self-

image, psychological support, reconstruction, provision of prosthetics, lymphoedema, fungating lesions and professional development. One area of redrawing boundaries which emerged from data in the present study was further distinctions between nursing undertaken by nurses, breast care nursing undertaken by nurses working in the speciality in a variety of settings, specialist nurses with varying degree of expertise and most recently advanced practice roles. The following remarks relate to the redefinition that has occurred over the ensuing eight year period:

“Initially when I started in ‘92 I saw every single lady who went through the system, benign or positive. That role has now become the outpatient nurses’. They have been trained up, they wanted to take it on. We needed to pull back the practical requirements, etc. So they take on the breast awareness, breast pain, while we pick up the positive ladies.”

(BCN 22)

In this case the territory has been redrawn only to encompass those women who are “positive”, that is have cancer. The other breast patients who in fact are the majority of attendees at breast units have been delegated to care by the less specialist. A noticeable feature is that since the work was colonised by breast care nurses, in order to delegate the work to out patient nurses ‘training’ was required. That training may of course represent changes in treatment or management of women with benign breast conditions and the out-patient nurses may not have had the requisite knowledge base. Nevertheless a feature of this once colonised area of practice is that it is subsequently redefined as requiring a unique knowledge base that is delivered to the enthusiastic second wave colonisers in order for them to accommodate the territory into their practice. This account holds a number of similarities with Breast Care Nurse 28’s experience:

“I think I really ought to write up about breast care support nurses because that has been another innovation. Mainly because I have three nurses who have been very keen. One, who is only an EN worked on Oncology for a long time, 20 years, and she is interested in prosthetics. I have trained her to do that when (Name of other BCN) was off⁵⁵ to take that off me so that I could do more visits and she was given the extra time. She loves it, absolutely adores it and she loves the patients. She is an older woman you know, 50s, like me I suppose. And then there was another young girl who had done body image stuff who is dead keen. So they brought her on board and then Sister upstairs decided she was interested and so we have taken

⁵⁵ Maternity leave

them to the discussion meetings and had them help us in clinics and taken them out on home visits. And now particularly with (EN) and the other two we can let them see a patient through. We don't usually let them see the oncology patients through because they haven't got the experience but tamoxifen onlys and the elderlys and the ones that are not going to have huge problems."

(BCN 28)

Both descriptions have some additional similarities. First, both suggest that patients have differing needs and that significance i.e. the burden of needs is determined by the diagnosis (benign versus malignant disease), the comparative demands of treatment (tamoxifen), age, and those "not going to have huge problems". This would suggest that some form of triage system is in operation, which discriminates between patient's needs. However, this discrimination appears to be based on a perception that demands are differently experienced due to prejudged criteria rather than an estimation of an individual's response to demands of the illness. The breast care nurses in effect appear to be judging those worthy of specialist intervention. In the case of the elderly women this could be construed as discriminatory and signalling that breast cancer is less challenging in older women's lives. Interestingly they are a group who form the majority of breast cancer patients. This does have connotations of rationing of expertise based on perceived worth and resonates with the presumption that illness has moral dimensions. A different approach adopted toward older women emerged in relation to discussions associated with sexuality concerns and information relating to reconstruction. An assumption expressed in some accounts was that intimacy was not a particular concern of older women. Another assumption used to justify exclusion of male partners from interaction was that older men would not wish to engage in interaction with breast care nurses about their partner's illness.

"I don't want to sound ageist because you can't make the assumption that body image and sex is anything to do with age, but most people have been of the older age group and that's not to say they don't have sex, but they don't talk about it. They never did and they're not going to start now just because they've got breast cancer. They're not going to are they? And to bring it up and stuff that would be highly offensive."

(BCN 10)

So, from these remarks the territory is constantly under review and is reconstituted in terms of falling inside and outside specialist breast care nursing.

Another dimension of territory related to de-skilling. This was particularly associated with nurses who work in close contact with breast cancer patients but whose work is bounded in a particular environment such as wards or out-patient departments. As Breast Care Nurse 29 discusses:

“They are being cared for by the ward nurses and you wouldn’t want to presume that you are the only person that could talk to them. But I like to see them pre-op and they seem to appreciate that. You know to see a familiar face.”

(BCN 29)

The expectation of a level of capability being available to women from nurses rather than the breast care nurse was discussed offering a more detailed account by Breast Care Nurse 5. This breast care nurse said that she visited women on the wards preoperatively, the day following surgery and before discharge. She commented:

“I like the ward staff to be able to do the pre-assessment clinic⁵⁶ because otherwise we (BCNs) are doing part of their job and it takes their skills away from me sitting down and talking to them. So I think it’s quite important and the patients usually build up a close relationship with them looking after them. And they are there, will be there when they are washing, when they are looking at the scar for the first time. If we go round taking their skills away from them they are not going to feel happy or confident about caring for people in those vulnerable times.”

(BCN 5)

From all these accounts it would appear that the boundary lines between specialist (breast care nurse) work and generalist work was blurred. Despite the blurred boundaries there was demarcation or rather a suggestion of levels of expertise. Ward staff were able to build up a relationship with patients, their concerns tend to be “very practical and very focussed “ (BCN 1). Though capable of providing a level of psychological support, ward staff were not perceived as having the range of skills that a

⁵⁶ A clinic appointment prior to admission where patients have blood taken for estimation of haemoglobin, urea and electrolytes and liver function tests, chest x ray and ECG, assessed for fitness for anaesthetic and have a nursing history taken to identify any problems which might impact on outcome of surgery.

breast care nurse might have to manage a “distraught woman” (BCN 15) or assess coping (BCN 17).

Patients, it was claimed, could discriminate between concerns that were ‘specialist’ and those which were within the domain of ward staff:

“Like there is a lady in at the moment that I went to see on the ward and she said: “The staff in here are lovely, they are really lovely but I don’t really want to ask but I can ask you now you are here”. So it is fears that they are afraid to, or felt they haven’t for the, they don’t want to take the others time up on the ward. And questions they want to ask. They feel they can ask one of us.”

(BCN 13, one of a team of four breast care nurses)

From these remarks breast care nurses would appear to have defined, albeit locally, care and support of the women whilst on the on the ward and largely determined specialist work as being particularly talk-based i.e. listening to concerns which might appear particularly distressing or involved providing information. Whereas generalist work related to physical care and psychosocial support associated with the acute needs of the peri-operative period.

Another aspect of redrawing territorial boundaries was the activity associated with surveillance during adjuvant treatment. Instead of undertaking home visits one breast care nurse delegated the work, in what appears a rather ad hoc fashion, to primary health care nurses:

“Now what I do is contact the primary health care team and hope the district nurse will go in and do those assessments in between chemotherapy. Sometimes they do, and sometimes they don’t. It depends on the district nurse, on her interests, her workload, and I suppose whether the patient gives her the impression that she doesn’t need that support. But that is what I have done you know more recently is involve the district nurse or very occasionally the health visitor if children are involved.”

(BCN 18)

To summarise, the territory of breast care nursing has been re-drawn over time for a number of the breast care nurses. A number of factors appear to have influenced that process of re-definition including workload management. Nevertheless it would appear

that a conceptualisation of specialist breast care nursing as contrasted with breast cancer nursing is developing. That conceptualisation in some part seems to emphasise advanced skills necessary to manage women's concerns and information needs of a more complex or complicated nature. This reframing of work as having greater complexity, therefore worthy of specialist intervention is occurring in other specialisms such as palliative care. Complexity appears to be a defining characteristic of specialist work. The corollary could, however, be that by defining work as complex affords the work greater status thereby making it worthy of specialist status and demanding specialists to manage the work. In the next section an aspect of the work of breast care nurses, which was colonised and now is the subject of encroachment is examined.

Colonising psychological support

The incidence of depression associated with breast cancer is claimed to be around twenty to thirty per cent of patients (Maguire 1994). As discussed in chapter two, the original work evidencing the potential role for specialist nurses to work with breast cancer patients was undertaken in 1980s (Maguire, et al. 1980a; Maguire, et al. 1982; Watson, et al. 1988). The approach adopted by Maguire et al. (1980a) was to train nurses to undertake psychological assessment in order to diagnose those women with anxiety and depression symptoms in order to initiate early intervention to reduce or prevent enduring psychological morbidity. The nurse's role was to assess, identify and refer those women with psychological problems to a clinical psychologist or psychiatrist, not to undertake a nurse led intervention. Tait's (1996) study suggested that only around three per cent of women assessed by breast care nurses were "diagnosed" as having depressive or anxiety states needing referral for specialist psychological support. There would appear to be some disparity between the two accounts. Whilst accepting that estimation of psychological morbidity is confounded with difficulties linked with reliable diagnosis, such as the definition of mental illness, nevertheless much of the early literature providing a rationale for the discipline of breast care nursing relates to a role in assessing women for mental ill health as a complication of the experience. The basis of communication training claimed to be used by the breast care nurses in this

study was a concerns-based (Maguire, et al. 1980a) or a patient centred non-judgemental approach (Rogers 1951). When questioned very few of the breast care nurses claimed routinely to use formal objective assessment measures to establish psychological morbidity. Of those who did use surveillance of psychological state this was on a regular basis⁵⁷ (at six weeks, three months, six months, nine months and one year) but more frequently on an irregular basis often initiated by the woman herself. This later approach was termed a 'crisis intervention' model by Tait (1994).

There does seem to be a disparity between the level of psychological morbidity assessed in clinical trials and that reported by breast care nurses of their patients. Although no measurement of cases of breast cancer patients and reports of depression or anxiety states were made in this study the breast care nurses appeared infrequently to identify mental illness needy of specialist intervention.

As Breast Care Nurse 8 remarked:

“and if you go off the research, that is around to say that breast care nurses won't change psychological problems but hopefully we are picking them up and referring them appropriately.”

(BCN 8)

It might be that communication strategies used by breast care nurses fail to elicit difficulties experienced in this area with any degree of sensitivity and the levels of morbidity remain static but largely hidden. Or breast care nurses have revised depression and anxiety associated with breast cancer and its treatment and somehow construct it as a reasonable level of distress associated with life threatening distress: in effect deconstruct it as pathology and normalise emotional distress.

This account from Breast Care Nurse 20 possibly gives some insight into why women are not construed as experiencing depression or anxiety states:

⁵⁷ Those breast care nurses who adopted a regular pattern were asked why the particular points were used for psychological assessment. The most frequent responses were that these were the points used in the original research and therefore had a basis in terms of natural history of mental ill health and/or they fitted with end and beginning points of treatment phases.

“It is usually women who are not supported within their personal environment. If they have got no family, no friends, no relatives, if they are living alone. If they have had recent bereavements themselves, recent difficulties. Sometimes people have a past psychiatric history. Might be prone to depression. And some people get stuck, you know they can’t move on and they are quite negative. They can’t get past the word cancer and dying. So anybody that gets stuck anywhere, people who can’t be positive for whatever reason I suppose and that’s when they have problems.”

(BCN 20)

In this commentary depression is located as a social condition, a product of absent social support, rather than a psychological illness. Whereas in Breast Care Nurse 6’s interview a recurring description of the focus of concern for women was fear of cancer. Teaching strategies to conquer the fear rather than labelling the individual as ill or disordered were advocated by this nurse.

“I truly believe as nurses in this field we should spend a lot more time on self awareness so that we can manage the hopeless, hopeless feelings that they’ve got. So they are not just there, that there is a process for managing it. Some people just want to stay with cognitions just be aware of IT is my fear. If they can give IT a name, my fear or my anxiety, they don’t need to know why its come over them as long as they can just say. This is my fear that’s making me feel this way. Recognising that something’s happened that my fear has grown. I think most human beings can do that much.”

(BCN 6)

This strategy avoids defining a woman’s concerns about cancer as mental illness thereby facilitating an alternative approach that can be managed without recourse to specialist psychological support. Avoidance of traditional approaches to psychological distress measurement also allows evasion of a diagnostic label that once applied demands management as illness. Moreover distress labelled as concerns has greater potential for self management or rather teaching skills to self manage such as relaxation techniques. As a strategy it arrests compartmentalisation of concerns into illness therefore avoiding problematisation and necessitating specialist intervention.

Failure of identification of ‘real’ mental illness as such has the potential for a breast care nurse to enter into conflict with other professionals as reported by Breast Care Nurse 11.

She comments here on such an occasion when her assessment of a woman's psychological state was questioned by the surgeon.

"I have got a couple of patients at the moment who I am not particularly worried about because I am keeping an eye on them. One of them (consultant) has been particularly worried about because he says she is depressed. She's adjusting to what she has had. She is angry with him and I think that's why he says she needs psychiatric help. (The) consultant has said to me twice that I should have given her some help because of depression but I don't feel she is depressed. I think she is just very cross because the surgery was delayed for 18 months and she should have been operated on. He says "This woman must be depressed" because she is giving him a hard time."

(BCN 11)

In this account different interpretations of distress are applied. The doctor uses a medical diagnostic label, "depression" and attributes causation to the disease, whereas the breast care nurse describes the woman as "adjusting" and "angry". Moreover, the breast care nurse, presents the anger as a reasonable response to treatment delay. Irrespective of the accuracy of either diagnosis, the labelling and alternative interpretations are illuminating within the context of the different discourse(s) used to problematise emotional distress. Wicks (1998) suggests that nurses "conceptualise and articulate their skills in a way that reflected their dual orientations to medical and nursing priorities" (p134). In this exchange the nurse talks of anger and depression and quite clearly can see distinct differences between the two states. The doctor, however, reduces behaviour directed toward him to pathology and labels it within the confines of a "mechanistic framework" (Wicks 1998:165). This account can of course be used to examine relationships between the two protagonists and the different status given to framing the problem. Nevertheless the labelling of the psychological distress as "depression" by a surgeon may well be a distancing strategy to absolve responsibility as psychological problems are not necessarily perceived as falling within their territorial concerns of physical disease managed surgically (Payne and Endall 1998). Further, the time constraints imposed by busy outpatient clinics may have greater impact on constraining effective psychological diagnosis than individual ability of the actors to diagnose.

When a woman's difficulties in this area appeared severe enough for the breast care nurse to seek specialist support by referral to another health care professional it was suggested in a number of the interviews that a more comprehensive psychological assessment, or rather one dominated by the discourse of the disciplines of medicine and psychology, was undertaken. This was discussed in chapter six and the use of medical criteria of depression i.e. insomnia, early morning waking, loss of appetite, reduced libido, to describe the patient's state were reportedly used. Medical discourse associated with psychological distress would appear to hold a privileged status in that breast care nurses are aware of need to use the language of another discipline in order to maintain their credibility as worthy to refer, while ensuring effective communication of the problem. Of the twenty nine participants only one claimed she was unable to refer to clinical psychologists or psychiatrists directly (BCN 25). A number of the breast care nurses claimed to contact general practitioners to initiate referrals. One breast care nurse claimed direct referral was permitted within the organisation she worked but preferred to request the surgeon to initiate the referral as it had greater authority than a referral initiated by her (BCN 24).

"I tend to go through the surgeons really to get them to because I just think it would speed up the process and it would help things."

(BCN 24)

Another trigger for referrals to another discipline for a number of the breast care nurses was when interaction between breast care nurse and patient became reportedly stagnant:

"The people I have actually referred on these people who on regular visits are going over the same ground. They are not moving on. They are in tears all the time. They just can't seem to come to terms with having cancer, or they have had done, accepting a mastectomy, or dealing with a prosthesis. It is all beyond them and whenever you see them two weeks, four weeks, whatever, they are at the same point. Now through my experience I have learnt that this is the beginning of them sort of going into a roll. One particular lady I felt who was okay, I came to a point at about six months realising I wasn't getting anywhere with her. And you know she wasn't moving on and I suggested she saw a clinical psychologist."

(BCN 15).

Breast Care Nurse 15 was not alone in reporting that patients who failed to improve in terms of their level of distress presented particular challenges. Some of the breast care

nurses with training in counselling used more formal approaches such as contracted intensive interactions, instruction in anxiety management and/or relaxation techniques, but when the woman remained “stagnant” sought expert help through referral. The difficulty, and this remains conjecture, for the breast care nurses in terms of maintaining the territory of psychological welfare of women with breast cancer, may not be related to their ability to define the causation, nature, and severity of problems using a shared/common/authoritative discourse but may relate more to the limited repertoire of interventions they can offer to ameliorate women’s distress.

Border skirmishes and retreat

The interaction reported by Breast Care Nurse 11 where her interpretation and attribution of causation for distress was at variance with that of the consultant surgeon’s could be read as representing a border skirmish. Psychological support is an area that has the potential to become disputed territory. The post Calman-Hine period has seen the development and bedding in of multidisciplinary teams to manage breast cancer care. The core team, as defined in the recent standards, (NHS Executive 2000a) is medically dominated with a lead clinician drawn from the core multidisciplinary team that includes a designated surgeon, breast care nurse, radiologist, histopathologist and oncologist. In addition the extended team includes other professionals such as a psychiatrist or clinical psychologist. The consultative standards also specify that: “There is a range of psychological, social and support services offered to meet the assessed needs of patients and carers. There is easy access to clinical psychology and to staff professionally trained in cancer counselling and other supportive therapists” (NHS Executive 2000a: Standard 1.11).

What was apparent in the interviews with the breast care nurses was the increasing ease of access to ‘specialist’ psychological support⁵⁸ for those women whose difficulties were beyond the skills of the individual breast care nurse. This is an area that has the potential to be fraught with tensions and inter-professional rivalry, particularly as breast

⁵⁸ Only one breast care nurse reported a six month waiting list for psychological services (BCN 21)

care nurses had to all intent and purpose colonised this aspect of care. It appeared, however to be an area where help was welcomed. For example Breast Care Nurse 6 who works in a team of two breast care nurses in an acute NHS Trust and is a trained counsellor recounted:

“We’ve just acquired a psychologist, only because of Calman-Hine and umm and (name) hasn’t really got going yet. So we’re trying to get some sort of evaluation so that (name) will start seeing women. It is only so we can monitor anxious patients. She specialises in health psychology and most of her referrals come from breast care nurses. She envisages joint sessions with breast care nurses (pause). And there is no specialness⁵⁹ about her and she will make a difference.”

(BCN 6)

From this narrative it would appear that it was envisaged that the nurse and psychologist would define the territory and because there was no “specialness” effective, in this case, joint working would ensue. In an account from Breast Care Nurse 29 who works in a team of three breast care nurses the border between the work of the clinical psychologist and breast care nurses was under negotiation. This narrative relates to the introduction of group supervision instigated by the clinical psychologist to reduce the burden of the work of the nurses:

“We tend to sort of discuss case studies and perhaps that we have got in common with her. You know since she arrived we are sending her hundreds of patients so the last time it was a lot to do with relationships. I mean it has only been running for about three or four months.”

(BCN 29)

In this account the breast care nurse reports that since the recent arrival of a clinical psychologist patients are being referred for what could be perceived as ‘specialist’ psychological support. Further, the referral pattern described as “hundreds of patients”, probably an exaggeration, was the basis for negotiating the territory of appropriate referrals by examining “relationships”. At another breast unit the availability of a clinical psychology service was a recent service improvement and had resulted in group supervision meetings for all nurses involved in cancer care and included the palliative

⁵⁹ “specialness” was interpreted as meaning willingness to work within the team rather than function as if holding a position of hierarchical authority over the breast care nurses.

care nurses. Yet again the focus of supervision was on “patients and the referral system” (BCN 3).

From these accounts ‘specialist psychological support’ is an area of contested territory. It is, moreover a territory that in one breast unit is willingly utilised and in others appropriate use was under negotiation. Psychological support given by breast care nurses versus that provided by ‘experts’ appears to be a site of territorial re-negotiation.

Support groups

I now turn to examine the aspects of psychological support that breast care nurses have chosen to devolve to others. In the following comments Breast Care Nurse 9 describes her perception of difference between support which can be provided by a lay network, a support group, and “professional support” delivered by the breast care nurse.

“Support groups are set up so patients can support one another through this difficult time. Now with the innovation of breast care nurses they have got the professional support so they don’t need to be tapping on somebody’s door or ringing them up to say I’ve got this pain here or my wound is like this they tap on the breast care nurse. So it’s an afternoon tea party.”
(BCN 9)

In this narrative there is clearly in the mind of the nurse a difference between psychological support offered within the context of an “afternoon tea party” and “professional support” although the description of breast care nurses unique contribution using physical examples is interesting within the context of support.

From the twenty nine interviews all the breast care nurses had been at some point in the past or were currently involved in support groups for women with breast cancer. Some appeared to have highly organised patient-managed organisations whose predominant function was social and/or fund raising – “pink ribbons and coffee mornings” (BCN 24). Other groups were formed to provide support at particular points in the treatment trajectory i.e. post mastectomy surgery or to support women with particular problems.

Other support groups had embraced political agendas and become involved in lobbying for greater investment in breast cancer care. Others have focussed on particular activity such as sport (BCN 24 and BCN 22). There was a wide range in the level of engagement breast care nurses had with support groups. Some appeared to be under the direction of breast care nurses whereas in others the breast care nurse was cast as a visitor and outsider to the organisation. Some breast care nurses expressed the value of the support organisations whereas others were less positive. One breast care nurse described the support group linked to the breast unit where she worked as “dysfunctional” (BCN 23). A number discussed support groups in terms of dynamic yet fragile networks that were particularly prone to disintegration in instances where key individuals in the membership developed recurrent disease or died.

There is an increasing literature examining the place of support groups within the context of cancer care and breast cancer (Damen, et al. 2000; Klawiter 2000). Much of that literature is descriptive and extols the benefits of volunteer action such as the US Reach for Recovery Programme. In the UK networking between cancer organisations has recently been emphasised as an important aspect of users shaping NHS cancer services. Through the Expert Patient Taskforce under the auspices of the Chief Medical Officer they will have a role in empowering “patients in their relationships with health professionals enabling them to assert control over their lives, build confidence and be active partners in their care” (Department of Health 2000b:66). This casting of self help groups as pressure groups relates more to ‘outer-focussed’ action (Williams 1989). Notably however, in the recent standards relating to the provision of patient centred care, the message is that it is not only that groups should be encouraged, but also education and training be provided to enable them to work effectively (NHS Executive 2000a). Despite this guidance, which fits with the current ideology of engagement with consumers of health care services, self help groups can also present tensions in terms of contested or border zone territory between professional support provided by health professionals and support given by women who have undergone the experience. An aspect of the tension may be connected to views that self help groups are “strange subcultures of deviants” (Damen, et al. 2000:332). They have the potential to be both

complementary and strained in their relations with health care professionals, for example:

“I have got a patient here who has set up a body image group which is quite good because she sort of had all these problems.....She actually felt so much she started the body image group and went on courses and things and actually people go to her as well.”

(BCN 17)

In this account Breast Care Nurse 17 talks of the benefits of having a group with a focussed agenda which functions to complement her work. The ex-patient leader is both trained and has had “problems”. Whereas for Breast Care Nurse 22 she claims to have a less easy relationship in terms of her not liking it and possibly the group not functioning in the way the breast care nurse wanted. Nevertheless she would appear to have persevered and persuaded some of the membership to take on “talking to people”.

“I feel I have to offer it in my package of information that I give even though I don’t particularly like it⁶⁰. I give them (patients) the leaflet about it. And four or five of them I got after a lot of talking to them, got five of them to do a two day course on counselling. Just on communication skills to talk to people which was useful.”

(BCN 22)

Whilst these two descriptions do not suggest that the breast care nurses see themselves as having the monopoly on expertise or knowledge in this area they do remain in some senses in control. This controlling dimension by breast care nurses of lay involvement in psychosocial support was described to an even greater extent in this description offered by Breast Care Nurse 25:

“We have a network of ex-patient volunteers and we match like to like. It is just so nice to have somebody who isn’t professional that they, are not perceived as having an agenda.”

(BCN 25)

In this unit women are recruited two years post diagnosis of breast cancer by letter to participate in a network of volunteers who act as a buddy to a new patient. Those women who accept the invitation are then interviewed and character references sought including a reference from the woman’s general practitioner. Following successful

⁶⁰ Self help group

management of the selection process the woman is invited to undertake a two-day communication skills course. On successful completion of the course women are matched in terms of age, geography, and likely treatment trajectory to newly diagnosed women who wish to use the network. The volunteers receive group supervision and hold a contract with the NHS Trust. Costs such as travel or telephone are reimbursed. This highly formalised process minimises risk in terms of an individual with an 'axe to grind' being let loose on a woman at a very stressful juncture in her life. The vetting process, training and surveillance of volunteers enables the professional 'gaze' to be distant yet controlling. Some of the concerns raised by health care professionals inherent in some of the work undertaken by self help groups relates to risk and responsibility. In an increasingly litigious society the lines of responsibility, accountability and ultimately liability has, if it is not monitored, the potential to be an area of contention.

The move to consumerism in health care which is manifest in current UK health policy is claimed to represent challenge to the dominant position of medicine; the term medicine is used in this context as a catch all label for health care professionals and their discourse. Two processes, proletarianism and deprofessionalisation, have been identified as aspects of this challenge. Proletarianisation "represents a process whereby organisational and managerial changes divest professions of the control over their work" (Hardy 1999: 821) whereas the "demystification" and "scepticism" of expertise has worked to challenge the authoritative nature of medicine. Using lay help in an area such as psychosocial support has the potential to devalue the expertise currently provided by breast care nurses and other experts and casts the patient as expert in the lived experience of the disease.

Cunningham (2000) argues that psychological therapies in cancer are not, for a variety of reasons, afforded the same status as other therapies particularly physical ones such as chemotherapy. This is despite evidence of benefit to well being. Using the example of a support group he suggests the uninformed view is that psychosocial intervention: "...is, after all, just 'sitting around and talking', very 'low-tech' something we all do socially" (Cunningham 2000: 370). He then argues that this perception has resulted in

psychosocial interventions frequently left to the enthusiastic untrained health care worker. He fails to provide an indication of preferred health care discipline in terms of necessary expertise to claim exclusive territorial rights but raises a number of pertinent issues relating to the knowledge and expertise necessary for effective psychological intervention. Breast care nurses have been afforded or grasped territorial sovereignty of psychosocial care for the majority of women with breast care yet that territory is under negotiation and encroachment would appear to be occurring on two borders. It may well be necessary for breast care nurses to map out their contribution within the terrain of psychological support and articulate that contribution so that it demonstrates the level of expertise used to deliver care more effectively.

Expansion of territory

In some aspects of breast cancer, care responsibilities and roles not previously undertaken by breast care nurses appear to be, in isolated pockets, becoming part of the work of breast care nurses. Many factors have influenced this work, once perceived as medical, becoming colonised by breast care nurses. These include the impact of the reduction in junior doctors hours (NHS Management Executive 1991), the increasing specialisation wrought by the post Calman-Hine reforms (Department of Health 1995), greater scrutiny of the basis of role demarcation generally in the NHS (Department of Health 2000e), extension of nursing roles in part influenced by the publication of the guidance in the UKCC's Scope of Professional Practice document (United Kingdom Council for Nurses 1992) and the expansion in advanced practice and consultant nurse roles (Department of Health 1999). One such area is breaking bad news and was discussed in chapter five. Traditionally breaking bad news in terms of diagnosis and prognosis has been the domain of medicine. Some of the breast care nurses expressed beliefs that bad news should remain the sole domain of the doctor and ability to perform the task appeared to be irrelevant to them. The assumption was that bad news was an aspect of the job however uncomfortable the individual physician found it fulfilling their responsibility. The view, offered by Breast Care Nurse 3, provides a representation of the majority opinion expressed in the interviews with breast care nurses.

“I think in the consulting room, they very much, they want to see the doctor. They want to hear the doctor’s opinion. That’s what they go for. So we tend to leave it to them, not say a lot.”

(BCN 3)

The BASO guidelines state “breaking bad news should be done in a professional way. The person conducting the consultation must be a member of multi-disciplinary breast team and should have the breast care nurse in attendance” (1998: 3). A pedantic point but nevertheless worthy of statement, that this guidance does implicitly suggest that irrespective of membership of the multidisciplinary team including the breast care nurse in this context, she is there as an attendant rather than having the role of harbinger. This in some ways is reinforced in the medical literature by such statements as “physicians have always been the bearers of bad news” (Ptacek and Eberhardt 1996:496). For four of the participant breast care nurses (BCNs 11, 14, 17, and 26) this work had become part of their role. In one case bad news was (BCN 26) an aspect of overall role expansion that included undertaking clinical examinations, diagnostic tests and conducting follow-up outpatient appointments. A number of the breast care nurses were currently discussing similar role expansion with medical colleagues and management (BCN 7, 23, 25, and 27). Two breast care nurses were at the time of interview involved in a research project examining the efficacy of nurse led follow up (BCN 2 and 12).

The four nurses appear to approach the task of giving bad news differently although there is some similarity in the accounts of BCN 11 and 14.

“I would come in and I would bring the notes in with me because the reports are there. And if you wanted to see the reports then I would show you them and I would put the notes down. I would sit on the bed or wherever they were sitting. I would try and sit close to them and I would say: “Well we’ve got your results back and I’m afraid the news isn’t good”. And then they don’t (pause). Usually they just wait for you to say the next thing. “Well you know you had two tests done today the needle test⁶¹ and the mammogram. The mammogram has been a bit suspicious showing a lump we have found in the breast has got a white light on it and the needle test has revealed some cells that look wrong. Sometimes they say “Does that mean it’s a cancer, or does that mean it’s a tumour?” So you respond a bit at a time. If they say to you “Is that cancer?” then I have got to respond “Yes it is a cancer”. If they

⁶¹ Fine needle aspiration of cells (FNAC)

don't get as near as that then you perhaps take it a step further and say something like "There is a growth there" and then you would move from growth to tumour, and from tumour to cancer."

(BCN 11)

The surgeon then enters the consulting room to discuss treatment options with the patient and her companion if she has been accompanied to the consultation. Breast Care Nurse 14 described a similarly managed event although she indicated that as the test results are reported there is a growing picture of suspicion and before mammography gives a "warning shot".

"Really as soon as all the tests have been completed, and, well apart from the mammography, I would go back into the patient with the mammogram card and sit with them and say "You know we do feel a little bit suspicious about this result". Or maybe "We are a bit worried about this". And try and draw them out to see if they have got any idea at that stage that it could be malignant."

(BCN 14)

Breast Care Nurse 17, who is frequently the bearer of bad news, reported trying to prepare women during the course of investigations for the bad news result. In this breast unit a one stop diagnostic service is provided.

"If it is positive, 50% of the time it will be me and 50% of the time it will be both of us giving the results. And we go through the treatment options of surgery, the implications of that and they often, unless there is obvious multifocal disease on the mammography they are always offered choice. And we talk about the choice and why they might choose to have a lumpectomy, why they might choose to have a mastectomy and go through all that with them. Then they get a date to come into hospital. They go away with booklets, information and after a couple of days I tend to get back in touch with them."

(BCN 17)

Whereas in the Unit where Breast Care Nurse 26 works she undertakes the fine needle aspiration of cells (FNAC) test and clinical examination and if the results show a malignant diagnosis she give the results to the woman.

"If I have diagnosed them then I will break the bad news to them because I think the ones that I do have built up that relationship with them. And then I get the consultant in to give their surgical opinion or the oncologist or whatever."

(BCN 26)

An interesting feature of the role changes was the perceived impact on the nurse-patient relationship as Breast Care Nurse 11 describes:

“Since I have started doing this (breaking bad news) I do find some patients I don’t have such a good relationship with because they get angry with me. I wouldn’t say everybody and certainly not the majority but for some people they focus there and it tends to be perhaps, this is categorising people, but it tends to be the more intellectual who don’t like the idea of me telling them they have got cancer. You tend to find the older people, the older woman and the ones that are probably less educated, that aren’t in professional work don’t seem to mind. Not that it’s just very simple but I would say that on the whole I do find that. And I think for those women who haven’t wanted my help it’s a shame.”

(BCN 11)

The colonising process

As discussed in chapter five prosthetic fitting was a dimension of the breast care nurses’ work that was colonised with the advent of these specialist roles (Parker 1996). It is an aspect of the work that from many of the accounts provided in the data gives job satisfaction.

It is to make them say wow (BCN 8)

I suppose my goal it has to be that the patient is happy with what they walk out of the door with (BCN 11)

To get that patient to feel as normal as possible, as comfortable as she can looking at it when she walks out (BCN 13)

I just love the way they walk out so differently, you know, “Oh my shape is back and this is great” and I get a lot of satisfaction out of that (BCN 25)

Irrespective of the value felt to emanate from fitting it has become an aspect of the work which in some units is becoming devolved. A feature, however, was that the actual task i.e. fitting the woman with the prosthesis was delegated, whereas other aspects such as the management of prosthetic services and in some cases assessment of body image concerns remained within the domain of specialist breast care nurses:

“The ward staff actually do, they don’t manage the prosthetics but they do the fitting.”

(BCN 18)

In the above situation the breast care nurse (BCN 18) retains management control which in real terms, as she went on to explain, meant budgetary control and the instigation of delegated responsibility involved training in this case ward based nurses. Moreover problems were referred to the breast care nurse reinforcing their expert status.

“Three nurses on the ward who have been trained to do prosthetic fittings so she is seen, although it is not us (BCNs), she is seen by a friendly face. If the nurses doing the prosthetic fitting feel there is a problem then she will refer them to me.”

(BCN 18)

Whereas Breast Care Nurse 27 had maintained involvement in the appointment for breast fitting but devolved the actual task, the physical care, to a trained health care assistant. The expert element, the “talk” was reserved for the breast care nurse.

“New patients get an appointment for a new prosthesis which is usually given at six weeks post op. They have an appointment with me half an hour before and I talk to them and take them through to the prosthetic appointment.”

(BCN 27)

From these accounts some aspects of care, once colonised and made part of the scope of the colonising specialist, become designated as requiring specialist expertise and remain within the repertoire of the nurse specialist. This could be seen as a form of asset stripping. Other aspects are deemed less demanding and therefore can be undertaken by the less specialised but only if they are trained by the breast care nurse, inculcated into the culture of the coloniser. Their training is limited to the elements of the task deemed amenable to delegation thereby ensuring supervision and control remains an aspect of the specialist nurse’s role. The difference between delegation of tasks from the breast care nurse to other nurses or health care workers and extended roles previously undertaken by medicine is the apparent requirement for protocols, risk management and consideration of the likelihood of claims in connection with liability.

A criticism often directed toward nurses undertaking advanced practice responsibilities is that they distance themselves from other nurses and the purpose of nursing. This

theme emerged in the data as an assumption offered particularly by those who had chosen not to undertake extended roles:

“I am sorry but I don’t think that the, you know, all this being a clever mini-doctor is giving the patients what they need from a specialist nurse.”

(BCN 28)

One of the participants who had taken on an advanced practice role claimed that nursing enhanced her capability to undertake new tasks. This nurse is one of two nurses whose role has evolved and both now undertake diagnostic work. This account relates to her role in follow up outpatients:

“There are no doctors in the clinic at all and they get to know us and we get to know them as well. And they sort of say it’s not like coming to hospital. So some of the fear has sort of gone. And they talk about all sorts of things that they probably wouldn’t talk to the doctors about. Sort of problems that they might have with their scar, or any problems at home, or with their marriage, sexual problems. You name it. I think they feel more comfortable because they know us and they say a lot more. Also we know them and we remember their breasts as well. So we get to know them really well and I think that’s the advantage of us doing the clinic.”

(BCN 28)

There are similarities between this account and a study examining patients’ perceptions of an advanced practitioner in primary health care setting (Chapple, et al. 2000).

Acceptability of the nurse in that study was on the basis that the service was structured in such a way that met patient needs rather than concerns over professional identity and status. That said, some respondents accorded higher status to the nurse seeing him as equivalent to doctors. Chapple et al, (2000) questioned whether the gender of the advanced practitioner in their case study influenced perception of client users and claimed, based on their interview data, that it did not. The practitioner in their study was male whereas in this study the practitioner is female. Moreover gender may have influenced the reported content within nurse-patient interaction. Description of the breast care nurse practitioner as a participant in the multi-disciplinary team meeting is also illuminating:

“I actually write the audit findings in the notes and again the junior doctors were writing and they couldn’t quite understand things and they were writing them down in the wrong order, you know bits and bobs. So now I do

it because I am used to the system, what's going on, but equally we play quite a big part because if we have seen a woman and we can actually say: "Well we know the lump was here" We can clinically input. But I think our biggest input is actually psychologically. In saying "Oh, I think she should have a mastectomy because..."

(BCN 26)

In this account the nurse has adopted what might be seen as a gendered or low status role in terms of annotating notes with clinical decisions, a task she assumed from junior doctors as they performed the task ineptly. Then she describes her contribution to clinical decision-making as being valued as she provides "psychological" input about the woman in much the same way as more traditional breast care nurses describe their advocacy role in multidisciplinary meetings.

Breast Care Nurse 26 throughout this account asserts the advantages afforded by her nursing antecedents in terms of facilitating 'knowing' the patient in a language not dissimilar to that of the other participant breast care nurses in this study. She accords value to knowing, in terms of the perceived benefits to patient-nurse interaction, yet dissimilarly provides an account of 'knowing' the physical body or rather the disembodied breast as it appears in her comments.

Scanning for new territory – expansion

The needs' of breast cancer survivors was a theme that emerged from some of the breast care nurses' accounts as an area currently uncharted. The breast care nurses' concerns related to two distinct aspects of survivorship. Firstly the ramifications of feelings of security engendered by active treatment suddenly ending and secondly long term enduring needs of women who had undergone treatment for breast cancer. Some discussion was offered relating to a potential role for breast care nurses in supporting women to move beyond having breast cancer to a status of having had breast cancer. Although separate from the debate concerning the efficacy of out patient follow up and the encroachment through advanced practice by breast care nurses on follow up

surveillance as an aspect of the breast care nurses work the issue is irretrievably linked in terms of coherence as a nursing concern.

The UK has until relatively recently had poorer rates of survival rates from primary breast cancer than other comparable countries in Europe and North America (Black 1997). The most recent figures demonstrate a considerable improvement in survival and this improvement has been accounted for by the introduction of screening, use of tamoxifen, reorganisation of cancer services with development of specialist expertise in breast cancer. The meaning of survival and the implications for health care providers has not until relatively recently been a focus of health care research and therefore insight into the broader ramifications of surviving a life threatening disease have been largely undocumented. More recently, and particularly from North America, some attention has been drawn in the nursing literature to lives of survivors in terms of family life, work, and broader society, and also in terms of long term health needs (Thibodeau and MacRae 1997; Hassey Dow, et al. 1999; Uttley 1999). The emergent concerns expressed in that work relate to existential issues associated with surviving. These are described as searching for meaning and reclaiming life; more practical concerns focussed on day to day realities of survival e.g. financial, functional, sexuality and fertility losses associated with treatment and its consequences; and the impact of both on family life.

A number of the breast care nurses in this study identified the cessation of primary treatment for breast cancer as a point of particular isolation for some women. As Breast Care Nurse 29 suggested:

“I think sometimes after the treatment is finished, well not sometimes, probably most times, that is really when a lot of the insecurity starts.”
(BCN 29)

This sense of unfinished business at the end of active treatment was confirmed in an audit undertaken by Breast Care Nurse 25:

“We did an audit in 97 and they (patients) came up with a few suggestions and one of them was that they would like to see us after treatment or speak to us after treatment. So we included a post treatment phone call in our care package. So we always make a note when the treatment’s going to end, and

we phone them. As this is a time they want the support because they are feeling very abandoned and quite concerned. Because it's "Oh what am I going to do now the treatment is finished".

(BCN 25)

Similarly Breast Care Nurse 20 recognised the end of treatment as a juncture where for some women feelings of emotional fragility were engendered. She had not altered care delivery to encompass contact at that point but recognised it as a 'status passage'.

"One of the areas I would like to do is I would like to do follow up visits when all the treatment is finished. Maybe two or three months after. I would like to do a phone call and maybe this is an area for research as well I don't know but I would like to do a phone call when the treatment is finished with a view to doing a home visit for a proper evaluation, reflection of the whole experience. Something in me tells me that at that point you might then be able to start to pick up long term issues."

(BCN 20)

Making meaning of the cancer experience is a recurring theme in research examining the 'lived experience' and is frequently a pervading narrative in the autobiographical cancer story literature. This is unsurprising when contextualised against the 'existential plight' produced by the diagnosis of cancer. Hassey Dow et al, (1999) in interpreting the findings of a survey examining the meaning of quality of life in cancer survivorship found that respondents appeared to be engaged in a struggle balancing dependence and independence in terms of personal autonomy. The ability to work or demonstrate productivity was an important aspect of that struggle. The authors recognised that there might be a role for nurses but were less specific as to what that might involve or the strategies nurses might use to assist survivors with that struggle. They noted that the nurse as a member of the cancer team may be branded symbolically as contributing to a previous period of dependency for the patient and incursions into a personal struggle moving from that state to independence may be unwelcome. That said, a number of the breast care nurses recalled encounters with women who were long term survivors who identified the nurse as someone to approach:

"At the moment I seem to have a run of patients who are going through a five year crisis and it still (pause), although we never give people the all clear, they have still got this barrier once they reach the five years. Then you know they can get on with formal life. But that's not quite right because

that's what frightens them. And I have had a lot of patients that have felt that life has passed them by. That cancer dominated their lives so much and it just seems to be this five year thing. And it is, I find it so interesting, such a fascinating part of the job, and sometimes sexual problems can come into that. Relationships are changing, relationships are becoming more aware of themselves and not just as an individual. The effect that it has on the family."

(BCN 25)

The significance of five year survival was another point for distress identified by the breast care nurses. This may be manufactured resulting from the construction of cancer survival in medical discourse of the disease; a form of iatrogenic distress. From this account five years following treatment some women remain emotionally disabled by the disease and its treatment. What is unknown is the anticipatory nature of those concerns in that they may well be engendered by a watershed hospital appointment and therefore transitory or if they are enduring anxieties which remain unresolved in the survival trajectory.

Conclusion

To summarise, this chapter has presented breast care nurses as colonisers of previously uncharted territory. They have been largely successful in the project to provide support for women through the primary treatment phase of breast cancer. Some aspects of the terrain appear to be well charted in terms of their contribution. Nevertheless breast care nurses are becoming to some extent the architects of potential territorial disputes. This is particularly related to psychosocial care where at one border there is challenge from health professional experts in the form of clinical psychologists and psychiatrists and to a lesser extent other specialist nurses (psychological support nurses and community psychiatric nurses). At another border breast care nurses have territorial incursions from lay experts, those who have experienced the disease and re-emerged to support other women.

Increasing surveillance of the practice of health care professionals is a feature of contemporary life. Media attention to poorly performing doctors is one example. In

cancer care the implementation of guidelines and standards monitored through regular accreditation, audit, and outcomes, has the potential to facilitate improvement in patient care. Expansion of the multidisciplinary team to include expertise, on the basis of contribution to patient care, has the potential to bring coherence to a previously fragmented care delivery system. Along with the shift to inclusive teams of various disciplines and (sub) specialisms within disciplines, comes scrutiny of contribution, negotiation of responsibility, and re-examination of traditional rituals and roles. This despite the relatively short history of breast care nursing appears to be underway. This was manifest in the interviews with breast care nurses where participants discussed service development and the shifting nature of role demarcation in response to policy but also to consumer demand. A feature of the data was the absence of permeation with accounts of inter-professional rivalry or conflict associated with territorial disputes. Nor were there descriptions of exclusion of breast care nurses from decision making or multidisciplinary teamwork. Interdisciplinary interplay appeared to be characterised by notions of mutuality and territory, although under discussion, appeared largely uncontested.

The traditional view of medicine as unassailably dominating nursing work has been revised in recent decades. Stein (1967) using the metaphor of a game to describe negotiation between nurse and doctor that facilitated both parties to achieve a reasonable outcome in terms of patient care yet offers little challenge to the authority of medical knowledge and control of nursing work. This view was revised by Stein, et al. (1990) in the light of the educational and professionalising agendas of nursing encroaching on the game plan establishing a different dynamic between the doctor and nurse. More recently 'negotiated order' (Strauss 1978) has been revisited as offering an organising conceptualisation to examine doctor-nurse relationships (Svensson 1996; Allen 1997). The underlying assumption is that negotiation both contributes to social order and social order give structure to interaction. A criticism is that if negotiation is the basis for interaction it infers that "everything is indefinitely negotiable" (Allen 1997: 499). Allen counters that critique by arguing that the impact imposed by organisational hierarchies, policies and rules may restrict the impact of negotiation but it does not, by default,

imply that negotiation is not a process used by health care professionals as a basis for organising and dividing work. An aspect of this changed dynamic within negotiation between nurses and doctors relates to macroscopic changes in the context where health care is enacted. Social knowledge of the patient has greater importance due to the emphasis in health care delivery on managing chronicity and ‘empowering’ patients to be active participants in decision making. Nurses have acquired a strong position in terms of knowledge of the social and this is manifest in the tendency to describe nursing as the group responsible for holistic care. Social knowledge is a terrain arguably colonised by breast care nurses and was examined in depth in chapter six.

Although Svensson’s (1996) analysis does not localise on the influence of gender in negotiated order, he does link alterations in the balance of power within negotiations as partly attributable to the feminising of medicine wrought by the changed demographic profile of the medical workforce. Interestingly, although surgery has traditionally been a bastion of male dominance in medicine the shift toward multidisciplinary team working may by default produce a changed gender profile and a feminising influence to breast cancer care. A feature of the interviews was the different relationships breast care nurses (BCN 8, 18, and 20) claimed to have with women surgeons and clinical psychologists (BCN 6 and 29). Since this is a one sided interpretation and from so few examples it is impossible to generalise but it would seem to suggest that change is under way.

The breast care nurses who had easy access to clinical psychologists appeared willingly to refer patients who previously they would have managed and appear to appreciate the surveillance of their work through the instrument of clinical supervision. It is interesting that something designed to examine and relieve the burden of clinician-patient relationship becomes the venue for negotiation of the process and the criterion for referral.

I have suggested that breast care nurses have in part been guilty or possibly naïve for failing to “develop and articulate their service and the levels of expertise at which they operate” (Tait 1994/5:7) particularly in relation to psychosocial care and knowing.

Alternatively the language used to describe their knowledge of the social world of women could be interpreted as nurses having expertise in at least two differently coded discourses and effectively use and contribute to patient centred care using both. I reinforce however the partiality of the social knowing of women with breast cancer particularly in connection with difference.

Then the stamp of approval given to breast care nursing by the Forrest Report (1986) and reinforced in numerous policy documents could be interpreted as poorly managed. As Tait concluded in her study :“The variety of the nurses’ work and size of their caseloads were open ended, presenting seemingly infinite possibilities to improve care in unclaimed territory. Many nurses experienced difficulties developing a distinctive focus, prioritising needs, placing boundaries around the care they offered and between their personal and professional work”. (1996:7)

However if examined in terms of multidisciplinary team working and negotiations inherent in organisations undergoing constant change, then breast care nurses have been highly successful. By developing expertise with knowing, however that skill is currently articulated, breast care nurses have encouraged a perception of participation of women in care, service innovation and improvement, and demonstrated a commitment to “being there for women”.

CHAPTER 8

TOWARDS AN ACCOUNT OF BREAST CARE NURSING: BEING THERE FOR WOMEN

Introduction

Breast cancer is a disease with many characters. It has a media profile. It is a disease that commands sympathy, political lobbying, charitable giving, and has recently emerged packaged as a T-shirt. It is also a disease that has been particularly spotlighted in policy as a site on which the “challenge of cancer” will be mastered. It has attracted inquisition to understand its mystery to a far greater extent than many other cancers. It is in the UK a disease where there is considerable consensus about best ways to manage and treat which have been translated into clinical guidelines. Since the implementation of the Calman-Hine report (Department of Health, 1995) the delivery of breast cancer services have been the focus of investment, scrutiny, criticism and praise. Breast cancer is also a burden in terms of the demands it places on women, and the small number of men, who develop the disease. It exerts costs through loss of earnings, body integrity, well being, and deaths of mothers, grandmothers, daughters and sisters. It is a disease that has many stories, often of heroic women battling against the odds, with some winning and some losing. It is against that background that the work of breast care nurses is enacted.

In this final chapter I intend to restate the key elements of my account of the work of breast care nurses. I will revisit the concept of knowing as a quality of the essence of breast care nursing. Firstly I will return to the original research aims for this work and discuss them within the context of the research findings. Secondly I wish to weave the threads of this thesis, as presented in the four findings chapters, in order to both illustrate the value of knowing yet emphasise the limitations of understanding of knowing.

The aims of this study as presented earlier in this thesis were:

1. To assess knowledge and attitudes of breast care nurses in relation to sexuality
2. To explore the knowledge and understanding gained through clinical practice by breast care nurses in their work with clients in relation to sexuality

3. To explore with women with breast cancer their experiences and the impact of the disease on their construction of self in relation to sexuality
4. To identify the congruence/dissonance between the client's lived experience and the experience of breast care nurses working with them
5. To identify implications for practice and/or education and training of breast care nurses and others working with this client group.

I will now summarise the findings of this work in relation to the success or otherwise of my efforts in achieving them.

Sex knowledge and attitudes of breast care nurses

My purpose underlining aim one was to establish a benchmark against which to judge breast care nurses with comparable groups and in many ways this was achieved. The results of the survey suggest that breast care nurses have marginally higher knowledge scores than other nursing cohorts. The attitudes displayed in the responses were far from surprising or unexpected. The demographic profile possibly suggests that more breast care nurses are engaging in continuing professional education and Tait's call for motivated rather "compassionate carers" (1994: 9) may be permeating through the specialism. Another feature of the results was the seeming demarcation between body image and sexuality work with clients. This may well relate to the availability of doing strategies, i.e. prosthetic fitting, rather than dependency on talk therapy as the main constituent of intervention. Possibly the most exciting finding, or my reading of the survey phase of the work, were the responses to the questions added to elicit information about lesbian and homosexual patients. I believe that I uncovered an understanding of sexuality, despite lip service to inclusion, within a sensibility that sees the world as heterosexual. To the extent that it was implicit and unnecessary to state the obvious: I liken it to the "normal" human portrayed as male. Suddenly from a serendipitous hearing of a conference paper a personal new way of looking at the delivery of health care emerged foreground by the issue of difference. What emerged in the data were

indications, however tentative, that I was uncovering an institutional blindness to difference in a group of nurses reputedly woman centred.

I now turn to a feature of the language used by breast care nurses in the interviews as it also fits with this notion of (in)visibility or blindness that I interpreted as emergent from the survey. This chapter is titled “Towards an account of breast care nursing: being there for women. An alternative title might be “being there for ~~women~~ ladies?” with the word women intentionally scored through. Throughout the interviews the breast care nurses referred to the women they encountered with breast cancer as “ladies”. Only three participant breast care nurses used woman, or women, with any regularity but all used “ladies” to describe women at some point in the interviews. This when viewed in connection with what became the recurring sub-theme of (in)visibility I believe is telling. English is a quirky language and “ladies” is often a term used in deference; as in ladies and gentlemen at the beginning of a public address. “Ladies” is a word with numerous meanings including “female head of a household, a woman which is the object of a man’s devotion, a woman of superior social position, the Virgin Mary, and as an honorific title, a woman whose manner, habits and sentiments have the refinement characteristic of the higher ranks of society,” (Oxford University Press 1989). I offer the argument that inclusivity is demonstrated through the use of language as well as through behaviour. Perhaps it is time to examine how the thoughtless use of words may exclude. I would suggest that the word “woman” speaks to assumptions underlying discourse whereas the use of “ladies” scripts behaviour and somehow diffuses protest.

Whilst not willing to shift from a position that language excludes and as Spender suggests “words help to structure the world we live in, and the words we have help to structure a sexist world in which women are assigned a subordinate position” (1998: 31). That reading might be too harsh an interpretation of what could in reality be a language usage of social nicety. Increasingly in modern use the term lady has become recognised as the “feminine analogue of gentleman, and is applied to all women above a loosely defined and variable, but not very elevated, standard or social position. Often used as a more courteous synonym for woman without reference to the status of the

person spoken of” (Oxford University Press 1989). This deserves further scrutiny before being discounted.

Nursing remains a predominantly female populated profession in the UK and all the breast care nurse informants were women. Tait made various claims to the ‘woman centredness’ of the labour of breast care nursing and I have no reason to dispute that this value was held dear by many of the breast care nurses who participated in this study. Nor do I wish to minimise the burden of communicating with women facing diagnosis and treatment for a life threatening disease and “acting as a midwife to patients’ own articulation of their needs” (Oakley 1993: 48). Nevertheless if that ‘woman centredness’ is confined within a sensibility that sees women within a narrow definition then meaning, interpretation, responses, and knowing the individual woman may be erroneous. What warrants further exploration is what constitutes good practice in delivering ‘women centred’ care to all women not merely those that articulate the ‘right’ concerns.

The delivery of breast cancer care

In chapter five the delivery of breast cancer care was linked to work undertaken by Costain Schou and Hewison (1999) which adopts the metaphor of the “treatment calendar” as explanatory for how cancer care is delivered and understood. Primary treatment for breast cancer has a relatively prescribed treatment trajectory and with the publication of clinical guidelines and standards (Department of Health 1997d, 2000a, NHS Executive, 2000b) this treatment trajectory is even more closely detailed and under surveillance. That is that health care organisations have an obligation to monitor and give account for achieving the baseline standards. This trajectory according to Costain Schou and Hewison (1999) orders the experience of cancer illness albeit based upon the medical imperatives of treatment it as moderated by the patient’s response to the demands of that regimen. Once a woman enters the health care system for treatment that trajectory is imposed, if only for a finite period, upon her life world. Moreover it is imposed along with a diagnosis which signals a threat to life. I suggested that parallel,

but not necessarily in synchrony, with it was the individual patient's personal calendar. I likened this to the notion of having to manage two diaries: one, over which the individual patient has little control, and a second one which she may well feel no longer in control of, due to events associated with diagnosis and subsequent treatment. The treatment calendar has a momentum almost like a moving pavement that the woman steps on, as does the personal calendar. The breast care nurse first encounters the woman at a point where she is just about to be presented with diagnosis, and then sets out the calendar for her. This process of setting out is through information giving.

Information is the medium through which interaction between patient and breast care nurse is mediated. In the staged event of breaking bad news the breast care nurse first observes thereby eliciting information about how the woman responds, and uses this information to manage or possibly exert control. I alluded to information particularly around diagnosis as both a prescription to control interaction by containing emotion and a prescription to engage the woman in decision making. The breast care nurse determines the flow of information according to her assessment of the woman's needs and humanises the information through her demeanour of friendliness. This initial event or meeting I would argue is the beginning of a relationship between nurse and woman based upon the exchange of information and characterised by friendliness. The breast care nurse provides information that enables the woman to know what the treatment calendar has in store, to inform in order to facilitate compliance with, and self-surveillance of, adjuvant treatment. In exchange the woman divulges information about herself, her life, her feelings so as to allow the breast care nurse to know the woman better. This knowing is an incremental process, sustained through interaction, and it is as if through knowing the breast care nurse can assist the woman by "walking with" her on the treatment calendar. This is achieved by being there for the woman predominantly through "listening and talking".

The information gleaned through knowing has other uses beyond the one to one nurse – patient relationship. It is reportedly used by breast care nurses to ensure that the woman's desires in terms of treatment options are known in arenas where she does not

have access and therefore cannot speak for herself. In effect one of the breast care nurse's contributions to multidisciplinary decision making is the social knowledge she brings of the patient to supplement 'objective' clinical information. The breast care nurse has become the authority of the individual whereas medicine remains the authority of illness. What is unknown is the status of that social knowledge within the context of multidisciplinary decision making. Some of the accounts presented suggest that social knowledge is heard both in terms of claims of being an advocate for women and specific examples associated with ensuring women receive the treatment they want. What has yet to be explored is if it is acted upon with regularity in that the social knowledge has a value in clinical decision making and what action emanates from communication of social knowledge across the multidisciplinary team. In effect how is knowing acted on? That said, I believe I went some way to achieve aim two when I sought to explore the knowledge and attitudes acquired experientially in clinical practice. That exploration although focusing on sexuality found, in common with much of the work breast care nurses undertake with women, it is not a neatly compartmentalised "problem". Aspects of sexuality permeate women's lives and the meaning and experience that an illness such as breast cancer brings to their lives. I would suggest, with reservations, that the agency of knowing which appears to be one of the purposes underlying breast care nurse – woman interactions may be an important aspect of effective sexuality care.

So far in this summary I have begun to construct an account that casts the work of breast care nurses in a positive light. However in the earlier chapters I presented data which suggests, and moreover I argued that the project of breast care nurses might well be "to know the woman" but that knowing is partial. My argument, predominantly presented in chapter six, was based on three premises. Firstly, breast care nurses appeared to believe that the quality of knowing was enhanced by its achievement staged in domestic settings: that domesticity ensured presentation of the authentic self. Secondly, that the experience of breast cancer had moral dimensions and a 'good' patient was one who worked to overcome the challenge. This was achieved through presentation of the 'right' attitude, willingness to accept any stigma associated with diagnosis or treatment and move on from it, accept invitations to participate, ensure that the 'right' reasons are

given for recourse to reconstructive surgery. Thirdly, that knowing was constrained by an assumption of heterosexuality. This last point may well be representational of other blind spots, which prevent breast care nurses from recognising difference or rather the range of difference(s) across women. Blindness may well undermine the premise that the breast care nurse is the authoritative voice of social knowledge of women.

I located the discussion of knowing within the theory of awareness contexts. I argued that many of the issues associated with diagnosis and prognosis of breast cancer had currency with those associated with awareness of dying. Timmermans (1994), as discussed in chapter six, provided an extension to the conceptualisation of awareness contexts. He suggested that the recipient (and other family members) contribute powerfully to an open awareness context; they are “powerful actors” (1994: 335). He proposes that information alone will not produce open awareness but the capacity to cope emotionally with the information determines the awareness context. I would add the capacity on either side, patient or health care professionals, to see differently and to avoid listening selectively (possibly) for moral accounts may also contribute to greater clarity of awareness. Although I intended to explore with women (aim three) their experiences and the impact of the disease upon personal constructions of sexuality I found I was only able to glimpse what might be reduced to sexuality concerns within a whole range of issues and experiences engendered by breast cancer. I also sought to identify any congruence and dissonance between accounts from breast care nurses and women (aim four). Breast care nurses, through the pursuit of knowing, are working toward a congruent understanding. I believe, however, there are constraints upon achievement of that project which are in part structural, i.e. imposed by the organisation of care, and partly the result of limited vision.

The territory of psychological support

In chapter seven I examined the territorial acquisitions achieved by breast care nurses and the boundary renegotiations and skirmishes occurring in the context of a delivery system seemingly undergoing constant redefinition and re-engineering. I argued that

breast care nurses might become victims of territorial disputes if they failed to give greater definition to the work they currently undertake associated with psychosocial care. I suggested that breast care nurses were failing to articulate their therapeutic role in psychological care. This was illustrated by the delegation of some aspects of support to non-professionals while at the same time failing fully to articulate the limits of their expertise at the interface with experts in psychological morbidity.

This failure to define territory is despite what can only be described as a major success. The early work undertaken to chart the extent of psychological problems associated with breast cancer suggested that twenty to thirty per cent of women would experience depression and or anxiety and a proportion of women, around twenty percent, would experience sexual problems. There is however a paucity of any recent outcome evaluations so those estimates could be generous. What was clear in this study, and found by Tait (1996), was that breast care nurses rarely reported referring women with problems which could be categorised under these labels to 'experts'. From this observation a number of explanations can be offered. It is possible, however improbable, that the large numbers of women with breast cancer who previously experienced 'mental illness' diagnosed by objective measurement, have been some how prevented or protected from this outcome by the support offered by breast care nurses.

Alternatively other factors could account for reduction in psychological problems in this client group. It is probable that the original estimations of psychological distress were generous due to over-zealous estimations, or extreme sensitivity of the measures used for assessment, or a bias imposed by the assessor(s). Reputable measures of distress were used i.e. Hospital Anxiety and Depression Scale and estimations of inter-rater reliability were made. Other explanations either in isolation or cumulatively, such as the effect of greater use of conservative surgical techniques, increased use of reconstruction, patient involvement in decision-making, greater provision of information, could all influence the incidence of depression, anxiety and sexual problems experienced by the breast cancer population. It is in all probability related to all these factors including the

work breast care nurses. This does however generate a number of exciting possibilities for further work.

Redefining territory

Redefining territory also emerged in terms of breast care nurses' relationship with other nurses and speculation and in some cases undertaking extended and advanced practice roles. An interesting feature of some aspects of the work relatively recently colonised by breast care nurses (such as prosthetic fitting) is the process of asset stripping which occurs prior to delegation. Some aspects of the task such as assessing psychosocial well-being remains specialist work whereas the prosthesis fitting task is under revision as a less demanding skill. Nevertheless it seemed as if prior to delegation occurring the breast care nurse trains the nurse (or health care assistant) to undertake the task thereby maintaining some control over the territory. In addition she often retains control by maintaining budgetary responsibility and/or expecting "problems" to be referred back, thereby creating a hierarchical ordering.

A second aspect of redefining territory was the activity of identifying new roles and new territory. I have alluded to the possibilities in terms of roles previously undertaken by junior doctors. These include diagnosis, follow up surveillance and some aspects of wound management, but breaking bad news also appears to be an area ripe for incursion. However, an area identified as currently uncharted is that of survivorship and if linked with follow up surveillance really opens possibilities for nurses to examine their therapeutic potential in terms of focused supportive interventions. Such progress would begin to offer support to those who have had breast cancer in addition to those that have breast cancer. This may also open up the role of the breast care nurse in terms of sexuality care. My interpretation of the breast care nurses' responses suggesting greater activity associated with body image work and less interactions focused on sexuality concerns may be explained by the point of the trajectory that the breast care nurse "walks with" the woman. It may well be that the real work of adapting and

reintegration is when a woman has “had” breast cancer not during the primary treatment phase.

To summarise, this study sought to explore the work of breast care nurses in order to understand better the sexuality and body image dimensions of women’s experience of breast cancer. What has been achieved is a further understanding of relationship that unfolds between nurse and woman, how nurses navigate organisational and domestic settings in order to better understand the individual woman, yet the account offered recognises the limitations that restricted vision may bring to the pursuit of authentic knowing.

Implications for education and research

In chapter three I set out five research aims which I believed I would address through the proposed research design. The first four have been discussed in the preceding body of this chapter. What I have yet to address is the final aim, that was to identify implications for practice and/or education and training of breast care nurses and others working with this client group. I now turn to that task but may well go beyond the limits of the data in accomplishing it.

Breast care nursing has developed over the last twenty years, but like many nursing roles the educational preparation and the research base to underpin effective practice has not fully kept pace. The proposed framework for nursing outlined in “Making a Difference” (Department of Health 1999) and more recently “The Nursing Contribution to Cancer Care” (Department of Health, 2000a) is beginning to articulate more clearly a clinical pathway for nurses which may well result in a real career structure for nurse specialists. It also links academic achievement, if only at the level of preferred rather than compulsory, to clinical roles. This has the potential to give breast care nurses the impetus to embrace scholarship to underpin their experience. This may also encourage the development of a research culture that focuses on exploring current practice in order to establish what works and what can be delegated and discarded without fear. If

education goes beyond providing knowledge and skills and enables nurses to examine how they see the world and challenge old ways of knowing then this may go some way to making those women that are currently invisible visible; and provide critical scrutiny of the moral journey of patients within the health care system. Talking and listening were the mainstay of interaction yet the breast care nurse informants claimed to use a variety of approaches ranging from “naturally good communicators” to more formalised schemas. While remaining cognisant of the need for tailoring interaction the repertoire of communication skills to underpin this central aspect of work may well require at least refreshing (and for some enhancing) if sensitive interaction is to ensue.

This project, in common with many research endeavours, uncovered more questions than provides answers. The following are areas identified as warranting further investigation:

- Exploration of difference in terms of inclusion and exclusion within nurse-patient interaction;
- An examination of the contribution of social knowledge gained through nurse-patient interaction in multidisciplinary clinical decision making;
- An exploration of the impact of setting: domestic and clinical, on the quality of knowing;
- A longitudinal intervention study examining the use of a standardised assessment approach to facilitate knowing and optimise support during follow-up surveillance;
- Identification and evaluation of strategies to support survivors of breast cancer;
- An examination of access to and uptake of breast reconstruction.

Limitations of the study

This thesis, despite the justification offered in chapter one, is limited by the absence of fieldwork through participant observation. At numerous junctures throughout this account the potential to unravel or illuminate has been constrained by what to all intents is hearsay evidence. Any further work in this area would be enhanced by fieldwork.

The survey presented in chapter four has limited value on two counts. The poor response rate achieved by a one round postal invitation could have been improved, and have greater claims to representing the attitudes and knowledge of breast care nurses, by a second administration of the questionnaire. The time frame of this postgraduate endeavour with the survey element completed so early in history of the project confines the results to something of a historical snapshot. Nevertheless when contrasted with Tait's (1996) results they illustrate a changing profile.

In all interpretative work, and particularly interview-based studies, the quality of the data is dependent upon the informants and the researcher presenting an accurate representation of the phenomenon under investigation. In order to enhance the credibility of the work I have made efforts to give due balance to informants and present a truthful account of the execution of the project. Nevertheless I remain mindful that irrespective of all claims of transparency it is easy to be influenced in that endeavour by personal beliefs and ability. It is for the reader to judge the authenticity of the account offered as representational of reality and a product of the description of project provided.

Conclusion

Finally, if knowing is central to the project of breast care nursing, and potentially significant in ameliorating the lived experience of breast cancer for women, then it is urgent that its essence is further explored. Secondly if, and I can only tentatively suggest that, breast care nurses are having a therapeutic effect on well being this needs to be defined, examined, possibly "bottled" as an intervention and measured for its efficacy. Then, and only then, can the contribution of breast care nursing have true authority to be the purveyor of "social knowing" and engage fully in "being there for women". Thirdly if it is necessary for patients and their partners to present the 'right reasons' in order to access health care then there is an urgent need to undertake a robust examination of the impact of moral scrutiny and judgement on patient equity.

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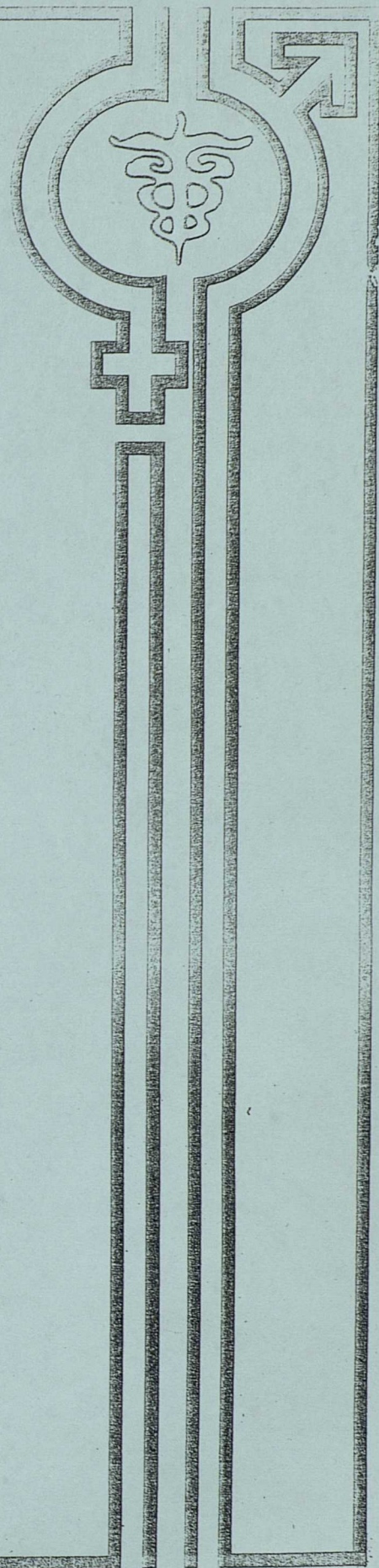
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Appendix One

Sex Knowledge and Attitudes (SKAT) Questionnaire

CENTER FOR THE
STUDY OF
SEX EDUCATION
IN MEDICINE



SEX KNOWLEDGE AND ATTITUDE TEST
(S. K. A. T.)

A TEST ON KNOWLEDGE ABOUT AND ATTITUDES
CONCERNING SEXUAL BEHAVIOR.

Second Edition
(REVISED 1972)

Division of Family Study
Department of Psychiatry
University of Pennsylvania
School of Medicine
4025 Chestnut Street
Philadelphia, Pennsylvania
19104

HAROLD I. LIEF, M.D.

DAVID M. REED, Ph. D.

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THIS TEST, OR ANY PARTS THEREOF, MAY NOT BE REPRODUCED IN ANY FORM WITHOUT
PERMISSION OF THE AUTHORS.

CODING AND GENERAL INSTRUCTIONS

1. Pencils — Use any type of soft lead pencil. Do not use an ink or ballpoint pen.
2. All answers are to be recorded on the separate answer sheet. Please make no marks on this booklet.
3. Regardless of the number of alternatives provided, please mark only one answer per question.

IDENTIFICATION INFORMATION

I. We strive to maintain complete confidentiality. Some identifying number is necessary simply for the processing of this material. If there is some concern about using your Social Security or Student I.D. number, make up your own unique number and retain the key. Identifying numbers are used only for matching information for pre-and post-test comparisons.

II. Please select the one alternative that best describes yourself:

- | | |
|------------------------|-------------------------------|
| A. High School Student | C. Graduate Student |
| B. College Student | D. Non-Student (Skip to VI) |

III. Which one of the following alternatives best describes your present occupation or field of study:

- | | |
|----------------|---------------------------|
| A. Medicine | F. Sociology/Anthropology |
| B. Theology | G. Humanities |
| C. Psychology | H. Nursing |
| D. Education | I. Law |
| E. Social Work | J. Other |

IV. If you are a medical student, intern or resident, please indicate your status:

- | | |
|---------------------|------------------------------|
| A. 1st year student | D. 4th year student or above |
| B. 2nd year student | E. Intern |
| C. 3rd year student | F. Resident |

V. If you are a medical student or a physician, please indicate proposed or present area of specialization:

- | | |
|--------------------------|-----------------------|
| A. General Practice | F. Pediatrics |
| B. Family Medicine | G. Surgery |
| C. Internal Medicine | H. Urology |
| D. Obstetrics-Gynecology | I. Community Medicine |
| E. Psychiatry | J. Other |

VI. Are you completing this questionnaire before or after a specific course in sex education?

- A. Pre-instruction B. Post-instruction C. Neither

VII. Please mark block A (to identify this as the 1972 version of SKAT):

PART I : ATTITUDES

Please indicate your reaction to each of the following statements on sexual behavior in our culture, using the following alternatives:

- A. Strongly agree
- B. Agree
- C. Uncertain
- D. Disagree
- E. Strongly disagree

Please be sure to answer every question.

1. The spread of sex education is causing a rise in premarital intercourse.
2. Mutual masturbation among boys is often a precursor of homosexual behavior.
3. Extramarital relations are almost always harmful to a marriage.
4. Abortion should be permitted whenever desired by the mother.
5. The possession of contraceptive information is often an incitement to promiscuity.
6. Relieving tension by masturbation is a healthy practice.
7. Premarital intercourse is morally undesirable.
8. Oral-genital sex play is indicative of an excessive desire for physical pleasure.
9. Parents should stop their children from masturbating.
10. Women should have coital experience prior to marriage.
11. Abortion is murder.
12. Girls should be prohibited from engaging in sexual self-stimulation.
13. All abortion laws should be repealed.
14. Strong legal measures should be taken against homosexuals.
15. Laws requiring a committee of physicians to approve an abortion should be abolished.

16. Sexual intercourse should occur only between married partners.
17. The lower-class male has a higher sex drive than others.
18. Society should offer abortion as an acceptable form of birth control.
19. Masturbation is generally unhealthy.
20. A physician has the responsibility to inform the husband or parents of any female he aborts.
21. Promiscuity is widespread on college campuses today.
22. Abortion should be disapproved of under all circumstances.
23. Men should have coital experience prior to marriage.
24. Boys should be encouraged to masturbate.
25. Abortions should not be permitted after the twentieth week of pregnancy.
26. Experiences of seeing family members in the nude arouse undue curiosity in children.
27. Premarital intercourse between consenting adults should be socially acceptable.
28. Legal abortions should be restricted to hospitals.
29. Masturbation among girls is a frequent cause of frigidity.
30. Lower-class women are typically quite sexually responsive.
31. Abortion is a greater evil than bringing an unwanted child into the world.
32. Mutual masturbation in childhood should be prohibited.
33. Virginity among unmarried girls should be encouraged in our society.
34. Extramarital sexual relations may result in a strengthening of the marriage relationship of the persons involved.
35. Masturbation is acceptable when the objective is simply the attainment of sensory enjoyment.

PART II : KNOWLEDGE

Each of the following statements can be answered either true or false. Please indicate your position on each statement using the following alternatives:

T. True

F. False

Be sure to answer every question.

1. Pregnancy can occur during natural menopause (gradual cessation of menstruation).
2. Most religious and moral systems throughout the world condemn premarital intercourse.
3. Anxiety differentially affects the timing of orgasm in men and women.
4. A woman does not have the physiological capacity to have as intense an orgasm as a man.
5. There is no difference between men and women with regard to the age of maximal sex drive.
6. Social class is directly correlated with the frequency of incest.
7. The use of the condom is the most reliable of the various contraceptive methods.
8. The incidence of extramarital intercourse is constant for males between the ages of 21 and 60.
9. Nearly half of all unwed girls in America have sexual intercourse by age 19.
10. There are two kinds of physiological orgasmic responses in women, one clitoral and the other vaginal.
11. Impotence is almost always a psychogenic disorder.
12. Transvestitism (a form of cross-dressing) is usually linked to homosexual behavior.
13. There was as much premarital coitus a generation ago as there is now.
14. Sexual attitudes of children are molded by erotic literature.
15. In some successful marriages sex adjustment can be very poor.
16. Homosexuals are more likely to be exceptionally creative than heterosexuals.
17. A woman who has had a hysterectomy (removal of the uterus) can experience orgasm during sexual intercourse.
18. Homosexuality comes from learning and conditioning experiences.
19. In responsive women, non-coital stimulation tends to produce a more intensive physiological orgasmic response than does coitus.
20. Those convicted of serious sex crimes ordinarily are those who began with minor sex offenses.

21. One of the immediate results of castration in the adult male is impotence.
22. The body build of most homosexuals lacks any distinguishing features.
23. Masturbation by a married person is a sign of poor marital sex adjustment.
24. Exhibitionists are latent homosexuals.
25. A woman's chances of conceiving are greatly enhanced if she has an orgasm.
26. Only a small minority of all married couples ever experience mouth-genital sex play.
27. Impotence is the most frequent cause of sterility.
28. Certain foods render the individual much more susceptible to sexual stimulation.
29. A high percentage of those who commit sexual offenses against children is made up of the children's friends and relatives.
30. A higher percentage of unmarried white teenage girls than unmarried black teenage girls in the United States have had intercourse with four or more partners.
31. The attitude of the average American male towards premarital intercourse is shaped more by his religious devoutness than by his social class.
32. In teaching their daughters female sex roles, middle-class mothers are more affected by cultural stereotypes than mothers in other social classes.
33. In most instances, the biological sex will override the sex assigned by the child's parents.
34. The onset of secondary impotence (impotence preceded by a period of potency) is often associated with the influence of alcohol.
35. Nursing a baby usually protects the mother from becoming pregnant.
36. In our culture some homosexual behavior is a normal part of growing up.
37. Direct contact between penis and clitoris is needed to produce female orgasm during intercourse.
38. For a period of time following orgasm, women are not able to respond to further sexual stimulation.
39. In some legal jurisdictions artificial insemination by a donor may make a woman liable to suit for adultery.
40. Habitual sexual promiscuity is the consequence of an above-average sex drive.
41. Approximately one out of three adolescent boys has a homosexual experience leading to orgasm.
42. Impotence in men over 70 is nearly universal.
43. Certain conditions of mental and emotional instability are demonstrably caused by masturbation.
44. Women who have had several sex partners before marriage are more likely than others to be unfaithful after marriage.
45. The emotionally damaging consequences of a sexual offense against a child are more often attributable to the attitudes of the adults who deal with the child than to the experience itself.

46. Sexual maladjustment is the major cause of divorce.
47. Direct stimulation of the clitoris is essential to achieving orgasm in the woman.
48. Age affects the sexual behavior of men more than it does women.
49. The circumcized male has more trouble with ejaculatory control than the uncircumcized male.
50. More than a few people who are middle-aged or older practice masturbation.
51. Varied coital techniques are used most often by people in lower socioeconomic classes.
52. Individuals who commit rape have an unusually strong sex drive.
53. The rhythm method, (refraining from intercourse during the six to eight days midway between menstrual periods), when used properly is just as effective as the pill in preventing conception.
54. Exhibitionists are no more likely than others to commit sexual assaults.
55. The ability to conceive may be significantly delayed after the menarche (onset of menstruation).
56. Many women erroneously consider themselves to be frigid.
57. Menopause in a women is accompanied by a sharp and lasting reduction in sexual drive and interest.
58. The two most widely used forms of contraception around the world are the condom and withdrawal by the male (coitus interruptus).
59. People in lower socioeconomic classes have sexual intercourse more frequently than those of higher classes.
60. Pornographic materials are responsible for much of today's aberrant sexual behavior.
61. For some women, the arrival of menopause signals the beginning of a more active and satisfying sex life.
62. The sex drive of the male adolescent in our culture is stronger than that of female adolescent.
63. Lower-class couples are generally not interested in limiting the number of children they have.
64. Excessive sex play in childhood and adolescence interferes with later marital adjustment.
65. There is a trend toward more aggressive behavior by women throughout the world in courtship, sexual relations, and coitus itself.
66. Sometimes a child may have cooperated in or even provoked sexual molestation by an adult.
67. LSD usually stimulates the sex drive.
68. Seven out of ten parents desire formal sex education in the schools.
69. For every female that masturbates four males do.
70. Douching is an effective form of contraception.
71. Freshmen medical students know more about sex than other college graduates.

PART III : BACKGROUND

This information will be treated as strictly confidential and will be used for research purposes only. In no way will it be used to reveal anyone's identity. Please mark your responses on Part III of the answer sheet.

1. Age

- | | |
|----------------|---------------|
| A. 17 or under | F. 26 - 27 |
| B. 18 - 19 | G. 28 - 30 |
| C. 20 - 21 | H. 31 - 35 |
| D. 22 - 23 | I. 36 or over |
| E. 24 - 25 | |

2. Sex

- | | |
|---------|-----------|
| A. Male | B. Female |
|---------|-----------|

3. Race

- | | |
|----------|--------------|
| A. White | B. Non-white |
|----------|--------------|

4. If you have been or are married, age at first marriage?

- | | |
|----------------|---------------|
| A. 17 or under | D. 27 - 35 |
| B. 18 - 22 | E. 36 or over |
| C. 23 - 26 | |

5. If you have been or are married, how long?

- | | |
|------------|--------------------|
| A. 1 year | D. 4 years |
| B. 2 years | E. 5 or more years |
| C. 3 years | |

6. Are you first born?

- | | |
|--------|-------|
| A. yes | B. no |
|--------|-------|

7. Father's Occupation:

- | | |
|-----------------------|-------------------|
| A. Physician | F. Executive |
| B. Clergyman | G. Clerical/sales |
| C. Lawyer | H. Skilled manual |
| D. Teacher | I. Semi-skilled |
| E. Other professional | J. Unskilled |

8. Number of siblings:

- | | |
|------|--------------|
| A. 0 | D. 3 |
| B. 1 | E. 4 or more |
| C. 2 | |

9. Please indicate the educational status of your father:

- | | |
|--|--|
| A. Non-high school graduate | D. College graduate |
| B. High school graduate | E. Attended graduate or professional school but did not graduate |
| C. Attended college but did not graduate | F. Holds graduate or professional degree |

10. Using the alternatives listed above, please indicate the educational status of your mother.

11. Religion:

- | | |
|---------------|-----------|
| A. Catholic | C. Jewish |
| B. Protestant | D. Other |

12. What was the earliest Church-affiliated sex education you received?

- | | |
|-----------------------|-----------------------|
| A. None | D. Sr. High (10 - 12) |
| B. Elementary (K - 6) | E. College |
| C. Jr. High (7 - 9) | |

PART IV: EXPERIENCE

It would be helpful if you would fill in the following questions. They refer to levels of experience with sex, and will aid our understanding of relationships between knowledge and attitudes. Please answer honestly, and feel free to omit any question or questions if you find them too personal.

For questions 1-5 indicate how many times you have had the following sexual encounters:

- A. Never B. Once C. Two—five D. Over five

1. Dating
2. Going steady
3. Sexual intercourse
4. Intercourse involving the exchange of money
5. Orgasm with partner of the same sex

For questions 6-9 indicate the number of people with whom you have engaged in the following sexual activities:

- A. None B. One C. Two—five D. Over five

6. Dating
 7. Going steady
 8. Sexual intercourse
 9. Orgasm with partner of the same sex
10. How do you rate yourself in comparison with your peer group's experience in sex?
- A. Far less experienced than most D. More experienced than most
B. Less experienced than most E. Far more experienced than most
C. As experienced as most

11. How do you rate yourself in comparison with your peer group's knowledge about sex?

- A. Far less knowledgeable than most
- B. Less knowledgeable than most
- C. As knowledgeable as most
- D. More knowledgeable than most
- E. Far more knowledgeable than most

12. How do you rate yourself in comparison with your peer group's sexual adjustment?

- A. Far less adjusted than most
- B. Less adjusted than most
- C. As adjusted as most
- D. More adjusted than most
- E. Far more adjusted than most

13. How would you rate the sexual permissiveness in your home when you were growing up?

- A. Very permissive
- B. Somewhat permissive
- C. Neither permissive nor repressive
- D. Somewhat repressive
- E. Very repressive

For questions 14-17, rate your value system with regard to sex:

- A. Not at all
- B. Somewhat
- C. Definitely
- D. Very definitely

14. Is your value system conservative (in favor of traditional standards)?

15. Is your value system liberal (in favor of changing standards)?

16. Is your value system influenced by religion?

17. Is your value system in conflict with your parents' values?

18. Age at which you first began masturbation.

- A. Never masturbated
- B. Under 10
- C. 10 - 12
- D. 13 - 15
- E. 16 - 18
- F. 19 or over

For questions 19-21 indicate the frequency with which you masturbated during the following time period

- | | |
|--------------------------|---------------------------|
| A. Less than once/week | C. Four—five times/week |
| B. Two —three times/week | D. Six or more times/week |

19. Junior High School

20. High School

21. College

For questions 22-26 indicate if you have ever engaged in sexual intercourse using the following birth prevention methods:

A. Yes

B. No

22. I. U. D.

23. Pill

24. Abortion

25. Sterilization

26. "Morning-after" treatment

27. Which one of the following contraceptive methods do you prefer?

- | | |
|--------------------------|------------------------------|
| A. Rhythm | F. I.U.D. |
| B. Douche | G. Pill |
| C. Withdrawal | H. Sterilization |
| D. Condom | I. "Morning-after" treatment |
| E. Foam and/or Diaphragm | J. Other |

Appendix Two
Williams-Wilson Sexuality Survey (WWSS)

Williams-Wilson Sexuality Survey

Demographic Variables:

1. Sex M _____
F _____
2. Age 21 - 25 _____ 40 - 50 _____
26 - 30 _____ 50 - 60 _____
31 - 35 _____ > 60 _____

Education:

Basic Nursing Program

Diploma _____
AA _____
BSN _____
MSN/MN _____

Highest Degree Held

BSN _____
MSN/MN _____
DNS _____
PHD _____
Masters in other field _____
Non-Nursing PhD _____

Membership

APON _____
ONS _____
Both _____

Primary Area of Practice :

Hospital in-patient	_____
Ambulatory Clinic	_____
Home Health Agency	_____
Private MD's Office	_____
Education Institution	_____

Primary Nursing Role:

Staff Nurse	_____
Chemotherapy Nurse	_____
Head Nurse/Supervisor	_____
Director of Nursing	_____
Faculty	_____
Clinical Nurse Specialist	_____
In-service Educator	_____
Nurse Researcher	_____
Independent practice	_____
Home Health Nurse	_____
Hospice Nurse	_____

Do you consider nursing to be your area of specialty?

Yes _____ No _____

If yes, how many years of experience do you have in oncology nursing:

1 - 2 years _____
3 - 5 years _____
6-10 years _____
>10 years _____

What percentage of your average client caseload is oncology patients?

_____ 100%
_____ 75 - 100%
_____ 50 - 75%
_____ 25 - 50%
_____ <25%

In the past two years, have you attended a state or national oncology educational program?

Yes _____ No _____

Have you ever had a diagnosis of cancer?

Yes _____ No _____

Has a significant other ever had a diagnosis of cancer?

Yes _____ No _____

Have you ever had a disease or a course of treatment (ie. surgery, chemotherapy, orthopedic procedures) that has impacted on your sexuality?

Yes _____ No _____

Williams-Wilson Sexuality Survey

- | | | Strongly Disagree | | | Strongly Agree | | |
|----|---|-------------------|---|---|----------------|---|---|
| | (Please circle) | 1 | 2 | 3 | 4 | 5 | 6 |
| 1. | Sexuality concerns should be a routine component of nursing care for cancer patients | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. | Hospitalized patients do not have the right to lock their doors | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. | It upsets or embarrasses me to see spouses or significant others lying in bed with patients | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. | If I were a cancer patient, I would want to receive sexuality counselling from a nurse | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. | If I were a patient, I would be comfortable in receiving sexuality counselling from a nurse | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. | Offering sexual counselling is not an integral component of primary nursing care | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. | At times I have felt that my nursing care of a client was incomplete because I had not addressed sexuality as a component of nursing care | 1 | 2 | 3 | 4 | 5 | 6 |

8. Sexuality is not a major concern for my patients 1 2 3 4 5 6
9. I am not comfortable initiating a discussion of sexuality with my clients 1 2 3 4 5 6
10. I am comfortable initiating a discussion of sexuality with my client's significant others 1 2 3 4 5 6
11. Discussion of sexual concerns contributes to the patient's recovery 1 2 3 4 5 6
12. I feel discouraged after offering sexual counselling to my patients because it never seems to make a difference 1 2 3 4 5 6
13. A specialist does a better job of discussing sexual concerns with patients than I could possibly do 1 2 3 4 5 6
14. I am comfortable discussing sexuality if the client initiates the discussion 1 2 3 4 5 6
15. I am comfortable discussing sexuality if the client's significant other initiates the discussion 1 2 3 4 5 6
16. Sexual desire is normally decreased during chronic illness such as cancer 1 2 3 4 5 6

17. I have felt uncomfortable in the past when I've interrupted patients engaged in sexual activity 1 2 3 4 5 6
18. Sexual activity is inappropriate under any circumstances while the patient is hospitalised 1 2 3 4 5 6
19. Nursing intervention in sexual problems/concerns increases the patient's well being 1 2 3 4 5 6
20. Sexual activity occurs whether someone is ill or well 1 2 3 4 5 6
21. My attitudes on sexuality are similar to those held by most other nurses 1 2 3 4 5 6
22. If I had cancer, sex would be the farthest thing from my mind 1 2 3 4 5 6
23. Some people with cancer can have a closer sexual relationship than they did prior to diagnosis 1 2 3 4 5 6
24. If I had cancer, my sex life would be negatively affected by the disease 1 2 3 4 5 6
25. A serious disease such as cancer can enhance a sexual relationship 1 2 3 4 5 6

If you are caring for paediatric clients, please continue to answer questions 26 - 31, then continue on with question 32. If not, please continue to answer questions 32-48.

26. Sexuality is a concern for adolescents experiencing cancer 1 2 3 4 5 6
27. I am not comfortable in answering an adolescent patient's questions regarding sexuality 1 2 3 4 5 6
28. Discussion of future sexuality issues for adolescents undergoing active treatment is an appropriate nursing function. 1 2 3 4 5 6
29. Sexuality should not be discussed with adolescents 1 2 3 4 5 6
30. It is the parent's responsibility to discuss sexual issues with their children/adolescents 1 2 3 4 5 6
31. I am comfortable discussing sexuality concerns with the parents of adolescent patients who are undergoing cancer treatment 1 2 3 4 5 6
32. Does your unit provide private time (uninterrupted time) for patients and their spouses or significant others?

Yes _____ No _____

33. In your routine nursing care of oncology patients, do you use the nursing diagnosis "Alteration in Sexuality? "

Yes _____ No _____

N/A _____

(The setting in which I'm employed does not use nursing diagnosis)

34. If yes, how many times in the past month have you used this diagnosis?

> 20 _____

10-19 _____

5 -9 _____

< 5 _____

Never _____

35. If yes, how many times in the past month have you used this diagnosis in planning postoperative care?

> 20 _____

10-19 _____

5- 9 _____

< 5 _____

Never _____

N/A _____ (your caseload of patients does not include surgical patients)

36. To how many patients and/or their significant others have you offered sexual counselling in the past 6 months?

25 - 50 _____

15 - 24 _____

5-14 _____

< 5 _____

0 _____

37. In caring for a cancer patient who has experienced an alteration in sexuality, how frequently do you initiate a referral to a specialist in order to provide for sexual counselling?

76-100% _____

50-75% _____

25-49% _____

< 25% _____

Never _____

38. If you have initiated a referral, which of the following specialists do you use most?

- _____ Clinical nurse specialist
_____ MD
_____ Psychologist/psychiatrist
_____ MSW
_____ Enterostomal therapist
_____ Clergy
_____ Sex therapist/educator

39. How many times in the past six months has one of your cancer patients and/or their significant other requested assistance regarding sexuality?

> 20 _____

10-19 _____

5-9 _____

1-4 _____

0 _____

40. Does your work setting offer continuing education programs in sexuality?

Yes _____ No _____

41. Have you discussed patient sexual concerns with another nurse in order to plan care for that patient?

Yes _____ No _____

42. Has the subject, alternations in sexuality, been a topic for nursing grand rounds on your unit?

Yes _____ No _____

43. Do you include "Potential for Alteration in Sexuality" in your nursing care plans?

Yes _____ No _____

44. Have you addressed possible alterations in sexuality with preoperative patients.

Yes _____ No _____

45. Have you discussed with patients their concerns about loss of attractiveness to sexual partner?

Yes _____ No _____

46. If yes, have you continued the discussion with their spouse or significant other?

Yes _____ No _____

47. Have you used any teaching tools or visual aids during a discussion of sexuality with an oncology patient (ie. penile implants, diagrams of sexual positioning etc)?

Yes _____ No _____

48. Have you discussed alternate positions for intercourse with an oncology patient who is experiencing an alteration in sexuality?

Yes _____ No _____

49. If not, what factor(s) would impede this discussion?

- _____ Embarrassment
- _____ lack of knowledge
- _____ Not the job of an RN
- _____ patient would be too embarrassed

50. Have you discussed alternatives to "genital to genital" sex with an oncology patient?

Yes _____ No _____

51a) If you are caring for a known homosexual patient, have you discussed alterations in sexuality that pertain to cancer and its treatment?

Yes _____ No _____

I have never cared for a known homosexual patient _____

51b) If yes, have you continued this discussion with his/her significant other?

Yes _____ No _____

51c) If no, have you made an appropriate referral to someone who would discuss the issue?

Yes _____ No _____

52. I am comfortable presenting a continuing education program on penile implants to co-workers

Yes _____ No _____

If you are caring for paediatric clients, please continue to answer question 53.

53. Have you discussed a possible alteration in sexuality with an adolescent patient who has undergone cancer treatment (eg. experienced the loss of limb, testicular relapse etc)?

Yes _____ No _____

Appendix Three

Questionnaire Including modified versions of SKAT and WWSS

A: The Sex, Knowledge and Attitude Test.

PART 1 : ATTITUDES

Please indicate your reaction to each of the following statements about sexual behaviour using the following alternatives:

1. Strongly agree
2. Agree
3. Uncertain
4. Disagree
5. Strongly Disagree

For example:

- a) Sexuality should not be discussed with children

Strongly agree Strongly disagree

☐ 1 ☒ 2 ☐ 3 ☐ 4 ☐ 5

Please be sure to answer every question.

- | | | |
|--|--|---|
| 1. The spread of sex education is causing a rise in premarital intercourse . | <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 | <div style="border: 1px solid black; width: 60px; height: 25px; margin: 0 auto;">Q1</div> |
| 2. Mutual masturbation among boys often leads to homosexual behaviour . | <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 | <div style="border: 1px solid black; width: 60px; height: 25px; margin: 0 auto;">Q2</div> |
| 3. Extramarital relations are almost always harmful to a marriage | <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 | <div style="border: 1px solid black; width: 60px; height: 25px; margin: 0 auto;">Q3</div> |
| 4. Abortion should be permitted whenever desired by the mother . | <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 | <div style="border: 1px solid black; width: 60px; height: 25px; margin: 0 auto;">Q4</div> |
| 5. The possession of contraceptive information is often an incitement to promiscuity . | <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 | <div style="border: 1px solid black; width: 60px; height: 25px; margin: 0 auto;">Q5</div> |
| 6. Relieving tension by masturbation is a healthy practice. | <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 | <div style="border: 1px solid black; width: 60px; height: 25px; margin: 0 auto;">Q6</div> |

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Use only

	Strongly agree		Strongly disagree		
7. Premarital sexual intercourse is morally undesirable	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	
8. Oral-genital sex play is indicative of an excessive desire for physical pleasure	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	Q8
9. Parents should stop their children from masturbating	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	Q9
10. Women should have coital experience prior to marriage	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	Q10
11. Abortion is murder	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	Q11
12. Girls should be prohibited from engaging in masturbation	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	Q12
13. All abortion laws should be repealed	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	Q13
14. Strong legal measures should be taken against homosexuals	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	Q14
15. Laws requiring independent medical approval for an abortion should be abolished	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	Q15
16. Sexual intercourse should only occur between married partners	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	Q16
17. The working class male has a higher sex drive than others	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	Q17
18. Society should offer abortion as an acceptable form of birth control	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	Q18
19. Masturbation is generally unhealthy	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	Q19
20. The Doctor who performs an abortion has a responsibility to inform the husband or parents of the women	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	Q20
21. Promiscuity is widespread on university campuses today	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4 <input type="checkbox"/> 5	Q21

Office
Use only

	Strongly agree	Strongly disagree	
22. Abortion should be disapproved of under all circumstances.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5		Q22 <input type="text"/>
23. Men should have experience of sexual intercourse before marriage.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5		Q23 <input type="text"/>
24. Boys should be encouraged to masturbate.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5		Q24 <input type="text"/>
25. Abortions should not be permitted after the twentieth week of pregnancy.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5		Q25 <input type="text"/>
26. Experiences of seeing family members in the nude arouses undue curiosity in children.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5		Q26 <input type="text"/>
27. Premarital sexual intercourse between consenting adults should be socially acceptable.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5		Q27 <input type="text"/>
28. Legal abortions should be restricted to hospitals.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5		Q28 <input type="text"/>
29. Masturbation among girls is a frequent cause of frigidity.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5		Q29 <input type="text"/>
30. Working class women are typically quite sexually responsive.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5		Q30 <input type="text"/>
31. Abortion is a greater evil than bringing an unwanted child into the world.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5		Q31 <input type="text"/>
32. Mutual masturbation in childhood should be prohibited.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5		Q32 <input type="text"/>
33. Virginity among unmarried girls should be encouraged in our society.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5		Q33 <input type="text"/>
34. Extramarital sexual intercourse may result in a strengthening of the marriage relationship of the persons involved.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5		Q34 <input type="text"/>
35. Masturbation is acceptable when the objective is simply the attainment of sensory enjoyment.	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5		Q35 <input type="text"/>

PART II : KNOWLEDGE

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Each of the following statements can be answered either true or false. Please indicate your position on each statement by putting a tick in the appropriate box.

T. True

F. False

Be sure to answer every question

	T	F	
1. Pregnancy can occur during natural menopause (gradual cessation of menstruation).	<input type="checkbox"/>	<input type="checkbox"/>	Q36
2. Most religious and moral systems throughout the world condemn premarital intercourse.	<input type="checkbox"/>	<input type="checkbox"/>	Q37
3. Anxiety differentially affect the timing of orgasm in men and women.	<input type="checkbox"/>	<input type="checkbox"/>	Q38
4. A woman does not have the physiological capacity to have as intense an orgasm as a man.	<input type="checkbox"/>	<input type="checkbox"/>	Q39
5. There is no difference between men and women with regard to the age of maximum sex drive.	<input type="checkbox"/>	<input type="checkbox"/>	Q40
6. Social class is directly correlated with the frequency of incest.	<input type="checkbox"/>	<input type="checkbox"/>	Q41
7. The use of the condom is the most reliable of the various contraceptive methods.	<input type="checkbox"/>	<input type="checkbox"/>	Q42
8. The incidence of extramarital intercourse is constant for males between the ages of 21 and 60.	<input type="checkbox"/>	<input type="checkbox"/>	Q43
9. Nearly half of all unmarried women in the UK have sexual intercourse by the age of 19.	<input type="checkbox"/>	<input type="checkbox"/>	Q44
10. There are two kinds of physiological orgasmic responses in women, one clitoral and the other vaginal.	<input type="checkbox"/>	<input type="checkbox"/>	Q45
11. Impotence is almost always a psychogenic disorder	<input type="checkbox"/>	<input type="checkbox"/>	Q46
12. Transvestitism (a form of cross dressing) is usually linked to homosexual behaviour	<input type="checkbox"/>	<input type="checkbox"/>	Q47
13. There was as much premarital sexual intercourse a generation ago as there is now.	<input type="checkbox"/>	<input type="checkbox"/>	Q48

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	T	F	
14. Sexual attitudes of children are molded by erotic literature.	<input type="checkbox"/>	<input type="checkbox"/>	Q50
15. In some successful marriages sex adjustments can be very poor.	<input type="checkbox"/>	<input type="checkbox"/>	Q51
16. Homosexuals are most likely to be exceptionally creative than heterosexuals.	<input type="checkbox"/>	<input type="checkbox"/>	Q52
17. A women who has had a hysterectomy can experience orgasm during sexual intercourse.	<input type="checkbox"/>	<input type="checkbox"/>	Q53
18. Homosexuality comes from learning and conditioning experiences.	<input type="checkbox"/>	<input type="checkbox"/>	Q54
19. In responsive women, non penetrative stimulation tends to produce a more intense physiological orgasmic response than does sexual intercourse.	<input type="checkbox"/>	<input type="checkbox"/>	Q55
20. Those convicted of serious sex crimes ordinarily those who began with minor sex offenses.	<input type="checkbox"/>	<input type="checkbox"/>	Q56
21. One of the immediate results of castration in the adult male is impotence.	<input type="checkbox"/>	<input type="checkbox"/>	Q57
22. Most homosexuals cannot be distinguished by their appearance.	<input type="checkbox"/>	<input type="checkbox"/>	Q58
23. Masturbation by a married person is a sign of poor marital sex adjustment.	<input type="checkbox"/>	<input type="checkbox"/>	Q59
24. Exhibitionists are latent homosexuals .	<input type="checkbox"/>	<input type="checkbox"/>	Q60
25. A woman's chance of conceiving are greatly enhanced if she has an orgasm.	<input type="checkbox"/>	<input type="checkbox"/>	Q61
26. Only a small minority of all married couples ever experience mouth-genital sex play.	<input type="checkbox"/>	<input type="checkbox"/>	Q62
27. Impotence is the most frequent cause of sterility .	<input type="checkbox"/>	<input type="checkbox"/>	Q63
28. Certain foods render the individual much more susceptible to sexual stimulation.	<input type="checkbox"/>	<input type="checkbox"/>	Q64
29. A high percentage of those who commit sexual offences against children is made up of the children's friends and relatives.	<input type="checkbox"/>	<input type="checkbox"/>	Q65

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	T	F	
30. In teaching their daughters female sex roles, middle class mothers are more affected by cultural stereotypes than mothers in other social classes.	<input type="checkbox"/>	<input type="checkbox"/>	Q67
31. In most instances the biological sex will override the sex assigned by the child's parents.	<input type="checkbox"/>	<input type="checkbox"/>	Q68
32. The onset of secondary impotence (impotence preceded by a period of potency) is often associated with the influence of alcohol.	<input type="checkbox"/>	<input type="checkbox"/>	Q69
33. Breast feeding a baby usually protects a mother from becoming pregnant.	<input type="checkbox"/>	<input type="checkbox"/>	Q70
34. In our culture some homosexual behaviour is a normal part of growing up.	<input type="checkbox"/>	<input type="checkbox"/>	Q71
35. Direct contact between penis and clitoris is needed to produce female orgasm during intercourse.	<input type="checkbox"/>	<input type="checkbox"/>	Q72
36. For a period of time following orgasm, women are not able to respond to further sexual stimulation.	<input type="checkbox"/>	<input type="checkbox"/>	Q73
37. Habitual sexual promiscuity is the consequence of an above-average sex drive.	<input type="checkbox"/>	<input type="checkbox"/>	Q74
38. Approximately one out of three adolescent boys has a homosexual experience leading to orgasm.	<input type="checkbox"/>	<input type="checkbox"/>	Q75
39. Impotence in men over 70 is nearly universal.	<input type="checkbox"/>	<input type="checkbox"/>	Q76
40. Certain conditions of mental and emotional instability are demonstrably caused by masturbation.	<input type="checkbox"/>	<input type="checkbox"/>	Q77
41. Women who have had several sex partners before marriage are more likely than others to be unfaithful after marriage.	<input type="checkbox"/>	<input type="checkbox"/>	Q78
42. The emotionally damaging consequences of a sexual offence against a child are more often attributable to the attitudes of the adults who deal with the child than to the experience itself.	<input type="checkbox"/>	<input type="checkbox"/>	Q79

	T	F	Office Use only
43. Sexual maladjustment is the major cause of divorce.	<input type="checkbox"/>	<input type="checkbox"/>	Q80
44. Direct stimulation of the clitoris is essential to achieving orgasm in the women.	<input type="checkbox"/>	<input type="checkbox"/>	Q81
45. Age affects the sexual behaviour of men more than it does women.	<input type="checkbox"/>	<input type="checkbox"/>	Q82
46. The circumcised male has more trouble with ejaculatory control than the uncircumcised male.	<input type="checkbox"/>	<input type="checkbox"/>	Q83
47. More than a few people who are middle aged or older practice masturbation.	<input type="checkbox"/>	<input type="checkbox"/>	Q84
48. Varied sexual practices are used most often by people in lower socioeconomic classes.	<input type="checkbox"/>	<input type="checkbox"/>	Q85
49. Individuals who commit rape have an usually strong sex drive.	<input type="checkbox"/>	<input type="checkbox"/>	Q86
50. The rhythm method, (refraining from intercourse during the six to eight days midway between menstrual periods), when used properly is just as effective as the pill in preventing conception.	<input type="checkbox"/>	<input type="checkbox"/>	Q87
51. Exhibitionists are no more likely than others to commit sexual assaults.	<input type="checkbox"/>	<input type="checkbox"/>	Q88
52. The ability to conceive may be significantly delayed after the onset of menstruation.	<input type="checkbox"/>	<input type="checkbox"/>	Q89
53. Many women mistakenly consider themselves to be frigid.	<input type="checkbox"/>	<input type="checkbox"/>	Q90
54. Menopause in a woman is accompanied by a sharp and lasting reduction in sexual drive and interest.	<input type="checkbox"/>	<input type="checkbox"/>	Q91
55. The two most widely used forms of contraception around the world are the condom and withdrawal by the male (coitus interruptus).	<input type="checkbox"/>	<input type="checkbox"/>	Q92
56. People in lower socioeconomic classes have sexual intercourse more frequently than those of higher classes.	<input type="checkbox"/>	<input type="checkbox"/>	Q93
57. Pornographic materials are responsible for the majority of contemporary deviant sexual behaviour.	<input type="checkbox"/>	<input type="checkbox"/>	Q94

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- | | T | F |
|--|--------------------------|--------------------------|
| 58. For some women, the arrival of the menopause signals the beginning of a more active and satisfying sex life. | <input type="checkbox"/> | <input type="checkbox"/> |
| 59. The sex drive of the male adolescent in our culture is stronger than that of female adolescent. | <input type="checkbox"/> | <input type="checkbox"/> |
| 60. Working class couples are generally not interested in limiting the number of children they have. | <input type="checkbox"/> | <input type="checkbox"/> |
| 61. Excessive sex play in childhood and adolescence interferes with later marital adjustments. | <input type="checkbox"/> | <input type="checkbox"/> |
| 62. There is a trend toward more aggressive behaviour by women throughout the world in courtship, sexual relations and sexual intercourse. | <input type="checkbox"/> | <input type="checkbox"/> |
| 63. Sometimes a child may have cooperated in or even provoked sexual molestation by an adult. | <input type="checkbox"/> | <input type="checkbox"/> |
| 64. Seven out of ten parents desire formal sex education in schools. | <input type="checkbox"/> | <input type="checkbox"/> |
| 65. For every female that masturbates four males do . | <input type="checkbox"/> | <input type="checkbox"/> |
| 66. Douching is an effective form of contraception . | <input type="checkbox"/> | <input type="checkbox"/> |
| 67. 1st Year medical students know more about sex than other college graduates . | <input type="checkbox"/> | <input type="checkbox"/> |

Q95

Q96

Q97

Q98

Q99

Q100

Q102

Q103

Q104

Q105

B: Williams-Wilson Sexuality Survey (WWSS)

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Please indicate your reaction to each of the following statements about sexuality by ticking one of the the following alternatives:

1. Strongly agree
2. Agree
3. Slightly agree
4. Slightly disagree
5. Disagree
6. Strongly disagree

For example:

- a) Sexuality should not be discussed with adolescent cancer patients

Strongly agree Strongly disagree
☐ 1 ☐ 2 ☐ 3 ☐ 4 ☒ 5 ☐ 6

-
1. Sexuality concerns should be a routine component of nursing care for cancer patients. ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6
 2. ☒ Hospitalised patients do not have the right to lock their doors ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6
 3. ☒ It embarrasses me to see partners lying in bed with patients ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6
 4. If I were a cancer patient I would want to receive counselling in relation to sexuality ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6
 5. If I were a patient I would be comfortable receiving counselling in relation to sexuality from a nurse ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6
 6. ☒ Offering sexual counselling is not an integral part of nursing care ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6
 7. At times I have felt that my nursing care of a client was incomplete because I had not addressed sexuality as part of nursing care. ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6

Q106

Q107

Q108

Q109

Q110

Q111

Q112

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Strongly agree

Strongly disagree

- | | | |
|--|-------------|------|
| 8. ✱ Sexuality is not a major concern for my patients | 1 2 3 4 5 6 | Q113 |
| 9. ✱ I am not comfortable initiating a discussion of sexuality with my clients | 1 2 3 4 5 6 | Q114 |
| 10. I am comfortable initiating a discussion of sexuality with my clients partner | 1 2 3 4 5 6 | Q115 |
| 11. Discussion of sexual concerns contributes to a patients recovery | 1 2 3 4 5 6 | Q116 |
| 12. ✱ I feel discouraged after offering sexual counselling to my patients because it never seems to make a difference | 1 2 3 4 5 6 | Q117 |
| 13. ✱ A specialist in psychosexual problems does a better job of discussing sexual concerns with patients than I could possibly do | 1 2 3 4 5 6 | Q118 |
| 14. I am comfortable discussing sexuality if the client initiates the discussion | 1 2 3 4 5 6 | Q119 |
| 15. I am comfortable discussing sexuality if the client's partner initiates the discussion | 1 2 3 4 5 6 | Q120 |
| 16. ✱ Sexual desire is normally decreased in a chronic illness such as cancer | 1 2 3 4 5 6 | Q121 |
| 17. ✱ I have felt uncomfortable in the past when I have interrupted patients engaged in sexual activity | 1 2 3 4 5 6 | Q122 |
| 18. ✱ Sexual intercourse is in appropriate under any circumstances while a patient is hospitalised | 1 2 3 4 5 6 | Q123 |
| 19. Nursing intervention about sexual concerns increases a patients wellbeing | 1 2 3 4 5 6 | Q124 |
| 20. Sexual activity occurs whether someone is ill or well | 1 2 3 4 5 6 | Q125 |

Strongly agree

Strongly disagree

21. My attitudes to sexuality are similar to those held by most nurses ☐1 ☐2 ☐3 ☐4 ☐5 ☐6

Q26

22. If I had cancer sex would be the farthest thing from my mind ☐1 ☐2 ☐3 ☐4 ☐5 ☐6

Q127

23. Some people with cancer can have a closer sexual relationship than they did prior to diagnosis ☐1 ☐2 ☐3 ☐4 ☐5 ☐6

Q128

24. If I had cancer my sex life would be negatively affected by the disease ☐1 ☐2 ☐3 ☐4 ☐5 ☐6

Q129

25. A serious disease can enhance a sexual relationship ☐1 ☐2 ☐3 ☐4 ☐5 ☐6

Q130

26. In your routine care of breast cancer patients do you use the problem "expressing sexuality" in the Care Plan

Yes ☐ No ☐

Q131

a) If yes, how many times in the past month have you used this problem (or potential problem)?

>20 ☐

10 - 20 ☐

5 - 9 ☐

<5 ☐

Never ☐

Q132

27. In your routine care of breast cancer patients do you use the problem "alteration in body image" in the care plan?

Yes ☐ No ☐

Q134

a) If yes, how many times in the past month have you used this problem, or potential problem ?

>20 ☐

10 - 20 ☐

5 - 9 ☐

<5 ☐

Never ☐

Q135

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28. In the past six months how many breast cancer patients and their partners have you offered to discuss sexuality issues with?

- >20 ☐
10 - 20 ☐
5 - 9 ☐
< 5 ☐
Never ☐

Q136

29. How frequently do you refer individuals to a specialist when caring for breast cancer patients who have experienced difficulties in relation to expressing sexuality?

- 76 - 100% ☐
50 - 75% ☐
25 - 49% ☐
< 25% ☐
Never ☐

Q137

a) Please indicate to whom you refer most regularly

- ☐ Clinical Psychologist ☐ Medical Social worker
☐ Psychiatrist ☐ Stoma Care Nurse
☐ Community Psychiatric Nurse (CPN) ☐ Other

Q138

b) If other, please indicate who.

.....

Q139

30. Do you ever discuss alternative positions for sexual intercourse with women with breast cancer who are experiencing difficulties in expressing sexuality?

Yes ☐

No ☐

Q140

a) If not, what factor(s) impede this discussion? (*Tick as many as you wish*)

Your embarrassment ☐

Q141

Lack of knowledge ☐

Q142

Patient would be embarrassed ☐

Q143

Other (*please specify*).....

Q144

31. Do you discuss alternatives to genital sexual intercourse with your patients?

Yes ☐

No ☐

Q145

32.(i) When caring for a known lesbian or homosexual patient with breast cancer do you discuss aspects of sexuality that relate to having cancer or treatment?

Yes ☐

No ☐

Q146

(ii) I have never cared for a known lesbian or homosexual patient with cancer. (*Tick here*) ☐

Q147

a) If yes, have you continued this discussion with their partner?

Yes ☐

No ☐

Q148

b) If no, did you refer the patient or their partner to someone who would discuss this issue?

Yes ☐

No ☐

Q149

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33. How long have you been caring for individuals with cancer in general and breast cancer in particular?

	Cancer Patients	Breast Cancer Patients
> 20 years	<input type="checkbox"/>	<input type="checkbox"/>
10 - 20 years	<input type="checkbox"/>	<input type="checkbox"/>
5 - 10 years	<input type="checkbox"/>	<input type="checkbox"/>
1 - 5 years	<input type="checkbox"/>	<input type="checkbox"/>
< 1 year	<input type="checkbox"/>	<input type="checkbox"/>

Q150

Q151

Q152

Q153

Q154

C: Information

Could you please complete the following information .

1. Age (please tick)

- 21 - 30 ☐
- 31 - 40 ☐
- 41 - 50 ☐
- 51 - 60 ☐
- > 60 ☐

Q155

2. Professional Qualifications (please tick as many as apply)

- EN ☐
- RGN ☐
- RMN ☐
- RM ☐
- RSCN ☐
- Health Visitor ☐
- District Nurse ☐
- RCNT ☐
- RNT ☐

Other (please specify).....

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3. **Post- Registration Professional Education**

ENB Courses (*please specify*).....

Q157

Counselling Course(s) (*please specify*).....

Q158

Others (*please specify*).....

Q159

4. **Academic Qualifications (*please tick*):**

☐ Diploma

☐ Ph.D/D.Phil

☐ Bachelor of Arts (BA)

☐ Bachelor of Science (BSc)

☐ Master of Arts (MA)

☐ Master of Science (MSc)

☐ M. Phil

☐ None

Other (*please specify*).....

5. **Are you a member of RCN Breast Care Nursing Society?**

Q161

Yes ☐ No ☐

6. **What is your clinical grade?**

Q162

7. **What is your Job Title?**

Q163

Thank you for your co-operation.

Appendix Four

Letter of Invitation



University of HUDDERSFIELD

SCHOOL OF HUMAN & HEALTH SCIENCES

DIRECT FAX: 01484 472794

14th March 1996

Dear Colleague

Re: Research Project - Breast Cancer and Sexuality

I am currently undertaking a research project exploring the experience of breast cancer in terms of sexuality. The preliminary part of the study involves a survey of breast care nurses and I am writing asking you participate in that survey.

The "mechanics" of the survey

If you are willing to complete the questionnaire please return it in the enclosed pre-paid envelope. I would appreciate immediate return so could you complete the questionnaire straight away. If you feel unable to complete the questionnaire I would really like to know. So could you return the questionnaire indicating your reasons - a short scribble on the back would be helpful.

About the questionnaires

Enclosed is a booklet which has three parts: The Sex Knowledge and Attitude Test (SKAT), the Williams-Wilson Sexuality Survey (WWSS) and an Information section. The WWSS addresses issues to do with sexuality in your practice whereas SKAT requires a more personal response. The SKAT test does ask you to respond to items which you may feel are private but your co-operation will be most valued. I appreciate the sensitivity of the subject and wish to assure you that your participation is both **anonymous** and **confidential**. The questionnaires are not coded so it will be impossible to identify you.

Getting feedback

If you would like to know the outcome of the survey please indicate on the enclosed sheet and give a forwarding address. Similarly if you would like more information about the questionnaires indicate in the same way.

Queensgate Huddersfield West Yorkshire HD1 3DH Telephone 01484 422288 Facsimile 01484 516151

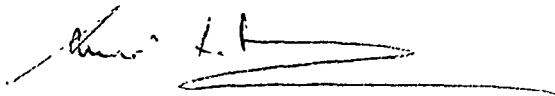
Vice-Chancellor and Principal: Professor John R Tarrant BSc PhD
An exempt charity and a centre of excellence for vocational education and research

Would you be willing to be interviewed?

Later in the project I hope to interview breast care nurses about their management of sexuality issues with clients. These interviews will be unstructured, conversational, and be arranged at your convenience. If you are willing to be interviewed, or would like to know more about what would be involved, please indicate on the enclosed sheet and return it to me in the pre-paid envelope. If you would like to talk to me my direct telephone line is (01484) 472548 or leave a message with my Secretary Judith Tolos on (01484) 472541.

I would like to thank you in advance helping me and look forward to receiving your completed questionnaire.

Best Wishes

A handwritten signature in dark ink, appearing to read 'Annie Topping', with a long horizontal flourish extending to the right.

Annie Topping
Senior Lecturer in Nursing/Health Studies

Appendix 5

Reply Sheet

**UNIVERSITY OF HUDDERSFIELD
SCHOOL OF HUMAN & HEALTH SCIENCES**

RESEARCH PROJECT: Breast Cancer & Sexuality

If you are willing to participate further or would like more information please complete this form and return in the pre-paid envelope. (*Tick as many boxes as apply*).

Please send me information on the questionnaires

☐

I would like a copy of the results of the survey

☐

I would like more information about being interviewed

☐

I am willing to be interviewed and await to hear from you

☐

Please Complete:

Name: _____

Address: _____

Post Code: _____

Telephone: _____ FAX: _____

Appendix Six

Table: Profile of Breast Care Nurse Participants

Appendix 6: Profile of Breast Care Nurse Participants

Breast Care Nurse	Years in post	Recorded Qualifications	A11 Breast Care Course	Counselling Course	Academic Qualifications	Other
1	6	RGN ¹	✓	Diploma	BSc	
2	20+	RGN	None	Diploma	MA	
3	4	RGN	✓	RSA	BSc, MSc	ENB 998 Teaching and Assessing
4	4	EN ² , RGN	✓	Diploma	BSc	
5	5.5	RGN	✓	RSA	BA	
6	8	RGN, HV ³	✓	MA	BA, MA	
7	4	RGN	✓	RSA	BSc	
8	6	RGN	✓		BSc	
9	8	RGN	✓			ENB 931 Care of the Dying
10	2	EN, RGN	✓		BSc	
11	6	RGN	✓			
12	3	RGN	✓			
13	2	RGN, DN ⁴	✓		BSc, MSc	ENB 931 Care of the Dying
14	6	RGN, HV	✓			
15	5	RGN	✓	Diploma		
16	9	RGN	✓			
17	9	RGN	✓		BSc	
18	4	RGN, DN	✓		BA	
19	12	RGN	✓	RSA	BSc	
20	7	RGN, RMN ⁵	✓			
21	5.5	RGN	✓			
22	9	RGN, HV	✓		MSc	ENB Lymphoedema Course
23	7	RGN	✓	'course' ⁶	BSc	
24	12	RGN	✓			
25	9	RGN	✓	Diploma		
26	7	RGN, RM ⁷	✓		MSc	ENB Lymphoedema Course
27	3	RGN	✓	'course'	BSc	ENB 998 Teaching and Assessing
28	12	RGN, DN	None		PG Cert	
29	7	RGN	✓	'course'	BSc, MSc	ENB Cancer Nursing Course

¹ Registered General Nurse

² Enrolled Nurse

³ Health Visitor

⁴ District Nurse

⁵ Registered Mental Nurse

⁶ Unspecified length or level

⁷ Registered Midwife

Appendix Seven

Table: Delivery of Breast Cancer – Profile of Breast Units

Appendix 7: Delivery of Breast Cancer Care – Profile of Participant's Breast Units

Breast Care Nurse	Number in Breast Care Team	Prosthetics undertaken by Breast care Nurse	Home Visits	Type of Hospital/Trust	One Stop Diagnostic Service
1	2	✓	✓	DGH	✓
2	5	Surgical Appliance Officer	Rarely if needed	Teaching Hospital	
3	2	✓	✓	DGH	
4	2.5	Ward Staff	✓	DGH	✓
5	2	✓	✓ negotiated	Teaching Hospital	✓
6	2		Occasionally	DGH	
7	1	✓	✓	DGH	
8	2	✓	✓	Teaching Hospital	✓
9	1.5	✓	Rarely	DGH	✓
10	2	✓	✓	DGH	✓
11	4	✓	✓	DGH	✓
12	5	Surgical Appliance Officer	Rarely	Teaching Hospital	✓
13	5	Surgical Appliance Officer	Rarely	Teaching Hospital	✓
14	4	✓	✓	DGH	✓
15	2	Assessment first + Surgical Appliance Officer	✓	DGH	
16	1+ 2, 0.5 WTE	✓	Occasionally	DGH	
17	1	✓	Occasionally	DGH	✓
18	5	'Problem' Patients to breast care nurse	Occasionally	Teaching Hospital	Has both OSC and delayed to next clinic
19	2.5	Ward Staff	✓	DGH	✓
20	5	Ward Staff	Occasionally	Teaching Hospital	Has both OSC and delayed to next clinic
21	2	✓	✓	DGH	
22	2	✓	✓	DGH	
23	0.8 + 0.6	✓	Occasionally	DGH	✓
24	1	✓	Occasionally	DGH	
25	1+ 2, 0.6 WTE	✓	✓	DGH	
26	3	Surgical Appliance Officer	No	Teaching Hospital	Has both OSC and delayed to next clinic
27	1	'Trained' Health Care Assistant	No	DGH	
28	2+ 0.5	✓	✓	DGH	
29	3	✓	✓	DGH	