PATTERNS OF CARE RECEIVED BY WOMEN WITH BREAST CANCER LIVING IN AFFLUENT AND DEPRIVED AREAS

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This thesis is dedicated to the memory of my father

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Abstract

Breast cancer occurs less commonly in socio-economically deprived women than in affluent women. Following diagnosis however, deprived women have poorer survival rates from breast cancer. Previous research suggests that their poorer survival is not due to the stage of the cancer at time of presentation. If poorer outcomes are not due to more advanced stage of disease at time of presentation alternative explanations are that the difference may be due to variations in treatment or host response mechanisms or environmental factors.

The research described in this thesis explores whether the known poorer survival of deprived women is related to the care they receive for breast cancer from the National Health Service. The process of care is described from presentation through referral, treatment and follow up, and comparison is made between patterns of care received by affluent and deprived women.

Patterns of care were described and compared by means of a three phase study: hospital records data collection, general practice records data collection and a postal questionnaire study. The review of case records in hospital and general practice produced data regarding diagnosis, delays, surgical and oncological treatment and follow-up in primary and secondary care. The postal questionnaire to patients provided further information on health status, current anxieties, sources of information about breast cancer, help seeking behaviour and life style changes as a result of a diagnosis with breast cancer. The process of care is investigated for women diagnosed with breast cancer in 1992 and 1993 in the most affluent and deprived areas in Greater Glasgow Health Board.

The data presented in this thesis show that women from affluent and deprived areas received similar surgical and oncological care and had the same access to services. Previous studies, which showed no relationship between stage at presentation and deprivation, are challenged by data demonstrating a greater proportion of advanced and metastatic presentations in women from deprived areas compared to women from affluent areas.

Evidence from all three phases of data collection (hospital records data collection, general practice records data collection, questionnaire study) point to women from deprived areas experiencing greater physical and psychological co-morbidity than those from affluent areas. Women from deprived areas were admitted to hospital for conditions not related to breast cancer more often than women from affluent areas. Although an increase in consultations with GPs were seen for all women, this increase was greater for deprived women. Deprived women had poorer SF-36 scores indicating greater psychological morbidity several years after diagnosis and reported greater anxiety than affluent women regarding health problems unrelated to breast cancer. Women living in deprived areas also expressed a greater degree of anxiety than women living in affluent areas about financial and family problems. These indications of greater co-morbidity may help to explain the poorer survival of deprived women with breast cancer.

This study produces evidence that the National Health Service in Glasgow delivered health care equitably to affluent and deprived women with breast cancer in 1992 and 1993. The presence of other co-existing physical and psychological morbidities in the context of greater social adversity may explain the known poorer survival of deprived women with breast cancer.

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Author's declaration

I declare the contents of this thesis to be all my own work except where acknowledged on the previous page.

The following publications have been prepared from material contained in this thesis:

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Breast cancer care: does the NHS discriminate against deprived women? [Poster] 1st European Breast Cancer Conference, Florence, Italy, September 1998.

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Breast cancer care: is socio-economic status relevant in determining care patients receive? International Society for Equity in Health inaugural meeting, Havana, Cuba, June 2000.

The information seeking behaviour and psychosocial support needs of women with breast cancer living in affluent and deprived areas [Poster] International Society for Equity in Health inaugural meeting, Havana, Cuba, June 2000.

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Definitions

The following abbreviations are used throughout this thesis:

Depcats	Deprivation categories
GGHB	Greater Glasgow Health Board
GP(s)	General practitioner(s)
ISD	Information and Statistics Division of the National Health Service in Scotland
NHS	National Health Service
SIGN	Scottish Intercollegiate Guidelines Network
UK	United Kingdom
USA / US	United States of America
WHO	World Health Organisation

Chapter 1

INTRODUCTION

1.1 Background to study

Women from socio-economically-deprived areas have been shown to have significantly poorer survival rates from breast cancer than women from affluent areas (Carnon et al. 1994; Schrijvers et al. 1995a; Schrijvers et al. 1995b). Carnon et al reported on data from the West of Scotland Cancer Registry regarding women with breast cancer and found a significant difference between the most affluent and the most deprived groups. For all women under 75 years, five year survival was 66% for the most affluent women and 55% for the most deprived women (Carnon et al. 1994). Schrijvers et al (1995a) reported on the survival of 29,674 women with breast cancer in South Thames between 1980-89. They documented a relative survival rate of 71% in the most affluent groups but 60% in the most deprived groups at five years. By ten years after diagnosis, the survival in the most affluent groups was 59% and in the deprived groups 48%. Studies from Finland (Karjalainen & Pukkala 1990), Sweden (Vagero & Persson 1987), the USA (Dayal, Power, & Chiu 1982; Bassett & Krieger 1986; Ansell et al. 1993) and Australia (Bonett, Roder, & Esterman 1984) have reported similar findings.

There are a number of reasons why such differences may occur. One possibility is that deprived women present later with breast cancer. This may be as a result of patient or system delay, or perhaps there are biological properties within the cancer resulting in more aggressive cancers having a shorter lead time to discovery. Alternatively, poorer outcomes for socio-economically deprived women may be due to different standards of health care received by these groups. Other explanations for these differences may be found in the interaction of other host factors such as genetic, physical, psychological or social problems.

Carnon's study, carried out in Glasgow set out to explore whether there was a relationship between stage of cancer at presentation and deprivation status (Carnon et al. 1994). They found no relationship between socio-economic deprivation and the pathological prognostic factors of tumour size, axillary lymph node status, histological grade and oestrogen receptor concentration. These findings suggested that poorer survival in deprived groups could not be explained by lateness in presentation. If lateness in presentation is excluded as a possible reason for the demonstrated poorer outcome of deprived women, then it follows from the above arguments that the explanations must be either related to host factors or to the care which women with breast cancer receive.

The purpose of the study described in this thesis was to build on the previous research carried out in the west of Scotland by Carnon et al (1994) and explore the relationship between socio-economic status of women with breast cancer and the care they received for breast cancer. The research was designed to address the question of whether affluent women with breast cancer have better outcomes from breast cancer because they receive superior care.

The first step in designing a study to answer this question was to define what was meant by "care." The diagnosis and management of breast cancer is a specialist task based in hospital. It is however to general practitioners (GPs) that women with breast cancer most usually present in the first instance with a concern about a breast problem. Any attempt to define and measure "care" must start at this point of initial presentation, and include a description of the referral process, treatment received in hospital and follow up arrangements. The process of care is not limited to the physical treatment of the cancer, but should also include psycho-social support, whether provided by health care professionals, the voluntary sector or family and friends.

Differences in management could include differences in the nature and extent of surgery, radiotherapy and drug treatment, and/or differences in the organisation and effectiveness of care. For example, the better survival of patients in placebo groups in cancer treatment trials compared to non-participants in such trials may be explained by the beneficial effect of receiving care according to a strict protocol (Karjalainen & Palva 1989). Similarly, the 20% reduction in cancer mortality in the US Hypertension Detection and Follow Up Programme Trial may be explained by the design of the trial, in which patients were randomised to treatment regimes comprising either comprehensive health care free at the time of use or referral to "usual medical care" (Hypertension detection and Follow-up Programme Co-operative Group 2979).

In view of their knowledge of patients and families, and their opportunities for regular contact, general practitioners have a potentially important role in providing continuity of care and review after the initial episode, particularly in relation to psychosocial support. However, little is known about the current balance between secondary and primary care services in the provision of such care.

Recent studies in the UK show considerable variation between clinicians in their views and practice concerning the management of women with breast cancer (Robinson, Forrest, & Stewart 1994; Chouillet, Bell, & Hiscox 1994). A study in the West of Scotland has shown that specialist surgical care confers considerable benefit on survival at 5 and 10 years (Gillis & Hole 1996). It is not known to what extent such variations are associated with patients' socio-economic status. There is also an ongoing debate about the appropriate duration, frequency and setting of follow-up arrangements required to detect recurrence (Dewar 1995).

Differences in host response may include biological and psychosocial factors, and these may be inter-related. The stresses associated with a diagnosis of breast cancer and its subsequent treatment are considerable (Maguire 1994; Fallowfield et al. 1990; Slevin 1992). Qualitative research suggests that women may suffer distress in areas of management which doctors do not suspect are important (Jones & Greenwood 1994). Women also vary in their coping responses. Some studies suggest that professional or lay support mechanisms improve survival, by improving psychosocial function (Spiegel et al. 1989). Self-help groups have been established to provide such understanding and support (Brown & Griffiths 1986).

The natural process of responding to the experiences of breast cancer may be more difficult in areas of socio-economic deprivation, because of the many other personal, social and economic problems with which families living in these areas have to cope. In population surveys carried out for the WHO MONICA Project in North Glasgow, the proportion of women aged 55-64 years with depression scores above the population mean ranges from 20.8% living in deprivation categories 1-3 (least deprived) to 54.3% in deprivation category 6 and 56.8% in deprivation category 7 (Morrison, C. Personal communication, 1994).

Another feature of primary care in areas of socio-economic deprivation is high general practitioner consultation rates, which results in shorter average consultation times, and less time within each consultation to address patients' multiple problems. It could be hypothesised that a version of the inverse care law (Tudor Hart 1971) applies to the care of women with breast cancer in areas of socio-economic deprivation, namely that women who need longer consultations for psychosocial support are less likely to receive them. The literature is conflicting on whether severe life events and social difficulties affect survival from breast cancer (Barraclough et al. 1992; Ramirez et al. 1989). However the issue had not previously been studied in an area such as Glasgow which contains 85% of postcode sectors in Scotland in the worst category of socio-economic deprivation.

In order to assess the contribution of differences in medical care to differences in survival this study compared the pattern of medical care in women from affluent and deprived areas. Care received by hospital specialists and GPs was assessed by means of data collections from hospital and general practice records. In order to assess the need for and provision of psychosocial support, women were surveyed directly and described their use and views of services for this aspect of care. The study is descriptive and analytical, in order to provide a sound basis for understanding the process of care.

This chapter introduces and describes the basis for the study. Having outlined the background to the study in this section, the relationship of deprivation and health care are discussed in section 1.2, followed by a discussion of the literature regarding socio-economic deprivation and breast cancer (section 1.3). Section 1.4 summarises current views and practice regarding the optimal care of women with breast cancer in order to place the care described in this work into the context of best practice, and the chapter ends with a discussion of the aims and objectives of the study (section 1.5).

1.2 Deprivation and health care

Introduction

Inequalities in health and in health care provision are not new concepts. The Inverse Care Law, identified by Dr Julian Tudor Hart in 1971 said:

> *"...the availability of good medical care tends to vary inversely with the need for it in the population served" (Tudor Hart 1971).*

Ten years later the Black report (1980) demonstrated large differentials in mortality and morbidity which favoured the higher social classes and were not being addressed by health care provision. Work a further 10 years on confirmed that the social class differences in mortality had widened (Davey Smith, Bartley, & Blane 1990; McCarron, Smith, & Womersley 1994). *The Independent Inquiry into Inequalities in Health* report by (Acheson 1998) in commenting on the preceding twenty years said:

> *"...the gap between those at the top and bottom of the social scale has widened."*

Even more recently, the authors of *The Widening Gap*, (Shaw et al. 1999) claimed:

> *"...at the end of the 20th century inequalities in health are extremely wide and are still widening in Britain".*

Deprivation and health in Glasgow

These inequalities in health outcomes are seen throughout the UK, but are particularly true of Greater Glasgow. Between 1981 and 1989 Glasgow, containing 80% of the most deprived postcode sectors in Scotland, showed a worsening mortality relative to the rest of Scotland (Forwell, 1993). Not only are parts of Glasgow the most deprived in the UK, but the differences between the most affluent and the most deprived are steepest. Shaw et al. (1999) in *The*

Widening Gap demonstrated these differences by using Standard Mortality rates (SMRs) which express death rates, adjusted for sex and age, in relation to a national average of 100 for the country as a whole. SMRs in 1991 – 1999 for the deprived areas of Glasgow Shettleston, Springburn and Maryhill (parliamentary constituencies) were 234, 217 and 196 respectively, while those for the affluent Strathkelvin and Bearsden (one constituency) and Eastwood were 99 and 86 respectively.

Role of the NHS in health inequalities

The existence of such clear inequalities in health outcomes raises the issue of the role of the health service in tackling inequalities. Equity of access to health care by need has been a fundamental principle of the NHS since it was established (Benzeval, Judge, & Whitehead 1995). Townsend & Davidson (2000) asserted:

> *"...any inequality in the availability and use of health services in relation to need is in itself socially unjust and requires alleviation."*

For health professionals concerned about equity of care for all, there are three relevant related questions. Firstly, is there equitable access to health care services across the social spectrum? Secondly, do people from different socio-economic groups receive the same treatment from the health service? And, thirdly, is there evidence that the delivery of optimum care can influence the known adverse outcomes for deprived communities?

Although the NHS is free at the point of need, researchers have found evidence that socially deprived communities do not have equal access to health care. Some studies have found lower uptake of immunisation in areas of high deprivation (Marsh & Channing 1987; Bennett & Smith 1992). Cartwright (1970) found less use of antenatal care, family planning clinics and birth control advice from GPs in women from manual social classes. Kogevinas et al. (1991) in an analysis of the *Longitudinal Study* found lower survival rates for cancers in which a good prognosis would normally be expected among people living in council housing. They postulate that delay in seeking treatment was the main factor contributing to this difference although they also raised the possibilities of differential treatment, host resistance and other factors. However, on the other hand, in a study which highlights the complexities of access issues and material deprivation, Bernard & Smith (1998) found higher emergency admission rates among older people living in deprived areas showing that access of this type is not biased in favour of affluent groups. It may be that these emergency admissions are related to morbidity or to lack of social support and care.

There are few studies that have shown that people living in socio-economically disadvantaged circumstances have received poorer treatment from the health service. Majeed et al. (1994) showed poorer access to services managing ischaemic heart disease. Kee et al. (1993) found no such relationship for access to coronary catheterisation. Ben-Shlomo & Chaturvedi (1994) found that the relationships between deprivation and surgical intervention were mixed although patients from more deprived areas consulted their GPs more. As the association was inconsistent (positive relationship for varicose veins, negative relationship for hip operations, no association for gallstones or hernia operations) it is likely that there were explanations other than socio-economic status to explain the differences.

If the NHS is to be concerned with equity in delivery of care, then it follows that more studies are needed to establish the relationship between equity and care. This thesis sets out such a study.

The third question posed above in relation to the equitable provision of health care was whether there was a known relationship between the delivery of optimum care and improved health outcomes for deprived communities. But it this a relevant question? If, as a matter of principle, we take the view that it is "socially unjust" (Townsend & Davidson 2000) to fail to deliver equitable health services, then it can be argued that proving that there is equitable delivery of care is of importance for the NHS. However, it is important to document the effect of the optimum delivery of health care in order to produce a greater understanding of the contribution of health care provision to tackling inequalities in health.

Although this thesis sets out to explore the potential role of the NHS in contributing to inequalities for women with breast cancer, the author is not advocating a view that the role of the NHS in health care is fundamental to the reasons for inequalities in outcomes being observed. Rather inequalities in health outcomes result from complex socio-economic parameters including employment, income, housing and environment. However the NHS has a role in ensuring that it does not add to these inequalities by discriminating in favour of people from more affluent socio-economic groups or by failing to adequately provide for the needs of those who are socio-economically-deprived. The evidences of adverse results of socio-economic inequalities in terms of poorer health outcomes are seen most clearly within the NHS. (Haines & Smith 2000)in the British Medical Journal's first editorial of 2000, said,

> *"...health professionals should be concerned about growing inequalities in health and wealth."*

They argue that as

> *"...health indicators provide a measure of the multidimensional nature of poverty"*

health should be the main indicator of the success or failure of policies to eliminate poverty. The complexity of these issues is perhaps most particularly seen in primary care where the meeting and interaction of physical, psychological and social needs is frequently apparent (Watt 1996).

Summary

The link between deprivation and health inequalities is clear. However the ways in which the NHS impacts on these inequalities is less clear. The study discussed in this thesis uses breast cancer as an example to describe and analyse the package of care received after diagnosis to explore whether NHS care is weighted in favour of affluent women. Access to care and treatment received are explored. Data on these aspects of care are then strengthened by information on psychosocial needs and support. The next section (1.3) will therefore discuss the relationship between deprivation and breast cancer.

1.3 Deprivation and breast cancer

Introduction

The role of the NHS in socio-economic deprivation has been discussed in the previous section. To put this current study into context an analysis of relevant data concerning breast cancer and socio-economic status will be presented in this section. Breast cancer incidence, outcome data from Europe and the USA and studies on psychosocial issues will be discussed, followed by a summary of the implications of these for research.

Breast cancer incidence

Several publications have shown affluent women to have a higher incidence of breast cancer than deprived women (Tomatis 1990; Leon 1988; Rimpela & Pukkala 1987). More recently, the Health Statistics Quarterly (Harding et al. 1999) presented socio-economic differentials in the incidence of breast cancer in England and Wales for 1976 – 90. The data presented suggested that the pattern of breast cancer incidence changed. In older women (65 years and older) the incidence continued to be higher in affluent women. However in women under 65 years, incidence rates in owner occupied and rented housing showed little difference. This was due to a larger rise in incidence among those in rented housing.

Scottish data have been published by the Scottish Cancer Intelligence unit at the Information and Statistics Division (ISD) of the NHS in Scotland (1998). These statistics relate to the years 1986 – 1995. The data presented shows a higher incidence of breast cancer in more affluent groups (deprivation measured by area based measures).

Various explanations have been offered as to why a higher incidence of breast cancer is seen in affluent women (Dixon, 1995). These include nulliparity, late age at first birth and late age at menopause. However the reason(s) for the differences remain unclear.

It would appear that the known higher incidence of breast cancer in affluent women applies to the Scottish population. Scotland appears midway in the international league table of breast cancer incidence (McLaren & Bain. 1998 p92). The age standardised incidence rates per 1000,000 person years at risk are 90.7 for the USA white population, 72.7 for Scottish women, 39.5 for Singapore Chinese women and 24.3 for Japanese women.

European outcome data

The Health Statistics Quarterly reporting English and Welsh data showed poorer survival for women aged under 65 from lower socio-economic groups over a period of 20 years follow up (Harding et al. 1999). Median survival time was 10 years among those in rented housing compared with 14 years for those in owner occupied housing.

Outcome data from ISD, Scotland for 1986 – 1995 show a survival rate of 68.6% in the most affluent group (area based) and 58.8% in the most deprived group (McLaren & Bain 1998). Reference has already been made to work by Andrew Carnon et al in Glasgow (page 15). They studied the relationship between socio-economic deprivation and pathological prognostic factors in women with breast cancer (Carnon et al. 1994). Their work showed that difference in survival was not related to the stage of disease at the time of presentation. Schrijvers and colleagues studying women with breast cancer in South Thames have subsequently confirmed this finding (Schrijvers et al. 1995a).

Schrijvers et al. (1995a), also reported the association between deprivation and the following cancers: lung, breast, colorectal, bladder, prostate, stomach, pancreas, ovary, uterus and cervix. This study was based on 155,682 patients diagnosed between 1980 and 1989 in the area covered by the South Thames Regional Health Authority. The data showed that patients from affluent areas had improved survival compared to patients from deprived areas for cancers of the lung, breast, colorectum, bladder, prostate, uterus and cervix. Stage of disease at time of diagnosis did not explain the survival differences by deprivation category (Carstairs index). For these cancer sites, the differences in survival imply a large potential reduction in cancer mortality among the lower socio-economic groups.

Italian data (Faggiano, Zanetti, & Costa 1994) has shown similar trends. One of the markers of socio-economic status in this group was educational status. Men with the lowest educational level showed an increased rate of lung and stomach cancers, but a decreased rate of skin, colorectal and prostate cancer. Women with a primary school education were protected against colorectal, skin and breast cancer, compared with university degree women, but were at risk of cancer of the cervix and stomach cancer. Trends of this kind had previously been reported also from Italy (La Vecchia, Negri, & Franceschi 1992).

Vagero & Persson (1987) studied the relationship of cancer survival (as opposed to mortality) to social class in Sweden. The study included 98 000 cases in the Swedish cancer registry. Social status was determined by occupational status: white collar workers, blue collar workers and self employed farmers. The data showed a clear survival advantage for white collar workers for cancers of the colon, rectum, kidney, ovary, cervix, uterus, breast. Smaller survival advantages were seen in white collar workers with cancers of the prostate, testis and bladder. No differences were detected in the cancers where survival is generally poor i.e. lung, pancreas and stomach.

The Finnish Cancer Registry (Auvinen, Karjalainen, & Pukkala 1995) carried out a similar review of social class and cancer. Survival from cancer was poorer among cancer patients from lower social classes in six cancers among men (stomach, rectum, prostate, kidney, bladder and non-Hodgkin's lymphoma, and in nine cancers in women (stomach, colon, rectum, breast, uterine cervix and corpus, ovary, brain and non-Hodgkin's lymphoma). Finnish data (Karjalainen & Pukkala 1990) has shown that those in the lowest social class had about 1.3 times higher relative excess risk of dying than those in the highest social class form breast cancer.

US outcome data

A great deal of research has been carried out in the USA concerning deprivation and breast cancer. There are difficulties in interpreting this work in terms of its relevance for the UK due both to the different system for the delivery of health care and due to the predominance in the US literature of the subject of ethnicity. Ethnicity is of relevance for some parts of the UK but is less so for Glasgow. However, there are lessons to be learned from the US literature, a summary of which will be presented here.

Breen, Kessler, and Brown, (1996) reviewed papers on 'underservice' and breast cancer. They explored the issue of race, socio-economic status and breast cancer survival. They concluded that although race is highlighted in many of these studies it only appears to be significant as there are much higher rates of poverty in non-white households in the US. Women with less education or lower incomes were less likely to be screened, to present early, to get standard treatment or to survive 5 years. The reasons for these differences in a divided health care economy like the US may be different from reasons in the UK.

Other US researchers agree that deprivation is more relevant than ethnicity in contributing to poor outcomes for women with breast cancer. Linden (1969) demonstrated that breast cancer patients in public hospitals had poorer survival rates than women treated in private hospitals, and argued that the type of hospital in California at that time could be taken as a proxy for social status. Berg, Ross, and Latourette (1977) suggested that economic differences could explain most of the survival differences between blacks and whites in Iowa. Dayal, Power, and Chiu (1982), showed a higher probability of survival in white women with breast cancer compared with black women which was not affected by adjustment for either age or stage at presentation. However, the relationship between race and socio-economic status were so strongly associated that racial differences became insignificant when they were adjusted for by socio-economic status. Bassett and Krieger (1986), who studied 1506 women in Washington state agreed and concluded that poorer social class was a determinant of poorer survival.

The study of cancer survival and patterns of care in the US has been taking place for some time. Lipworth, Bennett, and Parker (1972), studied the survival of cancer patients in Boston between 1960 – 62 and compared the 10 month survival of the private patients with the non-private patients. At 10 months after diagnosis, 89% of the private patients were alive, compared to 73% of the non-private patients. Ayanian et al. (1993) compared stage at presentation and outcomes for insured and uninsured women with breast cancer in New Jersey. They found that uninsured women and those covered by Medicaid presented with more advanced disease than did the privately insured patients. They suggest that this was due to lack of access to screening and optimal therapy. Similarly, Roetzheim et al. (1999) found patients who were uninsured or insured by Medicaid were more likely to be diagnosed with late stage breast cancer (data from 28 237 patients in Florida in 1994).

Others have been concerned with different tumour biology occurring in different socio-economic groups. Gordon looked at the association of social class and the oestrogen receptor status of breast cancer in Cleveland Ohio (Gordon 1995). A positive association between lower social classes and the incidence of oestrogen negative breast cancer was found. As oestrogen negative breast cancer is known to carry a poorer prognosis, it was thought that this might partially explain the poorer prognosis that is seen in women from deprived backgrounds. In addition she observed that the previously known associations of social deprivation with a higher intake of fat, a lower intake of carbohydrates, and a greater weight in childhood and in adult women. A diet high in fat has been implicated in increased levels of oestrogens. These findings led to the speculation that increased amounts of endogenous oestrogens may contribute to the incidence of oestrogen receptor negative tumours. Weiss et al. (1995) studied the biological molecular indices in breast cancers of women from several ethnic backgrounds and found no differences. Their findings suggest that the higher mortality form African Americans is related to more advanced stage, not to biologically more aggressive tumours. Their study does not support the theory that different groups of women have cancers with differing degrees of aggressiveness.

Moormeier, carried out a literature review of aspects of breast cancer in relation to black women. She concluded that the discrepancy in survival between black and white women exists because black women present with more advanced tumours which have different tumour biology and have confounding co-morbid conditions (Moormeier 1996). This is of particular interest, especially as there is so little UK work on co-morbidity and breast cancer. Confounding co-morbid conditions cited include diabetes, hypertension, heart disease, lung disease and kidney disease.

Studies have also been carried out regarding the treatment with socio-economically disadvantaged women received and have produced different results. Ayanian and Guadagnoli (1996), reviewed the US literature on variations in treatment for breast cancer. They conclude that women without medical insurance are less likely to receive treatment which conforms with national guidelines. Other groups are also less likely to get optimum treatment are older women, black women, those treated in non-teaching hospitals or smaller hospitals. Lazovich et al (1991), studied treatment of patients with breast cancer and found that breast conserving surgery was more likely to be performed among women from the most affluent communities.

However, not all researchers have observed these differences. Muss et al. (1992) studied racial differences in treatment for breast cancer. The study was designed to compare the black and white communities similarly to the comparison of women living in affluent and deprived areas in the study described in this thesis. They found no difference in treatment between the groups which would account for the survival advantage of 10% found in the white population. They also considered co-morbidity, and present data for co-existing hypertension and diabetes. They found a higher frequency of co-morbid conditions, especially hypertension in the black community. They also found that women with education beyond high school were twice as likely as less educated women to receive breast-conserving surgery, although this was also related to tumour size. Velenbovich et al. (1999) studied treatment patterns in 1250 patients in Detroit in an attempt to explain the known poorer outcomes for African American women which is a theme of the literature from the US. They found no differences in the surgical management of these women even after taking account of socio-economic indicators. Weiss et al. (1996) carried out detailed analysis on black and white women presenting with breast cancer and found that survival differences were only marginally significant in favour of white women when they examined other factors contributing to decreased survival (including stage, SES and treatment). This emphasises how complex these issues are and how difficult researchers in the USA have found it to get to the truth regarding breast cancer survival, race and deprivation. Although the issue of race does not apply to the study described here, the issues of deprivation and breast cancer experience remain complex.

Psychosocial issues

Several studies have shown a link between socio-economic status and broader psychosocial issues. Dean (1987), in a study of psychiatric morbidity following mastectomy for primary operable breast cancer found that social class had an effect, independent from other variables on psychiatric outcome at 12 months after mastectomy. Women in lower social classes had the worst outcome.

McEvoy and McCorkle (1990) studied quality of life in patients with disseminated breast cancer in Philadelphia. They quote research showing that most patients who present with advanced breast cancer are from lower socio-economic groups. They conclude that more attention ought to be given to patients who are economically disadvantaged and that these women may be particularly receptive to interventions which will enhance their quality of life. Downer et al. (1994), in a study in London of the use of complementary therapies by cancer patients, showed that the users of these therapies in Britain tend to be younger, of higher social class and female. These studies serve to illustrate the complexity of psychological and social issues.

Summary

In the study of the relationship between deprivation and breast cancer, a paradox emerges. Affluent women are more likely to be diagnosed with breast cancer, but following diagnosis, deprived women are less likely to survive. The reasons for this paradox remain unclear.

Breast cancer researchers have researched the relationship of many aspects of breast cancer to survival, and have found an association between outcome and stage at presentation, type of surgery carried out and adjuvant treatment (Early Breast Cancer Trialists' Collaborative Group 1992a). The purpose of this study is to identify the relevance of deprivation to breast cancer outcomes. Evidence has been presented from the UK that has shown no link between socio-economic status and stage of cancer at presentation (Schrijvers et al. 1995a; Carnon et al. 1994). There is a need to build on this work and investigate whether the poorer outcomes experienced by deprived women can be explained in terms of the care they receive. This thesis sets out such a study. The study presented here is the first UK study to explore differences in treatment for women with breast cancer from different socio-economic groups.

1.4 Optimal care of breast cancer

Introduction

Breast cancer is a disease in which diagnosis and treatment takes place in hospital. However patients usually present in primary care with their first concern about a breast problem. Little is known about the balance of care between primary and secondary care. Most of the literature to date has concentrated on the acceptability of follow up (Grunfeld et al. 1995b; Dewar 1995). In this section a summary of the current evidence and consensus on optimal care of breast cancer will be presented.

Over the past decade, several groups with an interest in breast cancer have published guidelines on optimal care for patients with breast cancer (British Association of Surgical Oncology 1995; British Breast Group 1994; Scottish Intercollegiate Guidelines Network 1998). Although this thesis is a comparison of care received by women with breast cancer in different socio-economic groups, nevertheless in order to set the discussion about comparisons of such care in context, it seemed important to summarise the consensus (much of which is evidenced based) on managing breast cancer. This section is mainly based on the recommendations contained in the SIGN (1998) document, which is more comprehensive than either of the other documents. It was developed in Scotland during the period this research was carried out, but based on evidence and best practice taking place in Scotland over the years prior to publication in 1998. The recommendations for primary invasive breast cancer are discussed, as these are relevant to this piece of work.

Referral

The importance of appropriate and prompt referral by the GP to a breast specialist is recognised. The National Health Service Breast Screening Programme (NHSBSP) and Cancer Research Campaign published guidelines for appropriate referral (Austoker et al. 1995) which were disseminated to all

GPs in the UK. These advocate referral to a specialist in the following situations:

- breast lumps (if new and discrete, in pre-existing nodularity, asymmetrical nodularity which persists, abscess not settling after one course of antibiotics, persistently refilling or recurrent cysts).
- breast pain (if associated with a lump, intractable pain, unilateral persistent pain in post menopausal women).
- nipple discharge (all women aged 50 and over, women under 50 with bloodstained discharge, bilateral discharge sufficient to stain clothes or persistent single duct discharge).
- any nipple retraction or distortion, nipple eczema.
- any changes in skin contour.

Conditions that can be managed initially in general practice are:

- Younger women (under 35 years) with tender, lumpy breasts and older women with symmetrical nodularity, provided there is no localised abnormality.
- Women with minor and moderate degrees of breast pain who do not have a palpable lesion.
- Women under 50 years with nipple discharge from more than one duct, or intermittent discharge which is not bloodstained or troublesome.

In addition, GPs and primary health care teams have a role in encouraging attendance at NHS Breast Screening Programme for women aged 50 – 64 years, promoting the early detection of breast cancer and co-ordinating the care of women with breast cancer.

Diagnosis

Evidence has been accumulating that patients with breast cancer managed in a breast unit or centre have a better outcome than women managed by general surgeons (Sainsbury et al. 1995a; Sainsbury et al 1995b; Gillis & Hole1996), therefore it is now recommended that women with suspected breast cancer are referred to a breast specialist. The initial assessment of these women should consist of triple assessment at breast clinic i.e. clinical examination, mammography and fine needle aspiration cytology or core biopsy.

Delay in being seen at a breast unit is associated with marked anxiety although it seems from current evidence that delays in onset of treatment of less than three months are unlikely to affect survival rates (Richards et al. 1994). However current Scottish standards as set by SIGN (Scottish Intercollegiate Guidelines Network 1998) recommend that:

- ☐ More than 80% of urgent referrals are seen within five working days after receipt
- ☐ The remainder are seen within 10 working days
- ☐ 70% of all new referrals are seen within 20 working days

Surgical treatment

The principle aims in managing operable breast cancer are local control of disease in the breast and regional lymph nodes and prevention of recurrence. Following the diagnosis of breast cancer, the decision regarding conservation surgery or mastectomy depends on patient's preference, ratio of tumour to size of breast, pathological features of the tumour, age of patient and fitness for surgery or radiotherapy. It is also recommended that patients with invasive operable breast cancer should have at least axillary sampling although a complete axillary clearance should be considered for tumours greater than two cms.

Adjuvant therapy

After local excision radiotherapy should normally be given to the breast and after mastectomy, radiotherapy should only be given to the chest wall if the patient is at high risk of local recurrence. However, all women with invasive breast cancer should be considered for adjuvant systemic therapy, either Tamoxifen, chemotherapy or ovarian ablation depending on menopausal status and risk status. In order to ensure appropriate developments in breast cancer treatment, patients should be entered into clinical trials where possible (Twelves et al. 1998b).

Communication

Recent guidelines have highlighted the importance of communication between health professionals and patients, within the multi-disciplinary team and between primary and secondary care (Scottish Intercollegiate Guidelines Network 1998). In particular, patients should be given full information about treatment options and should be involved in decision making. Prior to treatment, a multi-disciplinary team should discuss care and there should be good communication between primary and secondary care so that the GP is aware of information given to patients and relatives.

Psycho-social care

All women should have access to a breast care nurse and patients should be given appropriate information to meet their needs, including information about local support groups and voluntary agencies. Professionals should have a high level of awareness of psychiatric and psychological problems at all stages of the disease and refer as appropriate.

Follow up

The majority of patients with breast cancer have historically attended hospital for specialist follow up. The purpose of specialist follow up has been to detect local or current relapse and monitor for the complications of treatment. Little is known about the nature of the contact GPs have with women after a diagnosis of cancer. Some recent studies have explored a more primary care centred system of follow up (Grunfeld et al. 1995b; Grunfeld et al. 1999). These studies report that primary care follow up was possible and acceptable to patients and GPs. A questionnaire was sent to all 1716 GPs in the west of Scotland by the author (Macleod et al. 1998) prior to the study reported in this thesis asking for views on breast cancer care. There was a response rate of 68%. Follow up of women after treatment for breast cancer was thought to be the responsibility of both GPs and hospital doctors: 641 (54.8%) said this was a shared responsibility, 302 (25.8%) felt that this was mainly the responsibility of hospital doctors with some GP input. Current consensus among breast cancer specialists and among GPs based on the questionnaire study points to the continuation of regular hospital follow up for most women for the first few years after diagnosis (Scottish Intercollegiate Guidelines Network 1998).

Summary

Although these guidelines were formalised after the years this study covers, nevertheless they are an appropriate benchmark of care. This thesis is concerned with comparing the care received by women with breast cancer from affluent and deprived areas rather than being a critique of breast cancer treatment in Glasgow. However it is helpful to carry out these comparisons in the light of best practice.

1.5 Aims of research and hypothesis of thesis

The review in this chapter has demonstrated an extensive literature describing inequalities in health. There appears to be a paradox with respect to women with breast cancer: greater incidence in affluent women, but poorer survival rates in deprived women. In addition, Scottish work has shown that this poorer survival is not related to stage at presentation (Carnon et al. 1994). It was in this context that the research described in this thesis sought to take these issues further. If the stage of disease at time of presentation does not account for poorer survival, it follows that this poorer survival must be related to host factors and / or treatment issues. Host factors would include genetic predisposition and environmental issues such as diet. Alternatively, the poorer outcome noted in deprived women may be due to receiving less than optimal health care. Such a proposition would be in keeping with the Inverse Care Law (Tudor Hart 1971).

Our hypothesis therefore is:

Deprived women have poorer survival rates from breast cancer than affluent women because affluent women receive better care from the NHS.

In other words, do women from affluent and deprived areas receive different patterns of care for breast cancer?

In this investigation of 'patterns of care', a study was made of the whole package of care a woman received from the time she presented to her General Practitioner (GP) with breast symptoms, most often concern about a breast lump, or alternatively received an invitation to attend for breast screening. This package of care may include examination and explanation by the GP, referral by the GP, attendance at surgical outpatients, investigations, explanation, admission for surgery, adjuvant treatment, follow up and psycho-social support. The study therefore explored the balance of care between secondary, primary, voluntary and self-help sectors.

Chapter 2 gives an overview of the methodology used in carrying out this study.

Chapter 2

METHODS – A GENERAL OVERVIEW

2.1 Introduction

This chapter gives an overview of the methods used in the study. Following chapters (chapters 4 – 6) describe in detail the methods used in each stage of the study.

The purpose of this study was to compare and contrast the care which women who lived in affluent and deprived areas received after a diagnosis of cancer. In order to document the care which women received, three separate, but linked studies were carried out. In order to understand the total care received, information was obtained on access to care, delays in the process of care, actual treatment received, and contact with primary and secondary care. This was done by collecting data from hospital records, from general practice records and by sending a postal questionnaire to the study population. This chapter introduces the study population and then outlines the three studies in the order in which they were carried out.

2.2 Study design

Study population

Women who were diagnosed as having breast cancer in 1992 and 1993, living in the Greater Glasgow Health Board area were identified from the West of Scotland Cancer Surveillance Unit's Registry. The study population included sub-groups of women who lived in the most affluent postcode and most deprived postcode sectors (Chapter 3).

In order to assess the contribution of medical care to differences in outcome from breast cancer, case records were examined from both primary and secondary care. In order to assess the need for and provision of psychosocial support, women were then surveyed directly by means of a postal questionnaire and asked about aspects of their care and their use and views of services. The study is both descriptive and analytical, to provide an understanding of both the range of issues and the relationships between them.

Hospital record data collection

The nature and extent of medical care within secondary care was ascertained by case note review of hospital records (Chapter 4). This care was documented by recording the clinical stage and pathological features of the cancer at presentation, the type of treatments received and details regarding delays. Data about the primary / secondary care interface and follow up were also collected.

General practitioner record data collection

The nature and extent of medical care within general practice was ascertained by a case note review of GP records (Table 5.1). Information collected in this review included details regarding delays in diagnosis, consultation patterns, before and after diagnosis, content of consultations and communications from secondary care.

Questionnaire study

Women's current health status and their knowledge and experience of services, including self help groups and voluntary services, were ascertained by a postal survey (Chapter 6). The SF-36 questionnaire was used to measure psychological well-being and was followed by questions which related to information sources, help seeking behaviour, anxiety provoking issues and lifestyle.

2.3 Ethical considerations

Ethical approval for the study was obtained from the Greater Glasgow Health Board Local Community and Primary Care Research Ethics Committee. In the cases of Hospital Trusts allied to the University this was sufficient, but applications were submitted to the Medical Directors of the other Trusts, all of which met with success.

Many previous health service research studies have used cancer registries as sampling frames to carry out research on breast cancer presentation and care. This has also taken place in Glasgow (Carnon et al. 1994; Gillis & Hole 1996). In order to ensure that no women were contacted in the questionnaire stage who were inappropriate, either due to current physical or mental health status or to unrelated problems, the GPs of all the women were contacted on at least two occasions before contact was made with the participants. The questionnaire only referred to "breast problem" not "breast cancer" in order to ensure that if any woman was unaware that she had cancer, she did not learn from the study.

2.4 Statistical considerations

The main purpose of the analyses of quantitative data from hospital records, GP records and the questionnaire phases of this study was to compare events and outcome measures for affluent and deprived women. The null hypothesis was that there was no difference in the care that these two groups received from the NHS. The following statistical tests were used in the analysis of these data sets:

1. Chi squared test

The chi squared test is used to analyse categorical data. It compares proportions relating to different unmatched groups of subjects, for example to compare the proportions of women who received radiotherapy living in affluent and deprived areas. The data are arranged in a frequency table, and the observed frequencies are compared with the expected frequencies calculated from the distribution of the variables in the whole sample. The further the observed values are from the expected values, the less likely it is that the null hypothesis is true.

The Fisher's exact test is used for analysis of two-by-two tables where one cell has an expected frequency of less than five.

2. t-test

The t-test is used to compare normally distributed continuous data for two independent samples. It compares the difference between the sample means with the standard error of that difference.

3. Mann-Whitney test

This is the non-parametric alternative to the t-test for comparing data from two independent samples which are not normally distributed. The Mann-Whitney test ranks all observations, then calculates the sums of the ranks of the two groups. The test is a test of significance.

4. Paired t-test

This calculates the average differences between normally distributed continuous observations for pairs of subjects. The mean difference between the pairs is then compared with the standard error of that difference.

2.5 Summary

The data collated from these separate phases of the study allow a comparison of the patterns of care which women from affluent and deprived areas received for breast cancer. This thesis presents the three different studies carried out separately (chapters 4- 6). A description and discussion of the study population (chapter 3) precede this. A general discussion (chapter 7) links issues which cross these three studies and summarises the main findings.

Chapter 3

STUDY POPULATION

3.1 Introduction

The first step in studying the patterns of care for women with breast cancer in affluent and deprived areas was to select a study population. This chapter describes the process of selecting the study population and discusses the reasons behind that process and the difficulties encountered.

The general characteristics of the population are also described and discussed.

3.2 Sample selection

Target population

The target population consisted of all women resident in the Greater Glasgow Health Board (GGHB) area in whom a diagnosis of breast cancer was made in 1992 and 1993. There were 447 new cases of breast cancer in 1992 and 374 in 1993. The GGHB area comprises approximately 1 million people, with a range of socio-economic circumstances, with large concentrations of socially deprived groups, but including population groups with the best and worst health profiles in Scotland.

The sampling frame was the West of Scotland Cancer Surveillance Unit, then based at Ruchill Hospital.

Choice of study population

The study population consisted of those women within this target population who were under 75 years at time of diagnosis and were at either end of the deprivation spectrum. The Carstairs and Morris deprivation index (Depcat score) was used to define deprivation (Carstairs & Morris 1988). This index is census based and derived from male unemployment, car ownership, over-crowding and persons in social classes IV and V within individual post-code sectors. Depcats calculated on the basis of the 1991 census were used (McLoone 1994).

There were 421 women under 75 years of age diagnosed with breast cancer in 1992 and 1993 who lived in postcode sectors at the upper and lower end of the range. Of these 158 (38%) lived in Depcats 1 or 2, and 263 (62%) lived in Depcats 6 and 7.

The decision to study the women from 1992 and 1993 who lived in the most affluent and the most deprived post-codes was taken for several reasons. In view of the number of new patients each year, data from two years were needed to give sufficient numbers in both affluent and deprived groups. Although breast cancer is commoner among affluent women (Dixon 1995), about two thirds of the population of this study live in deprived areas reflecting the greater prevalence of deprivation in Glasgow. The decision to investigate the care of women at either end of the deprivation spectrum rather than including the whole of the spectrum was sufficient as this study was a comparison of whether women from affluent and deprived areas have different experiences of breast cancer care. This study was designed to be descriptive, and although the power of the study could have been increased by either studying women from a greater number of years than two, or extending the study beyond Glasgow, it was decided to curtail the number of women involved in order to gain the benefits of completing all the different parts of the study in the time available.

Classification of deprivation

The use of aggregate scores to judge social status has been an attempt to classify individuals more accurately. Previously, single markers have been used, most commonly in Britain, occupational status (Social classes I, II, IIIa and IIIb, IV and V). In other countries, markers such as years of completed full time education, car ownership or housing tenure have been used. None of these markers are sufficient on their own as indications of socio-economic status, and all have flaws. For example, the use of employment to mark social class does not take account of women who are not in paid employment, the unemployed, or students. In addition, changes in the structure of society have resulted in changes from traditional employment that had a fairly obvious social class, to a much more fluid labour market, where people change jobs and professions more frequently. The area-based scales of socio-economic status, such as Carstairs and Morris (Carstairs & Morris 1988) and the Townsend scale Townsend et al. (Townsend, Phillimore, & Beattie 1988), which has had wider application in England, have attempted to more accurately define social status than these single measures have done by relying on several factors. These scores are an aggregate description of the socio-economic conditions within a postal sector, but may not accurately represent each individual within that sector (the ecological fallacy). There is evidence that such misclassification is small and should lead to an underestimate of true gradients. Sloggett and Joshi found that excess mortality associated with residence in areas designated as deprived by census based indicators is explained completely by the concentration in those areas of people with adverse personal or household socio-economic factors (Sloggett & Joshi 1994). In deciding to use Carstairs and Morris Depcat scores to determine the study population, there was recognition that these designations would need to be checked to ensure the accurate assignment of the designations affluent or deprived to individuals. This was subsequently done by questionnaire and will be discussed later.

Scottish Cancer Registration Data

Cancer registration within Scotland has been shown to be of high quality. Brewster et al. examined a random sample of 2200 case records to identify whether cancer registration data across Scotland was accurate (Brewster, Crichton, & Muir 1994). They concluded that there was a high degree of accuracy between the records and the data held by the registry. In another study, they carried out an assessment of the completeness of Scottish cancer registry data by assembling a database from 14 separate sources (Brewster et al. 1997). They found an overall completeness of 96.5%. Throughout Scotland, only nine breast cancer registrations had been missed. The completeness compared well to that of registries outside Scotland.) They also compared the completeness of cancer registration with pathology records for 1992 in Scotland and found 133 'missed' registrations, 5.7% of the total (Brewster et al. 1996). They conclude that ascertainment of the Scottish Cancer Registry is high. Therefore the list obtained from the West of Scotland Cancer Surveillance Unit can be depended upon to be as complete as possible. The Registry included all women who had a diagnosis of breast cancer, irrespective of stage at presentation. The information obtained from the cancer registry included details of the hospital of registration, with which information the hospital records departments were approached and asked for permission to extract data from the notes. The Registry records the date of diagnosis separately from the date of registration, which may occur some months later. The Registry confirmed that all the registrations had been completed for patients diagnosed in 1992 and 1993.

Swerdlow et al. (1998) examined data available on incidence and mortality of cancer in Scotland. The data discussed for breast cancer cover 80 years. They show breast cancer to be the most common cancer in Scotland and the Scottish mortality rates are among the highest in the world. Recent mortality rates have improved, probably due to better treatment (Early Breast Cancer Trialists' Collaborative Group1992a).

3.3 Characteristics of study population

Introduction

The number of women in the study decreased at each stage (Table 3.1, page 59). Losses at the different phases of the study occurred for a number of reasons and are explained in this section.

Hospital records data collection

The study population consisted of the women who were diagnosed as having breast cancer in 1992 and 1993 and who lived in depcats 1 and 2 (affluent) and 6 and 7 (deprived) at time of diagnosis. There were 158 women from affluent areas and 263 women from deprived areas. Hospital records were requested for this group, and all but four were obtained, examined and data extracted. Four records were missing from the records departments (Table 3.1).

In order to compare the care received following a diagnosis of breast cancer, detailed analyses of surgical and oncological treatments were confined to data from women who were diagnosed as having primary breast cancer at the time of presentation. The management of locally advanced and metastatic disease depends on many factors, and there is debate regarding the best way to manage these advanced situations. The number of women in these categories was relatively small (51 in total). In terms of comparisons of treatment and care outcomes, the study was therefore largely confined to women with early stage disease. Therefore analyses are presented in this thesis for 146 women from affluent areas and 220 women from deprived areas. However analyses were carried out of the stage of presentation comparing the affluent and deprived women in the original whole study population (i.e. 158 women from affluent areas and 263 women from deprived areas).

Data were collected from the five hospitals in Glasgow where women with breast cancer are treated (Table 3.2, page 60). The numbers of women living in affluent or deprived areas attending each hospital reflects the catchment areas in which these hospitals are situated. For example, the majority of the women from affluent areas in the study were seen at the Victoria Infirmary and the Western Infirmary. All women who attended Glasgow Royal Infirmary lived in deprived areas. These differences impact on the interpretation of the results and are discussed in Chapter 4.

There was no statistically significant difference in the age at diagnosis of women living in affluent and deprived areas (women living in affluent areas: mean age 55.9 years, SD 11.1 years; women living in deprived areas: mean age 57.6 years, SD 10 years; $t = -1.6$, $p = 0.110$, Table 3.3, page 61).

In the management of breast cancer, menstrual status may influence the choice of adjuvant systemic treatment, so information on menstrual status at time of diagnosis was collected from the hospital records. There was no significant difference between women living in affluent and deprived areas, in terms of menstrual status at time of diagnosis, with the majority in both groups being post-menopausal (women living in affluent areas, 66.4%; women living in deprived areas, 73.4%, $p = 0.24$, Table 3.3). The groups of women living in affluent and deprived areas are comparable, in terms of age and menstrual status at time of presentation, suggesting that breast cancer occurs at the same chronological and biological stage of the lives of women at both ends of the deprivation spectrum

GP Records Data Collection

Details regarding the data collection from GP records are documented in Table 5.1 and a breakdown of the number of records seen according to whether the women lived in affluent or deprived areas is shown in Table 3.1 (page 59).

A reduction in the study population occurs at the stage of the GP records investigation. An attempt was made to access the GP records of all the women who had presented with early breast cancer. There were a number of reasons why this did not prove possible. Permission from the GPs was sought for access to their records. In addition to the women who were deceased, there were practices who refused access to notes for various reasons or who failed to reply after three contacts by post and further telephone calls. Data collection was stopped after 278 GP records had been examined (75.9 % of the total initially requested) (Table 5.1, page 151). These records related to 110 (75.3%) women from affluent areas and 168 (76.4%) women from deprived areas. It was regrettable that it did not prove possible to access the GP records of all the women studied as a result of the hospital records data collection. However, as the records of women from affluent and deprived areas were reviewed in equal proportions, it is unlikely that failing to obtain the entire sample will prejudice the conclusions reached from the data gathered from these records.

Questionnaire study

Subsequent to the GP records data collection, questionnaires were sent to those surviving women, who had originally presented with primary breast cancer, and whose GPs gave permission for them to be sent questionnaires. Therefore women who had not been included at the GP records stage could not be included in this stage. Immediately prior to sending out questionnaires the GPs were contacted again to inform them that the questionnaires were being sent out to avoid sending them to a woman who had recently died or where there was another situations which would have made approach inappropriate.

Questionnaires were sent to 218 women. Four addresses were incorrect and the questionnaire could not be delivered by the Royal Mail. Of 177 replies, 77 were from women living in affluent areas (86.5% response rate), and 100 from women living in deprived areas (77.5% response rate) (Table 3.1, page 59). The difference in response rate between women from affluent and deprived areas is not statistically significant ($X^2 = 2.79$, DF = 1, p = 0.095). Although the overall response rate of 81% is satisfactory, less than half the original study population returned the questionnaire.

As the women received the questionnaire between three and a half and five and a half years after diagnosis, the respondents are a selected group of survivors, and the responses may well reflect this. In discussing the data contained within the questionnaire responses it is interesting to consider this and to consider differences which may emerge if the same questionnaire was given to newly diagnosed patients. Also, because of the different time periods in the cancer journeys of the women at which the various parts of the study took place, there is a limit to which data can be linked between the different stages. For example, the degree of anxiety which is manifested in the data from SF-36 (questionnaire sent out mid 1997) cannot necessarily be linked to consultations patterns (as these were collected for the first 2 years after diagnosis).

Socio-economic characteristics of the women were obtained from the questionnaire. More women living in deprived areas had no children (Table 3.4, page 62), but among those who had children, the women from deprived areas had larger numbers of children. The questionnaire respondents were asked about the number of persons living in their household. There was no statistically significant difference between the groups in the proportion of women living alone (Table 3.4). Among those who lived with other people, most of the women in both groups lived with one other person (affluent areas 35/61 [57.4%], deprived areas 42/67 [62.7%]). Interestingly, there were more nulliparous women among those living in deprived areas. Nulliparity is known to increase the risk factors of developing breast cancer (1995). Women living in affluent areas were more likely to live in owner occupied houses with more rooms and were more likely to own cars than those living in deprived areas (Table 3.5, page 63). In addition, women living in affluent areas were more likely to have completed their education later, to be employed and to have an annual household income in excess of £10,000 than women living in deprived areas (Table 3.6, page 64). These socio-economic characteristics indicate that the ecological fallacy seems to have minimal effect here.

3.4 Summary

This chapter has described the issues that arose from the choice and characteristics of the study population.

The losses at each stage, which led to a decreasing sample size, were unfortunate, although predictable considering this was a retrospective study of women with breast cancer. In order to obtain useful information regarding patterns of care following diagnosis, it was necessary to follow the sample up for some time; inevitably in this time some of these women would be lost, either through death, or through ability to contact them or their general practitioners.

Having described the study population, the first of the set of three data sources, the hospital data can now be described (chapter 4).

TABLES

Table 3.1: The number of women living in affluent and deprived areas included at each stage of investigation

	AFFLUENT n	DEPRIVED n	TOTAL n
STUDY POPULATION*	158	263	421
HOSPITAL CARE			
Hospital records seen	157	260	417
Diagnosis of primary breast cancer	146	220	366
GP CARE			
GP records seen	110	168	278
POSTAL SURVEY			
Questionnaires sent	89	129	218
Questionnaires returned	77	100	177

*The study population was obtained from the West of Scotland Cancer Surveillance Unit, and consisted of women living within the Greater Glasgow Health Board area who were diagnosed as having breast cancer in 1992 or 1993 and who lived in Depcats 1, 2, 6 or 7 at the time of diagnosis.

Table 3.2: Hospital attended by women living in affluent and deprived areas

Hospital	AFFLUENT n, (%)	DEPRIVED n, (%)	Total
Western Infirmary	52 (38.2%)	84 (61.8%)	136
Glasgow Royal Infirmary	0	79 (100%)	79
Victoria Infirmary	74 (59.7%)	50 (40.3%)	124
Stobhill Hospital	24 (53.3%)	21 (46.7%)	45
Southern General Hospital	3 (10.3%)	26 (89.7%)	29
Total	**153**	**260**	**413***

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*The 4 patients in the study who had their original surgery carried out at a private hospital are excluded from this table.

Table 3.3: Characteristics of women from affluent and deprived areas at time of hospital presentation

	AFFLUENT *n = 157*	**DEPRIVED** *n = 260*	**Statistical test**
Age			
Mean	55.9	57.6	**t test:**
			t = -1.6,
Standard Deviation	11.1	10.0	**p = 0.110**
	missing n = 0	missing n = 0	
Menstrual status			
	n, (%)	n, (%)	
			Chi squared test:
Pre-menopausal	37 (25.9%)	51 (22.3%)	
			X^2 = 2.80
Peri-menopausal	11 (7.7%)	10 (4.4%)	**DF = 2**
			p = 0.24
Post- menopausal	95 (66.4%)	168 (73.4%)	
	missing n = 14*	missing n = 31*	

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*These data were obtained from hospital case records. The missing values (14 women from affluent areas, 31 women from deprived areas) are those for whom no documentation could be found of their menstrual status at time of diagnosis.

Table 3.4: Characteristics of women who responded to the questionnaire: children and co-habitees

	AFFLUENT n (%) *n = 77*	DEPRIVED n (%) *n = 99*	Statistical test
Number of children			
Nulliparous women	10 (13.0%)	28 (28.3%)	**Chi squared test:** **X^2 = 5.98,** **DF = 1, p = 0.014**
Parous women	Median 2 IQR 2 to 2 missing n = 0	Median 2 IQR 2 to 4 missing n = 1	**Mann Whitney:** **Z = -2.75** **p = 0.006**
Number of persons living in house			
Living alone	16 (20.8%)	32 (32.3%)	**Chi squared test:** **X^2 = 2.91,** **DF = 1, p = 0.088**
Living with others	Median 2 IQR 2 to 3 missing n = 0	Median 2 IQR 2 to 3 missing n = 1	**Mann Whitney:** **Z = -0.68** **p = 0.49**

Table 3.5: Characteristics of women who responded to the questionnaire: housing and car ownership

	AFFLUENT **n (%)** *n = 77*	**DEPRIVED** **n (%)** *n = 99*	**Statistical test**
Housing tenure			
			Chi squared test:
Owned	70 (90.9%)	33 (33.7%)	**$X^2 = 58.3$,**
			DF = 1,
Rented and other	7 (9.1%)	65 (66.3%)	**p = 0.000**
	missing n = 0	missing n = 2	
Number of rooms in house (excluding kitchen and bathroom)			
Mean	5	3	**t-test:**
			t = 10.92,
Standard Deviation	1.18	0.97	**p = 0.000**
	missing n = 0	missing n = 2	
Car ownership			
			Chi squared test:
No car	15 (19.5%)	56 (62.2%)	**$X^2 = 31.02$**
			DF = 1
One or more cars	62 (80.5%)	34 (37.8%)	**p = 0.0000**
	missing n = 0	missing n = 10	

Table 3.6: Characteristics of women who responded to the questionnaire education, employment and income

	AFFLUENT	**DEPRIVED**	**Statistical test**
	n (%)	**n (%)**	
	n = 77	*n = 99*	
Age at completion of education			
Median	16	15	**Mann Whitney:**
IQ Range	IQ range: 15 to 18	IQ range: 14 to 15	**Z = -6.87**
			p = 0.000
	missing n = 3	missing n = 3	
Employment status			
			Chi squared test:
Employed	29 (38.7%)	23 (24.0%)	
			X^2 = 4.30
Not employed	46 (61.3%)	73 (76.0%)	**DF = 1**
			p = 0.038
	missing n = 4	missing n = 3	
Annual household income			
			Chi squared test:
< £10,000 / annum	19(26.4%)	65 (74.7%)	**X^2 = 36.92**
> £10,000 / annum	53 (73.6%)	22 (25.3%)	**DF = 1**
			p = 0.000
	missing n = 5	missing n = 12	

Chapter 4

HOSPITAL RECORDS DATA COLLECTION

4.1 Introduction

Although the first contact in an individual woman's personal breast cancer story is most likely to involve her GP, (Table 4.13), it is in secondary care that the diagnosis is confirmed. For this reason the hospital data collection part of this study will be presented first. In addition, it was necessary during the field work to undertake the hospital record data collection first, as the information obtained from the West of Scotland Cancer Surveillance Unit contained hospital numbers, and not GP addresses.

The purpose of the hospital records data collection was to obtain data which would help test the hypothesis that the known difference in outcome between the most affluent and deprived women with breast cancer is due to a difference in the care they receive from the NHS.

4.2 Methods

Breast cancer is treated by surgeons at the five general hospitals in Glasgow: the Western Infirmary, Victoria Infirmary, Glasgow Royal Infirmary, Stobhill Hospital and the Southern General Hospital. Some of the patients are subsequently referred to either clinical or medical oncologists within the Beatson Oncology Centre at the Western Infirmary, which retains separate case records from the Western Infirmary. The hospital records data collection therefore involved applications to see case records from six separate records departments in Glasgow. The breakdown of case records requested and examined at the various hospital records departments is shown in Table 4.1.

In carrying out the hospital records data collection, information was collected on several aspects of care (Appendix 1). The decisions regarding which data to collect was made at meetings held with individuals from a variety of disciplines including surgery, oncology, general practice and public health. The data collected were:

- administrative and background clinical information
- pathological characteristics at presentation
- treatment received
- information regarding the primary / secondary care interface, at time of presentation, after referral to hospital and during follow up including a review of correspondence from hospital specialists to GPs
- details of recurrence and whether alive when last seen

Administrative and background clinical information

This information included postcode at presentation, any subsequent change in address, Beatson Oncology Centre case note number if referral made to Oncology, menstrual status at diagnosis, name and address of GP, date of birth and date of diagnosis.

Pathological characteristics at presentation

The pathological prognostic characteristics were collected both to compare the pathology at presentation between women living in affluent and deprived areas and also to compare this population with that previously studied by Carnon and colleagues (Carnon et al. 1994). The following data were collected:

- grade of tumour - as assigned by the pathologist at examination
- tumour size - as measured by the pathologist in the laboratory, using the same size categories as those in Carnon's paper
- nodal status - i.e. whether the axillary lymph nodes were infiltrated by tumour or not.

In addition, the clinical stage of the disease as determined at presentation by the surgeon was documented, as early, locally advanced or metastatic. The stage of disease determines management and therefore was important. The management of locally advanced and metastatic disease depends on many factors, and there is debate regarding the best way to manage these advanced situations. It was felt therefore that there may be biasing factors which would affect the treatment decisions regarding these women. It became evident that it would only be possible to compare accurately the treatment and care of women who presented with early stage breast cancer even although the numbers of women in these categories are relatively small. In terms of comparisons of treatment and care outcomes, the study was confined to women with early stage disease. However there will be analysis of the stage of presentation comparing the affluent and deprived groups for the whole of the study population.

Treatment received

The following details regarding the treatment received by the study population were collected:

- the nature and extent of breast surgery, including whether conservation surgery or mastectomy was performed
- whether axillary surgery was performed or not, and if so, whether it involved node sampling or clearance
- whether referral to Oncology had taken place
- whether radiotherapy was carried out, and if so, whether this was to chest wall, to breast and / or to nodal draining areas
- any adjuvant treatment given, namely chemotherapy and hormone therapy
- whether the woman had undergone any primary treatment before surgery
- involvement or not in a clinical trial

Information regarding the primary / secondary care interface

In order to obtain information on the balance of care between primary and secondary care, data were gathered regarding the mode of presentation, delays in presentation, inpatient stays and outpatient visits and the number and nature of communications with the patient's general practitioner.

Mode of presentation:

- via the breast screening programme

- via primary care i.e. by a referral from their GP

- via secondary care - i.e. a few patients had been attending a hospital clinic for some other reason, and were referred from there

- a small number of patients were referred in other ways, including personal referral and referral from private screening clinics.

Delays in presentation:

Two types of delay were studied.

- Number of days between the letter from the GP to the date of the clinic appointment.

- Number of days from the first clinic visit to operation

Inpatient stays and outpatient visits

The length of inpatient stay at the time of operation was recorded, as were any other admissions to hospital in the first two years after diagnosis. All admissions were recorded, including those for other illnesses. Information regarding admissions to other hospitals was obtained from the GP records data collection for the first two years after diagnosis. As much of the first year after diagnosis may be taken up with breast cancer related treatments, it was postulated that a two-year time period would allow data to be obtained about diseases unrelated to breast cancer

In addition, record was made of the number of outpatient visits, the number of times women did not attend a clinic visit (DNA) and the number of early visits (when an extra appointment was requested, either by the woman or her GP).

The number and nature of communications with the patient's general practitioner

A record was made of the dates of the letters sent to the GP from surgeons and oncologists in the first two years after diagnosis. Particular attention was paid to the content of the letters sent by the surgeons following the initial clinic visit and after discharge from primary surgery. The letter following the initial clinic visit was read for information regarding:

- probable diagnosis
- management plan
- indication of what the patient had been told

Similarly, the information in the letter sent to the GP on discharge after primary surgery was documented:

- diagnosis
- operative procedure
- further treatment plan
- follow up plan

Letters sent by oncologists to GPs were examined for similar information. The letter following the first visit to Oncology was read to see whether the management plan for the patient was clear with respect to:

- radiotherapy
- chemotherapy
- endocrine therapy

- prognosis
- what the patient had been told

Information was extracted from subsequent letters depending on the treatment options decided. If the patient had received radiotherapy treatment, letters were searched for details about whether the GP had been informed about

- the start of treatment
- the end of treatment
- complications of treatment, in particular, skin reactions and lymphoedema

If the patient had received chemotherapy, letters were searched for details about whether the GP had been informed about

the start of treatment

the end of treatment

expected adverse effects from treatment

complications of treatment

For patients who were commenced on endocrine therapy, details were collected on:-

- the expected duration of treatment
- whether the side effects of the therapy were stated
- if treatment was stopped due to side effects

Information regarding the outcome of early (unscheduled) visits and referral to other specialists was also documented.

Details of recurrence and whether alive when last seen

- date of recurrence
- whether the recurrence was local or distant
- whether detection of recurrence had taken place at a routine visit, by referral from the GP, or whether the patient had personally requested an early appointment.

Practical aspects regarding the hospital records data collection

All records departments had regulations whereby only their own staff had access to the record files, and they gathered case records from the list, usually in batches of about 20. The case records were then examined in the records departments. Data were extracted from the records onto a pre-designed form (Appendix 1) and subsequently entered into a specially constructed data base on SPSS for Windows (1999).

4.3 Results

This section presents the results obtained from the hospital records data collection. The pathological characteristics of the cancers at presentation will be presented first, followed by the treatment which women with early breast cancer received. Finally, data regarding the primary / secondary care interface which emerged from the hospital data records collection will be presented.

Pathological characteristics at presentation

No differences were detected between women living in affluent areas and women living in deprived areas for the following pathological prognostic factors: pathological size of tumour, histological grade of tumour, infiltration of axillary lymph nodes by cancer (Table 4.2, page 96). The number of women for whom there were results in each category varied due to the incompleteness of pathology records. This study was carried out after the inception of the NHS Breast Screening Programme and in order to study the effect of screening on presentation, the pathological data for screened and non-screened women are shown in Tables 4.3 – 4.5 (pages 97 – 99). No statistical differences were found for any of the pathological prognostic factors irrespective of participation in breast screening for women living in affluent and deprived areas in the population. In addition, there was no statistically significant difference in the population of women in the groups who had a screen detected cancer (women living in affluent areas: n = 41, women living in deprived areas: n = 48, $X^2 = 1.87$, DF = 1, p = 0.171).

Pathological grade of breast cancer is classified as Grade 1, 2 or 3, but in a considerable number of cases, the grade was reported as "unclear" (Table 4.2). The pathology specimens were processed by the Pathology departments in each of the five hospitals which women attended. Further analysis was carried out to investigate whether the reporting of pathological grade as "unclear" was a feature of reports from all the hospitals (Table 4.6, page 100). There was an excess of "unclear" reports from Hospital 2, with 50.7% of reports from that hospital defining the grade as "unclear". This makes it difficult to interpret the results as all patients attending Hospital 2 were from deprived areas. This consideration only applies to the grade of tumour.

In addition to the analyses of pathological prognostic factors, the stage of disease at time of presentation, as defined by the surgeon, was documented for the whole study population of women living in affluent and deprived areas (Table 4.7, page 101). Although few patients presented with locally advanced (n = 29) or metastatic beast cancer (n = 21), more women living in deprived areas presented in this way (women living in affluent areas: 6.4% *v* women living in deprived areas: 15.4%, p = 0.006, Table 4.7).

The following analyses regarding management of cancer refer to the women who presented with early breast cancer.

Management

There was no difference between women living in affluent and deprived areas in the percentage of patients undergoing mastectomy (44.4% *v* 52.0%) or conservative surgery (51.7% *v* 44.8%, p = 0.15, Table 4.8, page 102). However, more women living in deprived areas had axillary sampling rather than axillary clearance (sampling: 4.7% *v* 25.5%, p = 0.000). A description of axillary surgery carried out in each of the five hospitals indicates different practices (Table 4.9, page 103) with respect to whether axillary clearance or sampling was performed, with hospitals 2 and 5 undertaking a larger proportion of sampling operations than hospitals 1, 3 and 4. In order to relate this to deprivation, analyses of each of the hospitals were carried out for women living in affluent and deprived areas (Table 4.10). A comparison of Hospital 2 is not possible in this model because none of the patients lived in affluent areas. The numbers for each hospital are relatively small.

No statistically significant differences were detected between women living in affluent and deprived areas with respect to the percentage receiving radiotherapy (40.0% *v* 43.3%, p = 0.54), chemotherapy (20.0% *v* 13.9%, p = 0.12) or endocrine therapy (88.3% *v* 90.7%, p = 0.45) after surgery (Table 4.11, page 105).

Referrals were made to an oncologist for 57.5% of the women living in affluent areas and for 55.7% of the women living in deprived areas (p = 0.83) (Table 4.12, page 106). The clinical trials recruitment figures found in the notes were small (2.1% of women living in affluent areas *v* 5.2% of women living in deprived areas; Fisher's exact test: p = 0.11).

The primary / secondary care interface

There was no difference between the groups in terms of the percentage of women who had presented with their breast cancer via the breast screening programme, via their general practitioner or via secondary care (Table 4.13, page 107); the majority of both groups were referred by their GP.

The waiting time between referral letter and the first clinic visit was shorter in women from affluent areas (affluent: median 6 days, IQR 1 to 13; deprived: median 7 days, IQR 4 to 20, Z = -2.72, p = 0.006, Table 4.14, page 108). However there was no significant difference between the groups in the time from clinic visit to surgery (affluent: median 16 days, IQR 9 to 24; deprived: median 17 days, IQR 10 to 25, Z = -1.53, p = 0.13). An analysis of those who waited longer (Tables 4.15 and 4.16, pages 109 and 110) demonstrated no statistically significant differences between those living in affluent and deprived areas, but there is a trend for deprived women to wait for longer periods of time.

There was no statistical difference in the total number of inpatient days at the time of original surgery between the two groups (affluent: median 7 days, IQR

5 to 8; deprived: median 6 days, IQR 5 to 8, Z = -1.04, p = 0.29) (Table 4.17, page 111).

Admissions in the first two years following diagnosis were documented (Table 4.18, page 112), as admissions due to a breast cancer related problem, and admissions for other reasons. There was no difference in the number of admissions of women with problems related to the diagnosis of breast cancer (p = 0.12). By contrast, women from affluent areas were less likely to be admitted than women from deprived areas for problems not related to breast cancer (no admissions: 90.3% *v* 75.6%, p = 0.002).

Out patient attendances were recorded at both surgical and oncology clinics. However as some women attended one or the other and some women attended both, the attendances have been analysed together, as hospital follow up visits for the two years following the end of treatment for primary breast cancer (Table 4.19, page 113). No statistically significant difference was observed between affluent and deprived groups in the number of clinic attendances (mean number of attendances for women from affluent areas 7.63, SD = 2.76, mean number of attendances for women from deprived areas 7.98, SD = 3.14, t = -1.10, p = 0.27).

Data were also collected about the number of early visits (i.e. where the patient or GP had requested an appointment with the specialist prior to the scheduled appointment) and the number of DNA appointments (i.e. did not attend) (Table 4.19). The proportion of women requiring an early appointment did not differ between the groups. Although the numbers are small, there were more deprived patients failing to attend appointments (4.4% *v* 12.0%, p = 0.017).

The content of the correspondence sent from specialists to GPs was analysed (Tables 4.20 and 4.21, pages 114 and 115). There were no differences between the two groups of women in terms of the information given to the GP after the first clinic visit. The GP was informed as to what the patient knew about their visit in less than 50% of cases (Table 4.20). After surgery, there was no difference in information sent to the GP regarding diagnosis and operative procedure. However GPs of women who lived in affluent areas were statistically significantly more likely to have received information about their patient's further management and the arrangements for follow up (Table 4.20).

Correspondence from the Oncologists shows no difference between information communicated to the GPs of women living in affluent areas compared with those living in deprived areas with the exception of information regarding chemotherapy (Table 4.21). The GPs of women living in affluent areas were more likely to be told about the plan for chemotherapy in the initial letter than the GPs of women living in deprived areas (91% *v* 74%).

4.4 Discussion

The broad subject areas of pathological characteristics, management and the primary / secondary care interface will be discussed in this section in the order in which they were presented in the results section (4.3).

Pathological characteristics at presentation

The relationship between socio-economic deprivation and pathological prognostic factors in women with breast cancer was investigated in Glasgow by Carnon et al. (1994). They found that difference in survival from breast cancer by socio-economic deprivation category could not be accounted for by differences in pathological prognostic factors. In this study similar analyses to those carried out by Carnon were performed using the same definitions of grade, lymph node status and tumour size and produce similar results (Table 4.2, page 96). There were no differences in any of the pathological prognostic factors at time of surgery between women living in affluent areas and women living in deprived areas.

In addition to collecting pathological data from the notes, the definition of the stage of disease as defined by the surgeon at presentation was also documented (Table 4.7, page 101). It became apparent that the pathological prognostic factors presented above deal with patients for whom such details are available, that is women who have undergone primary surgery, and exclude women who present with metastatic breast cancer, where the diagnosis is commonly made by fine needle aspirate or tru-cut biopsy. In order to obtain a complete picture of patterns of presentation comparing affluent and deprived groups, all presentations were taken into account. In addition to excluding inoperable patients, Carnon's work excluded women in whom the diagnosis was made only from the death certificate (33 cases) and those without histological verification (131 cases). As the total number eventually included was 1361, this means that at least 12% of those who probably presented with the most advanced disease were excluded. In the current study which includes patients who presented with locally advanced and metastatic breast cancer, clinical stage at diagnosis is important, with women from deprived areas being more likely to present at hospital with large advanced cancers.

Deprivation and survival from breast cancer was also investigated by Schrijvers et al in women diagnosed with breast cancer between 1980 and 1989 in the South Thames Regional Health Authority area (Schrijvers et al. 1995a). There were 29, 676 women in this study, and as in Carnon's study, the better survival found for women living in more affluent areas was not associated with the pathological appearance of the cancer. This study did take clinical stage into account (which was recorded for about 80% of the women) and found a difference between women aged 30 - 64 years and women aged 65 - 99 years with no difference in stage of presentation across the socio-economic spectrum. This is not seen in the current study. The gradient in survival across deprivation categories was steeper for older women as women from deprived areas were less likely to survive, but they concluded that this gradient still existed after adjustment for stage at diagnosis and was likely to be due to other factors.

Socio-economic status and its relationship to breast cancer has been extensively investigated. Thirty years ago Linden demonstrated that breast cancer patients in public hospitals had poorer survival rates than women treated in private hospitals, and argued that the type of hospital in California at that time could be taken as a proxy for social status (Linden 1969). Some of the literature particularly from the United States has studied socio-economic status and race and their relationship to each other and to outcomes from breast cancer. Dayal et al. (Dayal, Power, & Chiu1982) showed a higher probability of survival in white women with breast cancer compared with black women which was not affected by adjustment for either age or stage at presentation (page 28). However, the relationship between race and socio-economic status were so strongly associated that racial differences became insignificant when they were adjusted for by socio-economic status. Berg et al. had previously postulated that economic differences could explain most of the survival differences between blacks and whites in Iowa (Berg, Ross, & Latourette 1977). This was confirmed by Bassett and Krieger (1986) who studied 1506 women in Washington state and concluded that poorer social class was a determinant of poorer survival. Farlry and Flannery (1989) studied late stage diagnosis of breast cancer from data in the Connecticut Tumor Registry and showed more women from lower socio-economic groups diagnosed with late stage breast cancer. A study from the New York State Tumor Registry by Mandelblatt at al. (1991) similarly showed older, black lower social class women, treated in public hospitals were 3.75 times more likely to present with late stage breast cancer than younger, white women of higher socio-economic status. More recently, Gordon et al. (1992) studied socio-economic status and race in breast cancer and again found that once adjustment was made for socio-economic status, race ceased to be significant. Women of either race whose socio-economic status was lower were likely to have a recurrence or die of breast cancer. Wells and Horm (1992), studying data from San Francisco, Oakland, Detroit and Atlanta (181 000 cases) also present data showing women from lower socio-economic groups presenting with later stage disease. However this has not been found consistently in the literature. Keirn and Metter (1985) found that stage of disease was the only predictor of survival outcome, and that this was irrespective of socio-economic status. There are difficulties in directly translating findings of studies done in the United States to the United Kingdom because of differences in the health care systems and in the classification of socio-economic status. Karjalainen and Pukkala studied social class as a prognostic factor in breast cancer survival in Finland which has a similar health care system to the UK (Karjalainen & Pukkala 1990). They studied a population of 10,181 women with breast cancer and found that those women in the lowest social classes had the greatest risk of dying. This was not completely explained by differences in stage at presentation.

The findings in the literature therefore vary in terms of results and interpreted connection between stage at presentation and socio-economic status. The UK literature however has not shown any such relationship. As discussed above, Carnon et al. (1994) and Schrijvers at al. (1995a) both concluded that stage at diagnosis was not related to socio-economic status. Roberts at al. (1990)

studied the socio-economic status of a random sample of all new cases of breast cancer in 1979 and the control group of the Edinburgh randomised trial of breast screening to determine stage and survival in relation to social class. They found no relationship between socio-economic status and women presenting with locally advanced or metastatic breast cancer.

The findings of the current study regarding socio-economic status and stage at presentation with breast cancer add to previous work, demonstrating a difference in clinical stage at presentation for the first time in the UK (Macleod et al. 2000a). The findings demonstrate need for further work to explore the reasons why women with breast cancer present with locally advanced or metastatic disease and why this may be more common among women living in deprived areas.

Management

Variations in the management of women with breast cancer have been extensively studied (Richards et al. 1997). In this study no difference was found in the hospital management of women living in affluent areas and women living in deprived areas, in terms of type of breast surgery performed, or whether they received radiotherapy, chemotherapy or endocrine therapy (Tables 4.8 to 4.11, pages 102 - 105). These results suggest that socio-economic status was not a factor in the surgical or oncological management of these women. Differences observed in axillary surgery are discussed below (page 86).

It is only relatively recently that attempts have been made to form a consensus between clinicians on best practice in breast cancer management. Initially this took the form of consensus developing conferences, and more recently the publication of guidelines. Three consensus conferences were held on the management of breast cancer in the 1980s. The 1980 National Institute of Health (NIH) conference in the USA covered the initial management of breast cancer, describing a trend towards more conservative surgery and the use of radiotherapy. A second NIH conference was held in 1985 (US National Institute of Health 1985) and concentrated on the role of chemotherapy and endocrine therapy. This was followed, in 1986, by the first consensus conference on breast cancer management in the UK, which was held by the King's Fund and produced a Consensus Statement (Anonymous, 1986) which covered a broad range of issues on breast cancer management and was a guideline on local and systemic treatment. A study comparing the initial management of 383 patients with breast cancer in two London teaching hospitals carried out in the same year as the King's Fund Consensus statement was published, showed differences between consensus guidelines and clinical practice, particularly in relation to axillary surgery and adjuvant therapy (McCarthy and Bore, 1991). This study was published before these differences could be related to survival. Further research regarding the impact of these guidelines on the management of patients with breast cancer showed wide variations in treatment by clinicians for patients within the same age group and stage of disease, in particular in relation to staging of disease and treatment with chemotherapy (Chouillet et al. 1994). Basnett et al. (1992) showed that, despite the King's Fund Consensus Statement, wide variations existed between a teaching and a non teaching hospital in the management of breast cancer with better survival at the teaching centre and significantly worse survival for women treated in the non teaching hospital.

Later work, studying differences in the treatment of women with breast cancer under the age of 50 years, between teaching and non teaching hospitals in the South east Thames region showed significant differences in treatment between hospitals (Richards et al. 1996). This did not have an adverse effect on survival. The treatments provided were frequently different from those recommended by the Kings Fund statement which had been published during the study period. Differences were noticed again with respect to axillary surgery and adjuvant systemic therapy. Further, Albain et al. (1996) studied breast-sparing (lumpectomy) operations in 5,172 patients and compared the prevalence of these operations with a number of patient characteristics. The socio-economic criteria they used were lack of college degree and income levels. They found an association between lower lumpectomy rates and either lack of college degree or lower income levels.

There has been interest in documenting variations in survival between women treated by specialists and women treated by general surgeons. A study carried out in Yorkshire (Sainsbury et al. 1995b), showed that surgeons with an expressed interest in breast cancer were more likely to treat a larger number of patients than other surgeons and to offer patients chemotherapy, radiotherapy and hormone therapy more often. A further study from Yorkshire (Sainsbury et al. 1995a) and a study from the West of Scotland (Gillis and Hole, 1996) have shown better survival in women with breast cancer treated by surgeons with a special interest in breast cancer. The West of Scotland study is of particular interest as it involves the same hospitals as the present study; however the data relate to women diagnosed with breast cancer between 1980 and 1988, whereas this study relates to those diagnosed in 1992 and 1993. Another Scottish study (Twelves et al. 1998a) showed regional differences in survival from breast cancer. The authors argue that these differences relate to the use of adjuvant systemic treatment rather than to either surgical case load or deprivation. This conclusion is strengthened by the known survival advantage with adequate adjuvant treatment (Early Breast Cancer Trialists' Collaborative Group, 1992a and b). Gage and Fouquet (1997) studied variations in breast cancer mortality in England before the introduction of the NHS breast screening programme. They looked at 'health care inputs' and 'health care activity', although these are quite different from those examined in this thesis. The health care inputs included expenditure on general surgery nurses and doctors, the number and type of general surgery nurses and doctors, and the physical condition of hospital buildings. The health care activity variables included number of admissions and average waiting times. Socio-economic factors were found to have a greater effect on mortality than health care variables.

Hospital 1 and Hospital 2 in this study are teaching hospitals; Hospital 3, Hospital 4 and Hospital 5 are non teaching hospitals, although the latter are closely connected to University departments. Both of the teaching hospitals have academic surgical units whose main interest is breast cancer. It is interesting that the only variation in practice detected in this study is in the management of the axilla which has been highlighted in so many previous studies. Recent data from Glasgow shows that since this study, the variation has virtually been eliminated with greater than 90% of women with breast cancer undergoing axillary clearances (H. Burns, personal communication, 1999). This is in keeping with recommendations in several recent guidelines issued by the British Breast Group (1994) the British Association of Surgical Oncologists (1995) and the Scottish Intercollegiate Guidelines Network (1998).

According to hospital records, very few women in the present study took part in clinical trials (Table 4.12, page 106). However, this may underestimate the true rate of participation which is closer to 20% (SCTN, personal communication). This is still much lower than ideal, especially in view of evidence pointing to the better survival of patients in placebo groups in cancer treatment trials compared to non-participants in such trials. This difference may be explained by the beneficial effect of receiving care according to a strict protocol (Karjalainen et al. 1989).

The present study did not find differences in the management of women from affluent or deprived areas that could not be explained by differences in hospital policy (page 86). A review of the literature failed to identify other studies that had investigated differences in management between areas of differing socio-economic status.

Breast Screening

One of the most significant developments in breast cancer care in the UK in the last two decades has been the implementation of the National Health Service Breast Screening Programme (Chamberlain et al. 1993). The data presented by Carnon et al (1994) from 1980 - 87 predated the National Health Service Breast Screening Programme, which started in Glasgow in 1988. As the data in the current study were collected from women diagnosed with breast cancer after the start of the Breast Screening Programme, some of the study subjects were diagnosed with breast cancer via the Programme. It was therefore necessary to explore differences between the groups as a result of the uptake of the Breast Screening Programme. No differences were found in either of the screened or non-screened populations in terms of pathological tumour size, grade of tumour and nodal status (Tables 4.3 – 4.5, page 97 - 99).

Data from ISD, Scotland (McLaren & Bain1998) demonstrated a difference in breast screening uptake between the most affluent and the most deprived groups in Glasgow. Between 1992 and 1995, 78.9% of the most affluent women invited for screening attended, whereas only 57.9% of the most deprived attended. Other studies from elsewhere in the U.K. agree that affluent women are more likely to attend for screening than deprived women (Ross et al. 1994; Sutton et al. 1994; Garvican, 1998). The breast screening programme is organised in a three year cycle so that a whole Health Board area (in Scotland) is covered within a three year time frame. This is organised on a GP practice basis, so it would require data from a full three years in order to detect any differences of relevance between different populations within the screened group. Nevertheless this anomaly did not have any effect on the results of this study.

Hospital effects

Glasgow has five hospitals at which surgery for breast cancer is carried out; three on the north side of the River Clyde and two on the south side. Although there are areas of affluence on both sides of the river, the geography is such that Hospital 2 largely serves a deprived population, and in the years of our study only women who lived in deprived areas were treated there (Table 3.2, page 60). When analysing the data this posed a particular problem as there are several factors, which initially appeared to be related to deprivation, but on closer inspection seem to be related to different practices and services within this hospital. Issues for which this appears relevant are axillary surgery (Tables 4.8– 4.10, pages 102 - 104), days from referral letter to first clinic visit (Table 4.14) and availability of breast care nurses (Tables 6.2, 6.5 pages 163, 166).

Although no difference is shown in the type of breast surgery between those living in affluent and deprived areas, the data for axillary surgery show that women from affluent areas were more likely to have an axillary clearance performed. Table 4.9 (page 103) shows the data for axillary surgery by hospital and Table 4.10 divides these data for the affluent and deprived groups. These tables establish that whereas in Hospital 1, Hospital 3 and Hospital 4, the vast majority of women were receiving axillary clearance operations, in Hospital 2 half were receiving axillary clearances and half axillary sampling operations. The numbers in Hospital 5 are small, although most of the women received axillary sampling operations.

These differences could be explained in two ways. Firstly, the difference may be related to the surgeon's definition of what constitutes an axillary clearance and what constitutes an axillary sampling. When collecting data, the surgeon's own description of the operation in terms of whether a sampling operation or a clearance operation had been carried out was documented, rather than collecting the number of lymph nodes found in the pathology specimen. The reason for this decision was because this work was not being undertaken to scrutinise surgical practice but to broadly explore patterns of care. It may be that many women were receiving similar operations on their axillae, but the definition of 'clearance' or 'sampling' was different.

An alternative explanation is that different surgeons were choosing to perform different operations. The surgical management of the axilla in women with breast cancer is currently being investigated in Glasgow and compared to survival outcomes following these different practices (D Kingsmore, personal communication). The purpose of the present thesis is to comment on differences in management for women from affluent and deprived areas. It is extremely unlikely that the apparent difference in axillary surgery carried out between women living in affluent and deprived areas is related to deprivation, but is more likely due to the effect of the hospital where treatment was carried out (Tables 4.8, 4.10, pages 102, 104). Hospital of treatment is therefore a confounding factor in this study.

The primary / secondary care interface

Delays at time of diagnosis

There are three phases to delay at diagnosis:

1. The length of time from the patient first noticing an abnormality to the time she sees her GP. This may be because she has decided to delay and / or because she waited some time to get an appointment to see the GP. This time may be preceded by an earlier unmeasurable delay, from the time the abnormality appears until the woman notices it.

2. The length of time from seeing the GP to hospital clinic appointment. There may be a delay at this phase because the GP delays in making the referral or the hospital may have a waiting list for appointments.

3. The third possible source of delay is between first clinic appointment and definitive treatment

It has been suggested that the largest component of delay between noticing symptoms and attendance at out patient clinic is patient delay (Nichols et al. 1981). Facione (1993) also believes this contributes largely to delay. She carried out a literature review on patient and provider delay in women with breast cancer. Meta-analysis of 12 studies estimated that 34% of women with breast cancer symptoms delay seeking help for more than 3 months. She postulates many reasons for patient delay. Among these she suggests that the presence of co-morbid symptoms masking symptoms of new disease might result in increased patient delay. The present study is not able to comment on the delay before the woman first consults her GP, but there is information from the GP records data regarding delay in referral. This is discussed on page 124. The data regarding delay at phases 2 and 3 above are shown in Tables 4.14 – 4.16 (pages 108 – 110). These data demonstrate a statistically significant difference with women from affluent areas waiting for a median of six days for their appointment and women from deprived areas waiting seven days. However, this difference is not clinically relevant and is most likely due to the availability of clinics (Table 4.14) as Hospital 1, at the time of the study, had two new patient clinics each week, whereas the other hospitals had one new patient clinic each week. These differences are not relevant in terms of survival outcomes, but in a study which is exploring patterns of care for women in different social groups, the reasons behind these differences may be important in understanding variations in care. For this reason an exploration was made of whether women who waited in excess of 14 days for a first appointment were more likely to come from deprived areas (Table 4.15, page 109). This was not found to be the case.

Similar analyses were performed on data regarding the next possible phase for delay, i.e. the time from clinic visit to surgery and no significant difference was detected between women living in affluent areas and women living in deprived areas (Tables 4.14 and 4.16, pages 108 and 110). Interestingly published data regarding cardiac surgery in the West of Scotland produced a different finding. Pell et al. (2000) studied 26, 642 patients waiting for cardiac surgery in Scotland to investigate whether the length of time waiting for cardiac surgery was related to deprivation status. They found that patients in the most deprived categories waited on average three weeks longer than patients in the most affluent group. These data were collected from routinely collected data and it was not possible to investigate why this was the case.

The relevance of early diagnosis for women with breast cancer is clear from work identifying earlier detection of tumours as the reason for the drop in mortality from breast cancer observed since the mid-1980s (Stockton et al. 1997). The relationship of delay to outcome is debated in the literature. Feldman and colleagues showed delay to be associated with poor survival for women with aggressive cancers, but no association for women with less aggressive cancers (Feldman et al. 1983). The GIVIO group in Italy found a greater proportion of women with advanced cancers waiting in excess of 3 months compared to waiting less than 3 months (GIVIO Investigators 1986a). Caplan and Helzlsouer, (1993) reviewed the literature on delay in breast cancer and found the majority of studies prior to that time had investigated system delay rather than patient delay. They suggested that further studies of factors contributing to delay are needed in order to understand and then minimise delay. Afzelius and colleagues found that a long patient delay was associated with an unfavourable outcome, as opposed to a long doctor delay (Afzelius et al. 1994). The subject of delay in breast cancer was recently explored in *The Lancet* (Coates, 1999; Richards et al. 1999; Ramirez et al. 1999 and Sainsbury et al. 1999). Different conclusions were drawn by Sainsbury and colleagues, who found no adverse impact of increasing delay by providers, and by Richards and his team who, reporting findings from a large systematic review concluded that longer delay was likely to be associated with worse survival. Coates, in a commentary on these papers (Coates 1999) argued that the explanation for the contradicting outcomes may be due to biasing factors. One source of bias may be a lead time bias, for example, if diagnosis is delayed, and measurement of survival starts at date of diagnosis, then survival is shorter. Alternatively, cancers may present in different ways; more aggressive tumours may have a rapid progression of signs and symptoms, thus leading the patient to present sooner and doctors to act quicker, thus resulting in shorter delays with poorer prognosis tumours.

Further work on the cause and effect of delays in breast cancer may be difficult to achieve in the UK following the UK Government's decision to ensure that all women with a possible breast cancer are seen within five days (Labour Party manifesto, 1997). The patients in this study did not wait excessive lengths of time to be seen. It would be of interest to explore patient delay in view of the finding that women living in deprived areas were more likely to present with locally advanced and metastatic disease (Table 4.7, page 101). However this may also be affected by the Government's targets as publicity regarding fast appointment times is likely to encourage women to present earlier.

The numbers of days which women in the study spent in hospital at the time of their operations were also similar. Other work in the south east of England has shown differences in hospital management for affluent and deprived women with breast cancer (Pollock & Vickers, 1998). This study obtained data from the 1991 census on deprivation using Townsend scores and data from the

Office for National Statistics and the Department of Health on inpatient episodes. More deprived women were admitted as emergencies and more affluent women were admitted as day-cases. Information on emergency admissions is not available from the present study, but data on length of stay for women with breast cancer in Glasgow do not show a shorter period of time for women from affluent areas. This may reflect local practice, rather than stage at presentation as suggested by Pollock and Vickers.

Follow up

Data were collected regarding clinic appointments especially additional clinic visits between scheduled appointments, and failures to attend. The proportion of women requiring an early appointment (requested by either patient or GP) did not differ between the groups (Table 4.19, page 113). Although the numbers are small, deprived patients seem less likely to attend appointments (Table 4.19). This may relate to difficulty of getting to hospital rather than lack of concern about follow up. Pal et al (1998) report the findings of a survey of 2555 outpatients who failed to attend rheumatology appointments. Although the commonest reason cited was forgetting the appointment, a significant number (16% of new appointments, 18% of return appointments) were too ill to attend the appointment. This may be relevant in the group of patients being studied here.

There were no differences between women living in affluent areas and women living in deprived areas in terms of the total number of times they were seen at a clinic. Much of the literature is unclear regarding the value of follow up of women with breast cancer at hospital clinics and there is little evidence linking intensity of follow up to outcome (Scanlon et al. 1980; Belen Ojeda et al. 1987; Dewar & Kerr 1985; Holli & Hakama 1987; GIVIO Investigators 1994; Del Turco et al 1994; Dewar, 1995 and Grunfeld et al. 1996). It is unlikely that the difference detected in the groups will have affected outcome. Findings regarding follow up from all three studies are discussed in Chapter 7 (page 186).

Co-morbidity

Analysis of the number of hospital admissions in the 2 years following diagnosis of breast cancer (Table 4.18) showed women from both ends of the deprivation spectrum being admitted to hospital equally often with problems related to breast cancer. Clearly the numbers of admissions are small; breast cancer is a disease which is largely treated in the community while women live at home. However, admissions to hospital for conditions unconnected with breast cancer are more common amongst women living in deprived areas than affluent areas. This is an indication of a greater number of other illnesses in women from deprived areas which may in turn translate into the poorer survival figures which have been reported from all causes (Eames, Ben-Shlomo, & Marmot 1993). It may therefore be the case that the reasons underlying the poorer survival for women from deprived areas with breast cancer noted in this study, and by others, may not be due to their breast cancer or its management, but to other factors which result in deprived women (and also men) having a reduced life expectancy compared with affluent groups. Similar findings have been discovered by other researchers. Bernard and Smith (1998) investigated the relationship between emergency admissions in older people and deprivation. They examined emergency admissions for patients aged 65 and over in Trent over a year (13 305 people had at least one emergency admission). Emergency admissions increased significantly for each age group. They concluded that the inequalities noted for all age groups persisted into old age. They postulate that material deprivation may be a proxy for differences in social support and care received.

Co-morbidity is discussed again in relation to the GP records data collection (chapter 5, page 128) and its relevance for this study is discussed in detail in chapter 7 (page 182).

Communication with primary care

The data gathered from letters sent from hospital doctors to GPs are shown in Tables 4.20 and 4.21 (pages 114 and 115) and raise some interesting points about continuity of care. There are no differences between the two groups of women in terms of the information given to the GP after the first clinic visit (Table 4.20). Similarly, after surgery, there was no difference in either the amount or type of information sent to the GP regarding the diagnosis and operative procedure. However, the GP was informed in less than 50% of cases as to what the patient knew about their first visit. More GPs of women who lived in affluent areas received information about their patient's further management and the arrangements for follow up.

Generally, these data support the view that there is poor communication about what the patient is told about their disease and plans for management. The data discussed earlier about admissions to hospital showed how little time women with breast cancer spend in hospital following their first admission. This must increase the necessity of adequate information being passed from specialist to GP. There may be a variety of reasons why the GPs of women living in affluent areas are told more about further management plans or follow up plans. It may be that the letter reflects the discussion between specialist and patient, or alternatively that a hospital effect is seen here also rather than a deprivation effect. Others have also found problems with communication between primary and secondary care in the management of women with breast cancer. Van der Kam et al. (1998) studied communication between hospital specialists and GPs about patients with newly diagnosed breast cancer, by sending a postal questionnaire to GPs and asking about the experience of communication in the last patient diagnosed in the practice with breast cancer. Of the 150 who replied, 45% indicated that the patient had contacted them after their initial consultation with the surgeon, at which time less than half of the GPs had received a report from the surgeon. In addition, 44% of the GPs indicated that they experienced problems with communication from the specialist. If good communication is important in producing good holistic care, it is important that these differences are addressed.

Summary

The data presented and discussed in this chapter have shed light on several aspects of breast cancer care in relation to the central issue of this thesis, i.e. whether affluent women receive better care for breast cancer than deprived women.

In the population under study, larger numbers of women from deprived areas presented with advanced cancers. It is unclear whether the reason for these later presentations was due to delay in diagnosis or to there being cancers with differing biology in deprived groups. This study found no evidence to suggest that these advanced cancers in deprived women were due to practitioner or service delay.

Several differences in the management of women from affluent and deprived areas were identified. However, some of these (e.g. management of the axilla) could be explained by differences in hospital policy. Others were unlikely to have any significant impact on outcome (e.g. slightly shorter waits for affluent women). It is concerning that the GPs of women in affluent areas received more relevant information, although this may again relate to differing hospital practices.

Evidence has pointed to greater co-morbidity in women from deprived areas. This is interesting and may be very relevant in understanding the poorer outcomes for deprived women with breast cancer. Co-morbidity is discussed again in Chapter 7.

It may be that the reasons underlying the poorer survival for women from deprived areas with breast cancer are not due to their breast cancer or its management, but to other factors which result in deprived women having a reduced life expectancy from all causes compared with affluent groups (Eames, Ben-Shlomo & Marmot 1993).

TABLES

Table 4.1: Numbers of hospital case records requested and examined, divided according to hospital

	Records requested n	Records examined n
Western Infirmary	138	136
Victoria Infirmary	125	124
Royal Infirmary	80	79
Stobhill Hospital	45	45
Southern General Hospital	29	29
Private sector	4	4*
TOTAL	**421**	**417**

*Beatson Oncology Centre case records were examined only in these patients as the private sector records are not accessible.

Table 4.2: Pathological prognostic factors for women living in affluent and deprived areas

		AFFLUENT n = 146	DEPRIVED n = 220	Chi squared test result
SIZE				
	0 - 19mm	70 (51.5%)	106 (54.6%)	$X^2 = 0.53$
	20 - 49mm	62 (45.6%)	81 (41.8%)	**DF = 2**
	>50mm	4 (2.9%)	7 (3.6%)	**p = 0.76**
		*missing n =10**	missing n = 26*	
GRADE				
	1	17 (15.5%)	30 (19.2%)	$X^2 = 0.66$
	2	67 (60.9%)	92 (59.0%)	**DF = 2**
	3	26 (23.6%)	34 (21.8%)	**p = 0.72**
		*unclear / missing n = 36**	*unclear / missing n = 64**	
NODAL STATUS				
	Positive	48 (37.5%)	72 (36.7%)	$X^2 = 0.01$
	Negative	80 (62.5%)	124 (63.3%)	**DF = 1**
		*missing n = 18**	*missing n = 24**	**p = 0.88**

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* The data presented in this table were obtained from pathology reports within the case records. There are differences in the *n* in each cell due to differences in the information presented in the reports.

Table 4.3: Tumour size for screened and non screened women living in affluent and deprived areas

Tumour size		AFFLUENT	DEPRIVED	Chi squared test result
SCREENED POPULATION				
		*n = 38**	*n = 44**	
	0 - 19 mm	26 (68.4%)	35 (79.5%)	**Fisher's exact**
	20 - 49 mm	12 (31.6%)	7 (15.9%)	**test:**
	> 50 mm	0	2 (4.5%)	**p = 0.12**
NON SCREENED POPULATION				
		*n = 101**	*n = 169**	
	0 - 19 mm	44 (43.6%)	74 (43.8%)	**X^2 = 2.04**
	20 - 49mm	53 (52.5%)	81 (47.9%)	**DF = 2**
	> 50 mm	4 (4.0%)	14 (8.3%)	**p = 0.36**

* The data presented in this table were obtained from pathology reports within the case records. There are differences in the *n* in each cell due to differences in the information presented in the reports.

Table 4.4: Grade of tumour for screened and non screened women living in affluent and deprived areas

Grade of tumour	**AFFLUENT n (%)**	**DEPRIVED n (%)**	**Chi squared test result**
SCREENED POPULATION			
	*n = 33**	*n = 39**	
Grade 1	9 (27.3%)	12 (30.8%)	**$X^2 = 0.14$**
Grade 2	20 (60.6%)	23 (59.0%)	**DF = 2**
Grade 3	4 (12.1%)	4 (10.3%)	**p = 0.93**
NON SCREENED POPULATION			
	*n = 80**	*n = 133**	
Grade 1	8 (10.0%)	18 (13.5%)	**$X^2 = 0.58$**
Grade 2	49 (61.3%)	78 (58.6%)	**DF = 2**
Grade 3	23 (28.8%)	37 (27.8%)	**p = 0.74**

* The data presented in this table were obtained from pathology reports within the case records. There are differences in the *n* in each cell due to differences in the information presented in the reports.

Table 4.5: Nodal status for screened and non screened women living in affluent and deprived areas

Nodal status		AFFLUENT n (%)	DEPRIVED n (%)	Chi squared test result
SCREENED POPULATION				
		*n = 38**	*n = 44**	
	Positive	6 (15.8%)	12 (27.3%)	**X^2 = 1.57**
	Negative	32 (84.2%)	32 (72.7%)	**DF = 1**
				p = 0.21
NON SCREENED POPULATION				
		*n = 93**	*n = 171**	
	Positive	45 (48.8%)	77 (45.0%)	**X^2 = 0.27**
	Negative	48 (51.6%)	94 (55.0%)	**DF = 1**
				p = 0.60

* The data presented in this table were obtained from pathology reports within the case records. There are differences in the *n* in each cell due to differences in the information presented in the reports.

Table 4.6: Grade of tumour reported from hospital notes

Hospital	Grade 1 n (%) *n = 47*	Grade 2 n (%) *n = 158*	Grade 3 n (%) *n = 60*	Grade missing or unclear n (%) *n = 96*
1	14 (12.1%)	57 (49.1%)	21 (18.1%)	24 (20.7%)
2	9 (13.4%)	19 (28.4%)	5 (7.5%)	34 (50.7%)
3	19 (16.5%)	55 (47.8%)	23 (20.0%)	18 (15.7%)
4	5 (13.2%)	16 (42.1%)	6 (15.8%)	11 (28.9%)
5	0	11 (44.0%)	5 (20.0%)	9 (36.0%)

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*For the purpose of this analysis, the 4 patients in the study who had their original surgery carried out at a private hospital are excluded.

Table 4.7: Stage at presentation for women living in affluent and deprived areas

STAGE AT PRESENTATION	AFFLUENT n (%) *n = 156*	DEPRIVED n (%) *n = 260*
Early	146 (93.6%)	220 (84.6%)
Locally advanced or metastatic	10 (6.4%)	40 (15.4%)

Chi squared test results: $X^2 = 7.42$, DF = 1, p = 0.006

The 1 person missing from this table presented with breast and ovarian cancer simultaneously

Table 4.8 : Initial surgical treatment for women living in affluent and deprived areas

Type of surgery	AFFLUENT n (%)	DEPRIVED n (%)	Chi squared test result
SURGERY TO THE BREAST			
	n = 142	*n = 215*	
Mastectomy	64 (45.1%)	104 (48.4%)	$X^2 = 0.37$
			DF = 3
Conservation surgery	78 (54.9%)	111 (51.6%)	**p = 0.54**
SURGERY TO THE AXILLA			
	n = 129	*n = 196*	
Axillary clearance	123 (95.3%)	146 (74.5%)	$X^2 = 23.73$
			DF = 1
Axillary sampling	6 (4.7%)	50 (25.5%)	**p = 0.0000**

Table 4.9: Axillary clearance and sampling performed in NHS hospitals

Axillary surgery	**CLEARANCE** **n (%)** *n = 265*	**SAMPLING** **n (%)** *n = 56*	**Missing values / no surgery** *n = 41*
Hospital 1	107 (99.1%)	1 (0.9%)	9 (7.7%)
Hospital 2	31 (51.7%)	29 (48.3%)	7 (10.4%)
Hospital 3	103 (96.3%)	4 (3.7%)	8 (7.0%)
Hospital 4	21 (80.8%)	5 (19.2%)	12 (31.6%)
Hospital 5	3 (15.0%)	17 (85.0%)	5 (20.0%)

Table 4.10: Axillary clearance and sampling performed in NHS hospitals for women living in affluent and deprived areas

HOSPITAL	PROCEDURE	AFFLUENT n (%)	DEPRIVED n (%)	Chi squared test result
Hospital 1		*n = 45*	*n = 63*	**Fisher's exact**
	Clearance	44 (97.8%)	63 (100%)	**test:**
	Sampling	1 (2.2%)	0	**p = 0.42**
Hospital 2		*n = 0*	*n = 60*	
	Clearance		31 (51.7%)	
	Sampling		29 (48.3%)	
Hospital 3		*n = 64*	*n = 43*	**Fisher's exact**
	Clearance	64 (100%)	39 (90.7%)	**test:**
	Sampling	0	4 (9.3%)	**p = 0.02**
Hospital 4		*n = 14*	*n = 12*	**Fisher's exact**
	Clearance	11 (78.6%)	10 (83.3%)	**test:**
	Sampling	3 (21.4%)	2 (16.7%)	**p = 0.58**
Hospital 5		*n = 2*	*n = 18*	**Fisher's exact**
	Clearance	0	3 (16.7%)	**test:**
	Sampling	2 (100%)	15 (83.3%)	**p = 0.72**

Table 4.11 : Radiotherapy and adjuvant therapy for women with breast cancer living in affluent and deprived areas

Treatment received	AFFLUENT n (%)	DEPRIVED n (%)	Chi squared test result
	n = 135	*n = 208*	**$X^2 = 0.35$**
Radiotherapy	54 (40.0%)	90 (43.3%)	**DF = 1**
			p = 0.54
	n = 145	*n = 216*	**$X^2 = 2.37$**
Chemotherapy	29 (20.0%)	30 (13.9%)	**DF = 1**
			p = 0.12
	n = 145	*n = 216*	**$X^2 = 0.57$**
Endocrine therapy	128 (88.3%)	196 (90.7%)	**DF = 1**
			p = 0.45

Table 4.12: Referral to oncology and entry into clinical trials for women living in affluent and deprived areas

Treatment received	AFFLUENT n (%)	DEPRIVED n (%)	Chi squared test result
	n = 146	*n = 219*	
Referral to Oncology	84 (57.5%)	122 (55.7%)	**$X^2 = 0.11$** **DF = 1** **p = 0.73**
	n = 145	*n = 213*	
Entry in a clinical trial	3 (2.1%)	11 (5.2%)	**Fisher's exact test:** **p = 0.11**

Table 4.13: Presentation details for women living in affluent and deprived areas

Presentation	**AFFLUENT** **n (%)** *n = 151**	**DEPRIVED** **n (%)** *n = 257**
Screening	41 (27.1%)	48 (18.7%)
Primary care	95 (62.9%)	189 (73.5%)
Secondary care	9 (6.0%)	16 (6.2%)
Other or unclear	6 (4.0%)	4 (1.6%)

Chi squared test results: $X^2 = 8.67$, **DF = 4, p = 0.07**

*These data refer to the whole of the initial study population

Table 4.14: Number of days from GPs referral letter to clinic visit, and from first clinic visit to surgery for women living in affluent and deprived areas

	AFFLUENT (median, IQ range)	**DEPRIVED (median, IQ range)**	**Mann-Whitney test**
	*n = 117**	*n = 183**	
No of days from referral letter to clinic visit	6 IQ range: 1 - 13	7 IQ range: 4 - 20	Z = -2.72 p = 0.006
	*n = 129**	*n = 203**	
No of days between first clinic visit and surgery	16 IQ range: 9 - 24	17 IQ range: 10 - 25	Z = -1.53 p = 0.13

* Data are presented here for women with early disease for whom these data were available. If there was no referral letter in the notes , it was unclear when they were referred.

Table 4.15: Women in affluent and deprived areas waiting more than 14 days for first clinic appointment

Waiting time	**AFFLUENT** *n = 141*	**DEPRIVED** *n = 242*
14 days or less	86 (61.0%)	125 (51.7%)
>14 days	55 (39.0%)	117 (48.3%)

Chi squared test results: $X^2 = 3.14$, **DF = 1, p = 0.07**

Table 4.16: Women in affluent and deprived areas waiting more than 28 days for surgery

Waiting time	**AFFLUENT** *n = 130*	**DEPRIVED** *n = 227*
28 days or less	105 (80.8%)	174 (76.7%)
>28 days	25 (19.2%)	53 (23.3%)

Chi squared test results: $X^2 = 0.82$, DF = 1, $p = 0.36$

Table 4.17: In patient stay at time of initial surgery for women living in affluent and deprived areas

	AFFLUENT (median, IQ range) *n = 142*	**DEPRIVED (median, IQ range)** *n = 215*	**Mann-Whitney test**
No of in patient days at time of initial surgery	7 IQ range: 5 - 8	6 IQ range: 5 - 8	Z = - 1.04 p = 0.29

Table 4.18: Admissions in first 2 years after initial treatment for breast cancer for women living in affluent and deprived areas

	AFFLUENT n, (%)	DEPRIVED n, (%)	Chi squared test result
Breast cancer problems			
	n = 133	*n = 214*	
0 admissions	120 (90.2%)	180 (84.1%)	**$X^2 = 2.77$**
1 admission	10 (7.5%)	28 (13.1%)	**DF = 2**
>1 admission	3 (2.3%)	6 (2.8%)	**p = 0.25**
Other problems - NOT breast cancer related			
	n = 134	*n = 213*	
0 admissions	121 (90.3%)	161 (75.6%)	**$X^2 =12.15$**
1 admission	8 (6.0%)	38 (17.8%)	**DF =2**
>1 admission	5 (3.7%)	14 (6.6%)	**p = 0.002**

Table 4.19: Out patient attendances in first 2 years after diagnosis for women living in affluent and deprived areas: early and did not attend appointments

Out patient visits in first 2 years after treatment	AFFLUENT n, (%) *n = 135*	DEPRIVED n, (%) *n = 210*	Chi squared test result
Early appointments			
YES	13 (9.6%)	27 (12.9%)	$X^2 = 0.83$
			DF = 1
NO	122 (90.4%)	183 (87.1%)	p = 0.36
Did not attend for appointment			
YES	6 (4.4%)	25 (12.0%)	$X^2 = 5.65$
			DF = 1
NO	129 (95.6%)	184 (88.0%)	p = 0.017

Table 4.20: Content of correspondence from surgeons for women living in affluent and deprived areas : routine letters

Content of letters	AFFLUENT n, (%)	DEPRIVED n, (%)	Chi squared test result
Following initial clinic visit:			
	n = 116	*n = 200*	
Probable diagnosis	98 (84.5%)	164 (82.0%)	**$X^2 = 0.32$, DF = 1** **$p = 0.57$**
Management plan	106 (91.4%)	190 (95.0%)	**$X^2 = 1.62$, DF = 1** **$p = 0.20$**
Indication of what patient has been told*	58 (50.0%)	81 (40.5%)	**$X^2 = 2.68$, DF = 1** **$p = 0.10$**
Discharge letter from admission for primary surgery stating:			
	n = 119	*n = 191*	
Diagnosis	111 (93.3%)	176 (92.1%)	**$X^2 = 0.14$, DF = 1** **$p = 0.71$**
Operative procedure	115 (97.5%)	185 (96.9%)	**$X^2 = 0.09$, DF = 1** **$p = 0.76$**
Further management plans	92 (78.0%)	115 (60.2%)	**$X^2 = 10.4$, DF = 1** **$p = 0.001$**
Follow-up plan	112 (94.9%)	160 (83.8%)	**$X^2 = 8.6$, DF = 1** **$p = 0.003$**

*A very low hurdle was set when collecting this information for 'yes' to be recorded, e.g. "we have discussed this with the patient" or "the patient understands the situation", even though such phrases are ambiguous and fall short of the ideal explicit communication of what the patient knows.

Table 4.21: Content of correspondence from oncologists for women living in affluent and deprived areas: routine letters

Content of letters	AFFLUENT *n = 66*	DEPRIVED *n = 89*	Chi squared test result
Letter sent following first clinic visit:	66 (90.4%)	89 (80.2%)	**$X^2 = 3.47$, DF = 1 $p = 0.06$**
Details in letter following first clinic visit: management plan clear re: *			
Radiotherapy	56 (84.8%)	71 (79.8%)	**$X^2 = 0.66$, DF = 1 $p = 0.42$**
Chemotherapy	41 (62.1%)	50 (56.2%)	**$X^2 = 0.55$, DF = 1 $p = 0.46$**
Endocrine therapy	43 (65.2%)	56 (62.9%)	**$X^2 = 0.08$, DF = 1 $p = 0.77$**
Prognosis	3 (4.5%)	6 (6.7%)	**$X^2 = 0.33$, DF = 1 $p = 0.56$**
What patient has been told	8 (12.1%)	7 (7.9%)	**$X^2 = 0.78$, DF = 1 $p = 0.37$**
If Radiotherapy			
GP informed at start	45 (68.2%)	63 (70.8%)	**$X^2 = 0.12$, DF = 1 $p = 0.73$**
GP informed at end	48 (72.7%)	68 (76.4%)	**$X^2 = 0.27$, DF = 1 $p = 0.60$**
If Chemotherapy			
GP informed at start	24 (36.4%)	29 (32.6%)	**$X^2 = 0.24$, DF = 1 $p = 0.62$**
GP informed at end	19 (28.8%)	21 (23.6%)	**$X^2 = 0.53$, DF = 1 $p = 0.46$**
If endocrine therapy			
Info re duration	5 (7.6%)	5 (5.6%)	**$X^2 = 0.24$, DF = 1 $p = 0.62$**

*by 'management plan clear' was meant no ambiguity about further treatment. Each possible treatment did not have to be mentioned explicitly, e.g. "this lady only requires Tamoxifen" was recorded as being clear regarding radiotherapy and chemotherapy in addition to endocrine therapy.

Chapter 5

GENERAL PRACTICE RECORDS DATA COLLECTION

5.1 Introduction

The next step in the process of building up a picture of the experience of women with breast cancer was to examine GP case records. At the outset it was understood that GP records serve a different purpose to hospital records, and thus differ in the nature, content and detail of information. There are, for example, differences about the degree of effort which different practices will take to ensure that every contact with a patient is documented in the patient's notes. Even where a practice is careful to ensure the notes are written up, situations arise in primary care in which this may not occur, such as a GP visiting another family member and contributing something to the woman's care at the same time. In addition, GP notes are usually written as an aide memoire for the GP, rather than, as is the case for hospital records, for other health care professionals. Records were examined only for women who had presented with early stage disease.

5.2 Methods

The GPs of individual patients were identified from hospital case records and checked against the current list of GPs practising within Greater Glasgow Health Board. A database was created on Microsoft Excel with the GP names, practice addresses, patient names and study numbers. Practices were contacted by letter in batches of 20-25 at a time. Practices were spread throughout Glasgow, to reduce travelling, those within reasonably close proximity to each other being contacted at the same time. The letter sent to practices described the study, sought permission to review the case record and asked the GP's opinion regarding the suitability of the individual to be sent a postal questionnaire. A proforma for reply was enclosed, with a pre-paid reply envelope. Two separate reminders were sent to practices which did not reply. (Letters and form for reply shown in Appendix 2). On receipt of the reply, the practice was contacted and an appointment arranged to review the case record(s). Table 5.1 describes the number of practices involved, and the responses received. After the GP record review, Practitioner Services at the Health Board were contacted for permission to view the records of deceased patients: 51 deceased records were examined.

A proforma was developed for abstracting information from GP case records. An initial proforma was developed and modified after being piloted on some case records of women with breast cancer who were not in the study. (Appendix 3). The information collected included:

Background information, including current address

Presence of a problem list in the notes, and if present, whether breast cancer is mentioned. The presence of a problem list or summary is accepted as one marker of quality in general practice, and necessary for practices which are training practices.

Dates when first seen with a breast related problem and when referred to hospital

Consultation patterns before the diagnosis of breast cancer, including the number and content of consultations in the 12 months before diagnosis. A period of 15 months to 3 months pre diagnosis was used for these figures to avoid any bias from appointments immediately prior to diagnosis.

Consultation patterns after the diagnosis of breast cancer, including the number of consultations with the GP in the first and second 12 months after diagnosis and whether these consultations had taken place in the surgery or in the woman's home. Note was taken of particular references to either breast related problems or psychological problems. As different consulters have their own means of recording these items a wide range of possibly relevant comments were recorded. For example, a GP might record 'seems brighter' or 'chat - seems OK'. Although these are non-specific, notes such as these were recorded as consultations containing a psychological component.

Referral for management of psychological problem: any reference to referral to an external agency for counselling or support was recorded.

Communications received from secondary care: the number and nature of communications received after referral and in the 24 months following diagnosis were recorded. The dates of letters containing information regarding the diagnosis and treatment plan were recorded, in order to calculate delays in GPs receiving this information. A checklist was developed for assessing the content of correspondence between primary and secondary care which included the date of correspondence, the sending department, the reason for the letter (e.g. clinic attendance, discharge from in-patient stay, results of investigations), and the information contained in the letter, (i.e. details about the diagnosis, treatment plan, information given to patient, psychosocial care and plans for review.)

Breast screening centre: the dates of any letters from the breast screening centre were recorded along with the information contained in them.

Past medical history: significant physical and psychological morbidity in the past were recorded

Drug history: as this related to either breast cancer or psychological or psychiatric problems was recorded, with the dates of prescription of the medication.

Data were extracted from the records onto a pre-designed form (Appendix 4) and subsequently a data base was set up on SPSS for Windows (1999) and the data entered in to this, ready for analysis.

5.3 Results

Delay

There was no difference detected between women living in affluent and deprived areas in the number of days from the woman's first visit to her GP with a breast complaint to the date on the referral letter to the specialist (Table 5.2, page 132).

Problem list

A problem list was present in 93.0% of the notes of women living in affluent areas and in 76.2% of the notes of women living in deprived areas. (p = 0.09, Table 5.3, page 133). A problem list containing breast cancer as a diagnosis was found in 73.6% of the notes of women living in affluent areas and in 64.3% of the notes of women living in deprived areas (p = 0.10, Table 5.3, page 133). These results are not statistically significant but there is a trend in favour of the notes of women living in affluent areas being more likely to contain a problem list.

Consultations

A review of consultations in primary care in the year prior to diagnosis showed that a large majority of women had consulted their GP in that year but there was no difference between those living in affluent and deprived areas (86.0% *v* 88.1%, p = 0.61, Table 5.4, page 134). Only a small number consulted for a breast problem (7.4% *v* 5.7%, p = 0.57). There were few consultations in which the only reason for consultation appeared to be a request for a repeat prescription or for a sickness certificate.

In the years before diagnosis there was a trend towards more consultations by women living in deprived areas, with women in deprived areas consulting five times (median) compared to those in affluent areas consulting four times (Table 5.5, page 135), but this is not statistically significant.

In the immediate 12 months following diagnosis, all women consulted more often than prior to diagnosis, and women living in deprived areas consulted even more frequently (mean = 12.1) than women living in affluent areas (mean = 9.7). Although the frequency of consultations were less during the second year after diagnosis, it was still greater than pre-diagnosis, with women in deprived areas continuing to consult more often (mean = 8.8) than women in affluent areas (mean = 6.8, Table 5.6, page 136). It is interesting to concentrate on the data in Table 5.6 which shows those women who attended their GP on more than 12 occasions throughout the year. In the first year after diagnosis, 28.7% of affluent women and 41.4% of deprived women consulted more than 12 times. In the second year after diagnosis, 15.9% of affluent women and 27.0% of deprived women consulted more than 12 times. These data demonstrate an excess of frequent consultations among the deprived group in this study.

Analysis of the content of consultations during the two years after diagnosis shows no difference between women living in affluent and deprived areas in terms of whether the consultation contained discussion about breast cancer or psychological issues (Table 5.7, page 137). No difference was detected between the two groups in the percentage receiving home visits.

There was no difference in the number of women who had at least one consultation, the record of which contained a reference to their psychological state (women living in affluent areas: 59.8% *v* women living in deprived areas: 56.5%, p = 0.59). The numbers referred to psychiatry, psychology or to a counsellor were small (Table 5.8, page 138).

Communication with secondary care

No significant difference was detected between those living in affluent and deprived areas for the number of days from initial consultation until letter received containing diagnosis (women living in affluent areas: median = 26, IQR = 12 to 46; women living in deprived areas: median = 29, IQR = 14 to 57; Z = -1.04, p = 0.29) (Table 5.9, page 139). However the GPs of women who live in affluent areas were more likely to receive details of the management plan significantly earlier than the GPs of women living in deprived areas (women living in affluent areas: median = 43, women living in deprived areas: median = 54 days) (Table 5.9). There was no difference in the number of letters received in the first two years after diagnosis by the GPs of women living in affluent and deprived areas from either surgeons or oncologists (Table 5.10, page 140).

5.4 Discussion

Delay

Issues to do with delay have been discussed in Chapter 4 (page 88). The data gathered in this part of the study corroborated the data previously collected. There was no difference in the number of days from consultation to referral between affluent and deprived women (Table 5.2, page 132). This finding strengthens the case presented in Chapter 4 that this study produced no evidence of provider delay.

Problem list

These results regarding the presence of a problem list in the notes of women living in affluent and deprived areas showed no statistically significant difference but there was a trend in favour of the notes of women living in affluent areas being more likely to contain a problem list. This may be due to a larger number of training practices in these areas, but it is not possible to confirm this from this data set.

Reference has already been made to the particular nature of General Practice record keeping. Although there has been a move from Lloyd George to A4 records in Scotland, there is still a large variation between practices in the extent of record keeping. Records in general practice, with the exception of copies of letters to and from hospital specialists, are largely written for the GP himself / herself, rather than for others to read or as a potential research tool. It was therefore understood at all times during the GP data collection that the information contained in the notes was likely to be an under estimate of the total care that the women had received from their GPs.

It was not possible to collect data from other records in primary care, for example, those held by district nurses, Macmillan nurses, social workers etc.

The results therefore only contain data held within GP records, thus again underestimating contact within primary care.

Consultations

The data presented here show more consultations in women living in deprived areas compared with those living in affluent areas. This finding is not new. The decision making process which results in patients consulting their GP is complex, and has been extensively examined in the medical literature (van de Kar et al. 1992). It has been shown that the apparent greater use which patients in lower socio-economic groups make of the health service compared with those in higher socio-economic groups is eliminated when consideration is given to the higher morbidity of lower socio-economic groups (Blaxter 1984). Saxena at al. (1999) analysed the consulting behaviour of 106, 102 children in 60 practices. They found that consultation rates increased from social classes I – II through to IV – V (registrar general's classification). This was true for both serious and minor illnesses. The increased morbidity seen in adults in deprived communities thus appears to begin in childhood. The fourth national study (1991 – 92) of morbidity statistics from general practice found that patients of low socio-economic status were more likely to consult a general practitioner about a complaint subsequently diagnosed as cancer (McCormick, Fleming, & Charlton 1999). Further work from the same study carried out by Carr Hill at al. (1996) related socio-economic status and health factors to general practitioner workload. They show that the socio-economic characteristics of patients are an important predictor of consultation rates in general practice. Indeed other researchers have demonstrated that the greater workload caused by social disadvantage is underestimated by measuring simple consultation rates (Worrall, Rea, & Ben-Shlomo 1997). Balarajan et al. (1992) studied the impact of relative deprivation on general practice consultation rates. They predicted a difference of 1600 consultations per 2000 patients per year between the most affluent and the most deprived electoral wards. They also pointed out that consultation rates reflect demand rather than need, and therefore utilisation of health care among the socially deprived probably underestimates need. Campbell and Roland (1996) undertook a literature review of what was known about factors leading to patients consulting doctors. They concluded these were complex issues and determined by socio-economic and demographic factors, and as consultation rates were higher in socially disadvantaged areas this needs to be reflected by resource allocation.

The data presented here have also shown that following the diagnosis of breast cancer, not only are women living in deprived areas more likely to consult their GP more frequently than women living in affluent areas, but the number of consultations in both groups increases compared with prior to diagnosis (Table 5.6, page 136). This finding has not been previously reported in the literature and it has significant implications for workload in general practice. If women with breast cancer consult more often after diagnosis, then it is likely that similar consulting patterns are seen with other malignancies. This is particularly interesting as cancer treatment is largely considered to take place in secondary care (unlike other diseases which are mainly treated in primary care, or where shared care is usual, in which cases an increase in consultations after diagnosis would be expected e.g. ischaemic heart disease, rheumatoid arthritis, diabetes). Also, if the greater consultation rate demonstrated in breast cancer for those living in deprived areas was also seen in other cancers, this would have significant implications for the delivery of services in these areas. The incidence of breast cancer is greater in affluent women (although the demography of Glasgow is such that there are greater actual numbers in the deprived group in this study). However other cancers, most significantly lung cancer, have a greater incidence in deprived groups. The extra workload generated by a diagnosis of cancer therefore disproportionately falls on GPs who work in deprived areas.

Although it may seem obvious that GP consultations increase after a diagnosis such as breast cancer, it is not clear from these data the actual reasons leading to the decision to consult. In considering consulting patterns it is clear that there are many factors influencing a decision to consult the doctor. Van de Kar et al. (1992) suggested that need for information was an important reason to consult a GP. This may be relevant in considering the group of patients studied here. Others have shown that high consultation rates are usually associated with a clearly defined illness (Corney 1990; Westhead 1985 and Wright 1988) which would include this study population. Still other researchers have found that the fear that symptoms may be caused by internal physical causes leads to higher consultation rates (Pilowsky, Smith, & Katsikitis 1987; Garralda & Bailey 1987; Ingham & Miller 1983 and Martin et al. 1991). After a diagnosis of breast cancer, symptoms previously dismissed as minor and self limiting may induce a fear in the women that the symptom is related to their breast cancer, prompting them to present themselves to their GP. Other explanations for an increase in consultations after a diagnosis of breast cancer would include problems with breast or axillae wounds or issues to do with Tamoxifen, the most commonly used endocrine therapy, either due to initiation or side effects such as vasomotor symptoms. A minority of women with breast cancer who are still working may require sickness certification while receiving chemotherapy or radiotherapy. Women with breast cancer in Glasgow do not receive other treatments for breast cancer, such as chemotherapy, directly from general practice.

Many of the women in both groups had consultations which contained a reference to psychological issues (Table 5.8, page 138). This would be expected, as other workers have reported high rates of psychological morbidity following a diagnosis of breast cancer (Ford, Lewis, & Fallowfield 1995). Only a few patients were referred for specialist help for psychological or psychiatric problems; they may, however, have been referred from secondary care.

There are aspects of GP consultations about breast cancer which this study was unable to address. Only 10% of referrals of women who are referred to breast clinics with breast problems from primary care are diagnosed with breast cancer, the remaining 90% have benign breast disease (WD George, personal communication). The burden of breast disease in general practice remains unclear and is clearly much greater than that of breast cancer.

Communication with secondary care

The hospital data have already provided information regarding communication between primary and secondary care. Although the GPs of women living in deprived areas received the management plans later than the GPs of women living in affluent areas, this is likely to be related to the hospitals in which these women were seen. It could be postulated however that a reason for this might be the more difficult conditions in which professionals working in hospitals serving deprived communities work under, due to the burden of local morbidity and mortality.

Co-morbidity

Data presented from the hospital records data collection (Chapter 4) pointed to the presence of greater co-morbidity in women living in deprived areas (page 92). The argument for this is strengthened by the data presented here from primary care showing more consultations with GPs after diagnosis by women living in deprived areas (Table 5.6, page 136). As there are no more consultations with breast cancer related problems (Table 5.7, page 137), the excess in consultations may be due to consulting about other illnesses than breast cancer. From these data it appears likely that at least part of the explanation for the poor survival in women living in deprived areas is due to the presence of other diseases. It may be however that the excess consultations compared with women living in affluent areas are due not merely to more physical disease, but also to a greater burden of psychological distress and social problems.

Maiden at al. report the follow up of patients with rheumatoid arthritis in Glasgow over 12 years and found that while 36% of their patients living in the most affluent areas had died in this time, 61% of the patients in the most deprived areas had died (Maiden et al. 1999). They postulate the reasons for this and suggest that the adverse effect of deprivation on mortality may be exacerbated in patients with chronic diseases.

Further work with a larger study group needs to be done to address the issue of co-morbidity and its effect on deprivation in general and breast cancer mortality in particular.

The arguments regarding co-morbidity which pertain to the several sections of this thesis are discussed together in greater detail in Chapter 7 (page 182).

5.5 Summary

The data in this chapter show that women in deprived areas continue to consult their GP more frequently even up to 2 years after diagnosis, both compared with women living in affluent areas and with their own consultation rates before diagnosis. These findings may point to excess co-morbidity in women living in deprived areas, but do not support the hypothesis that the poorer outcomes of women in deprived areas are due to their having less access or contact with the health services.

TABLES

Table 5.1: Details of GP records collection

Number of patient GP records requested	366
Number of GP practices contacted	138
Number of patients in which the practice refused access	11
Number of patients whose GP requested that the patient be contacted first	8
Number of patients, whose GP was unknown initially or who moved practice	3
Number of deceased patients (who presented with early disease)	20
Number of deceased files seen	51
Total number of practices visited	119
Total number of records examined	**278** **(75.9% of requested)**

Table 5.2: Referral times for women living in affluent and deprived areas

Number of days from consultation to referral	AFFLUENT n, (%) total n = 64	DEPRIVED n, (%) total n = 93
same day	27 (42.2%)	47 (50.5%)
1 - 2 days	21 (32.8%)	19 (20.4%)
3 - 7 days	12 (18.8%)	18 (19.4%)
8 - 14 days	2 (3.1%)	3 (3.2%)
> 14 days	2 (3.1%)	6 (6.5%)
Mean, median, Inter Quartile Range	**Mean = 4, Median = 1** **IQR = 0 to 2.7**	**Mean = 4, Median = 0** **IQR = 0 to 4**

Mann Whitney: Z = -0.34, p = 0.74

Table 5.3: Presence of a problem list in GP records of women living in affluent and deprived areas

Problem list	AFFLUENT n, (%) *n = 110*	DEPRIVED n, (%) *n = 168*	Chi squared test result
Present	93 (84.5%)	128 (76.2%)	**$X^2 = 2.85$, DF = 1** **$p = 0.09$**
With breast cancer	81 (73.6%)*	108 (64.3%)#	**$X^2 = 2.67$, DF = 1** **$p = 0.10$**

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* 73.6% of all case notes, but 87.1% of notes which ontained a problem list

\# 64.3% of all case notes, but 84.4% of notes which contained a problem list

Table 5.4: Consultations in the year before diagnosis for women living in affluent and deprived areas

Consultations pre-diagnosis*	**AFFLUENT n, (%)** *Total n = 110*	**DEPRIVED n, (%)** *Total n = 168*	**Chi squared test results**
Number who consulted in the year before diagnosis	92 (86.0%)	141 (88.1%)	**$X^2 = 0.26$, DF = 1** **p = 0.61**
Number who consulted with a breast problem	8 (7.4%)	9 (5.7%)	**$X^2 = 0.32$, DF = 1** **p = 0.57**
Number who consulted for a repeat prescription	6 (5.6%)	13 (8.1%)	**$X^2 = 0.64$, DF = 1** **p = 0.42**
Number who consulted for a sick certificate	0	7 (4.4%)	**Fisher's exact test** **p = 0.03**

* A period of 15 months - 3 months pre diagnosis was used for these figures to avoid any bias from appointments immediately prior to diagnosis

Table 5.5: Frequency of consultations in the year before diagnosis for women living in affluent and deprived areas

Consultation frequency	AFFLUENT n (%)	DEPRIVED n (%)
None	15 (14.0%)	19 (11.9%)
1 - 2 times	24 (22.4%)	32 (20.0%)
3 - 5 times	33 (30.8%)	33 (20.6%)
6 - 8 times	15 (14.0%)	36 (22.5%)
9 - 12 times	10 (9.3%)	18 (11.3%)
> 12 times	10 (9.3 %)	22 (13.8%)
Mean, median, Inter Quartile Range	Mean = 4.9, Median = 4 IQR = 1 to 7	Mean = 6.2, Median = 5 IQR = 2 to 8

Mann Whitney: Z = -1.88, p = 0.06

Table 5.6: Frequency of consultations after diagnosis for women living in affluent and deprived areas

Consultation frequency	AFFLUENT n, (%)	DEPRIVED n, (%)
1ST YEAR AFTER DIAGNOSIS		
None	3 (2.8%)	2 (1.2%)
1 - 2 times	9 (8.3%)	13 (8.0%)
3 - 5 times	17 (15.7%)	18 (11.1%)
6 - 8 times	17 (15.7%)	26 (16.0%)
9 - 12 times	31 (28.7%)	36 (22.2%)
> 12 times	31 (28.7%)	67 (41.4%)
Mean, median, Inter Quartile Range	Mean = 9.7, Median = 10 IQR = 5 to 13	Mean = 12.1, Median = 11 IQR = 6 to 16
	Mann Whitney test	Z = -2.03 p = 0.04
2ND YEAR AFTER DIAGNOSIS		
None	11 (10.3%)	9 (5.9%)
1 - 2 times	20 (18.7%)	13 (8.6%)
3 - 5 times	24 (22.4%)	44 (28.9%)
6 - 8 times	18 (16.8%)	29 (19.1%)
9 - 12 times	17 (15.9%)	16 (10.5%)
> 12 times	17 (15.9%)	41 (27.0%)
Mean, median, Inter Quartile Range	Mean = 6.8, Median = 5 IQR = 2 to 10	Mean = 8.8, Median = 7 IQR = 4 to 13
	Mann Whitney test	Z = -2.49 p = 0.01

Table 5.7: Content and place of consultations with GP in first 2 years after diagnosis

Consultations	AFFLUENT median, IQ range	DEPRIVED median, IQ range	Mann Whitney test
CONTENT			
Total number of consultations	*n = 108** 15, (IQR: 8 to 24)	*n = 162** 17, (IQR: 10 to 26)	**Z = -2.09** **p = 0.036**
Breast cancer component	*n = 107* 5, (IQR: 2 to 9)	*n = 162* 5, (IQR: 3 to 10)	**Z = -0.93** **p = 0.34**
Psychological component	*n = 107* 1, (IQR: 0 - 4)	*n = 161* 1, (IQR: 0 - 3)	**Z = -0.98** **p = 0.32**
PLACE			
Surgery consultation	*n = 107* 14, (IQR: 6 - 22)	*n = 160* 16, (IQR: 9 - 24)	**Z = -2.6** **p = 0.009**
Home visits	*n = 107* 1, (IQR: 0 - 4)	*n = 159* 1, (IQR: 0 - 4)	**Z = 0.98** **p = 0.32**

* The missing numbers include women who died within the first year after diagnosis, and those for whom the clinical notes were absent. Numbers lost further down the table are those for whom it was impossible to extract the information from the notes, mainly due to the illegiblity of the handwriting.

Table 5.8: Outcome of consultations with psychological component for women from affluent and deprived areas

	AFFLUENT n (%) *n = 107*	DEPRIVED n (%) *n = 161*	Chi squared test result
Consultation with psychological component	64 (59.8%)	91 (56.5%)	**X^2 =0.28, DF = 1 p = 0.59**
Referral for psychological related to breast cancer*	9 (8.3%)	10 (6.3%)	**X^2 =0.40, DF = 1 p = 0.53**
Referral for psychological problem NOT related to breast cancer*	2 (1.9%)	8 (5.0%)	**Fisher's exact test p = 0.18**

*These referrals were to a variety of specialists in psychological problems including psychiatrists, psychologists, counsellors.

Table 5.9: Time from initial consultation with GP until hospital letter for women from affluent and deprived areas

Number of days from initial consultation.....	AFFLUENT median, IQ range	DEPRIVED median, IQ range	Mann Whitney test
	n = 68	*n = 106*	
...to letter containing diagnosis	26, IQR: 12 to 46	29, IQR: 14 to 57	Z = -1.04 p = 0.29
	n = 65	*n = 104*	
...to letter with management plan	43, IQR: 32 to 80	54, IQR 37 to 91	Z = -2.01 p = 0.04

Table 5.10: Letters from specialists for women from affluent and deprived areas

Number of letters.....	AFFLUENT median, IQ range	DEPRIVED median, IQ range	Mann Whitney test
	n = 109	*n = 162*	
From surgeons	9, IQR: 7 to 11	9, IQR: 7 to 11	**Z = -0.31** **p = 0.76**
	n = 109	*n = 161*	
From oncologists	3, IQR: 0 to 7	3, IQR: 0 to 7	**Z = -2.19** **p = 0.83**

Chapter 6

POSTAL QUESTIONNAIRE

6.1 Introduction

The hospital and general practice records data collections described in this thesis have provided an objective assessment of the care received by women with breast cancer from primary, secondary and tertiary care. However in order to reach a fuller understanding of the patterns of the care received by women with breast cancer it was necessary to obtain information from the women themselves. In addition to the care documented in hospital and general practice records, women may have received care or support from other agencies including breast care nurses, community nurses, voluntary organisations, friends and family. Women may also have obtained information about their disease and related issues from leaflets, magazines, newspapers, books and television. In order to obtain a more complete picture of the care women receive for breast cancer, it was important to understand what contribution these different agencies or information sources made to their overall care. In the context of this study it was particularly relevant to understand how the contributions made by different agencies or sources might vary across the social spectrum. In order to achieve these objectives, a postal questionnaire was developed and sent to the women in the study.

This stage of the study was particularly important as it removed the focus for understanding the experience of care received following a diagnosis of breast cancer from the point of view of health care professionals (especially doctors) to the women themselves.

6.2 Methods

Development of the questionnaire

A number of detailed discussions took place in which the author was joined by an experienced health services researcher and Professor Lesley Fallowfield (Fallowfield 1996; Fallowfield, Ford, & Lewis 1995; Fallowfield 1995a b, c and d; Fallowfield, Ford, & Lewis 1994; Fallowfield 1994; Fallowfield 1993a and b; Fallowfield 1990; Fallowfield et al. 1990; Fallowfield, Baum, & Maguire 1986). The purpose of these sessions was to identify the main themes of the questionnaire. As a result of this exercise, several important issues were addressed in the questionnaire.

i. General health status: The questionnaire included a section to measure the general health and psychological status of the women at the time of receiving the questionnaire. The SF-36 Health Survey is well validated and has been widely used in primary care research (Garratt et al. 1993; Jenkinson, Coulter, & Wright 1993; Ware 1993; Wilkin, Hallam, & Doggett 1992). The advantages of it are that it takes only between five and ten minutes to complete, is suitable for postal administration (Wilkin, Hallam, & Doggett 1992), and to be used as part of a longer, more specific questionnaire (Ware 1993). Although it was developed in the US, a British version is available and British studies have reported acceptable levels of internal consistency (Brazier et al. 1992; Jenkinson, Coulter, & Wright 1993). A recent study from Nottingham (Brown et al. 2000) has shown the SF-36 to be a more sensitive tool than the Nottingham Health Profile in studying survivors of myocardial infarction and emphasised again its suitability for UK patients. Permission was obtained for the use of the SF-36 from the Medical Outcomes Trust in the USA (Ware et al. 1993).

ii. Information issues: it was postulated that there may be a difference in information obtained by affluent and deprived groups. This was tested by asking where the respondents had received information about breast cancer: from family and friends, GP, hospital specialist, breast care nurse, alternative practitioner, three voluntary organisations who have offices in Glasgow, (BACUP, Breast Cancer Care, Tak Tent), magazines, newspapers, books, leaflets, or television. They were asked if there were other sources where they had obtained information, and if so to state them, and to say which of the information sources had been most helpful. As a separate question, the respondents were asked about where they had received advice about practical problems, and given the same list of options.

iii. Follow up at hospital clinics: Women were asked: *Do you still attend a hospital clinic about your breast problem? If Yes, how long is there between your appointments?*

iv. Help seeking behaviour: They were asked what action they were likely to take if they became anxious about their breast problem, and asked to reply: *yes/no/possibly.* The following options were presented: keep it to yourself, speak to family or friends, speak to your GP, contact breast care nurse, contact hospital specialist, contact voluntary organisation, such as BACUP or Tak Tent. They were then asked which of these had been most helpful in the past. The purpose of this question was to ask about behaviour related to the diagnosis of breast cancer and in so doing to discover whether the women perceived their GP to have a role in this regard.

v. Anxiety provoking issues: In addition to the psychological questions asked in SF-36, the questionnaire asked: "Do you worry about any of the following?" money problems, job security, breast cancer, other health problems, family problems and relationship problems. The respondents were asked to grade their responses *very much/somewhat/a little/not at all.*

vi. Lifestyle: As this study is primarily a comparison of the experiences of different social groups it was necessary to check that the social categories which had been assigned to individual women on the basis of postcode were correct. This was done by asking about home and car ownership, age at completion of full time education, and household income. The women were also asked about any changes to their lifestyle since they had received a diagnosis of breast cancer. It had been hypothesised that affluent women may be more likely to be active copers, and that this may be demonstrated by making changes to their life style. The women were asked about their smoking history, and about changes in their behaviour in a number of ways following diagnosis with breast cancer: started yoga, taken up more sport, avoided animal fats, eaten less red meat, used relaxation tapes, taken evening primrose oil, or taken vitamins.

Piloting of questionnaire

After developing the questionnaire, a pilot study was carried out at the breast clinic at the Beatson Oncology Centre. Following this pilot, a few changes were made to the questionnaire (Appendix 6).

Distribution of questionnaire

Before approaching women, their GP was contacted in order to ensure that no new circumstances had arisen which would make it undesirable for the women to receive a questionnaire.

The addresses of the patients had been obtained at the time of the GP data collection. The women were sent the questionnaire, with a covering letter (Appendix 7) and a reply paid envelope. Two reminders were subsequently sent to those who had not replied (Appendix 8). An overall response rate of 81% was achieved (Table 3.1).

6.3 Results

The results will be presented in this section in the order in which the questions appeared in the questionnaire (Appendix 6).

SF 36

For each of the SF-36 scales, with the exception of bodily pain, a statistically significant difference was demonstrated between women living in affluent and deprived areas. Women living in deprived areas were more likely to have lower scores (Table 6.1 page 162). The greatest degree of statistical significance was seen in the physical functioning, role - physical and mental health scales.

Information issues

Women were most likely to have obtained information about breast cancer from their hospital specialist, but women living in affluent areas were more likely to have done so than women living in deprived areas (94.8% *v* 76.0%, p = 0.0007, Table 6.2, page 163). Women from affluent areas were also more likely to have obtained information from breast care nurses (70.1% v 40.0%, p = 0.00007), and to have acquired information from their family and friends (29.9% *v* 16.0%, p = 0.027). More than half of the women had received information from their GP, and this was similar for the two groups (57.1% *v* 54.0%, p = 0.68). Very few women had received information from voluntary organisations. The organisation which was contacted for information most frequently was Breast Cancer Care; women living in affluent areas were more likely to remember having received information than women living in deprived areas (23.4% *v* 11.0%, p = 0.03).

There were differences between women living in affluent and deprived areas in terms of the types of media from which they had obtained information (Table 6.3, page 164). Women from affluent areas were more likely to have acquired information from magazines (50.6% *v* 33.0%, p = 0.02), from newspapers (45.5% *v* 22.0%, p = 0.0009) and from leaflets (49.4% *v* 31.0%, p = 0.013). Information was sought from books similarly in both groups (26.3% *v* 18.0%, p = 0.18). Women living in affluent areas were more likely to have obtained information from television news (45.5% *v* 26.0%, p = 0.007) than women from deprived areas. There was no statistical difference between the groups for television documentaries (53.2% *v* 39.0%, p = 0.06) or television drama (16.9% *v* 13.0%, p = 0.47). Analysis was carried out of information obtained from any source (Table 6.4, page 165). Most of the women who replied had obtained information either from family, friends, professionals or voluntary organisations, but the women from affluent areas more than the women from deprived areas (98.7% *v* 92.0%, p = 0.04). Information obtained from any of the media were more commonly acknowledged by women living in affluent areas (75.3% *v* 53.0%, p = 0.002).

There are only three categories where more than 20% of the women obtained advice regarding practical problems: hospital specialists, breast care nurses (Table 6.5, page 166) and leaflets (Table 6.6, page 167). There was no difference between practical advice obtained from hospital specialists for either group (32.5% *v* 36.0%, p = 0.62), but women from affluent areas were more likely to have obtained advice from a breast care nurse (62.3% *v* 42.0%, p = 0.007) and used leaflets (23.4% *v* 11.0%, p = 0.03) than women from deprived areas.

Follow up at hospital clinics

The majority of the women were still being seen either 3 - 6 monthly or 6 - 12 monthly, with no difference between women living in affluent and deprived areas. Only 3.9% of the women from affluent areas and 4.0% of the women from deprived areas did not attend a hospital clinic (Table 6.7, page 168). This was not statistically significant and was in keeping with the data from the hospital records data collection.

Help seeking behaviour

In order to discover the different ways women from different backgrounds responded to anxiety the following question was asked: *If you become anxious about your breast problem, which, if any, of the following are you most likely to do?* (Table 6.8, page 169). There was no statistically significant difference between the groups for any of the options presented: keep it to yourself, speak to family or friends, speak to your GP, contact breast care nurse, contact hospital specialist, contact a voluntary organisation, such as BACUP or Tak Tent. The most likely action of the respondents if they became anxious was to speak to their GP (70.8% of respondents from affluent areas, 72.4% of respondents from deprived areas), contact hospital specialist (60.6% v 67.1) or speak to family or friends (50.8% v, 53.4%).

Anxiety provoking issues

Table 6.9 (page 170) records data from responses to the question - *do you worry about any of the following?* The respondents were offered the responses *very much / somewhat / a little / not at all.* These data were analysed comparing the response "very much" with all other responses. Only small numbers of women reported "very much" anxiety, the commonest cause being anxiety about breast cancer, with no difference shown between women living in affluent and deprived areas (23.0% *v* 30.1%, p = 0.30). The areas in which a difference between the groups were detected all demonstrated greater anxiety in women living in deprived areas: anxiety regarding money (2.8% *v* 12.2%, p = 0.02), anxiety regarding other health problems (8.2% *v* 22.1%, p = 0.02) and anxiety about family problems (6.9% *v* 17.5%, p = 0.049).

Lifestyle issues

Women from affluent areas were more likely to have never smoked than women from deprived areas (49.4% *v* 30.9%), but women from deprived areas were more likely to be ex-smokers (35.1% *v* 38.1%) or to be current smokers (15.6% *v* 30.9%) (Table 6.10, page 171).

The respondents were asked about changes they had made to their lifestyle following the diagnosis of their breast problem (Table 6.11, page 172). Changes in diet was the most commonly cited of the options offered, with women from affluent areas more likely to have avoided animal fats (51.9% *v* 33.0%, p = 0.01) and more likely to have eaten less red meat (57.1% *v* 42.0%, p = 0.04).

Breast cancer was not a cause of a change in working situation for many women from either affluent and deprived areas (Table 6.12, page 173).

The social status of the respondents has been discussed in chapter 3.

6.4 Discussion

Each of the subjects areas in the questionnaire will be discussed in the order they were presented in the previous results section (6.3). As this chapter was being prepared it became apparent that the breadth of the material was so great that a thesis could have been constructed around the questionnaire findings themselves. The intention in discussing the findings from the questionnaire study in this chapter is to relate these findings to the theme of this thesis, i.e. the balance of care for women with breast cancer in affluent and deprived areas. What follows therefore, is not a complete discussion of each of these areas, but an attempt to refer to appropriate literature and it relationship to this study.

SF-36

In this study, women living in affluent areas were found to have statistically significant higher SF-36 scores for each domain, with the exception of bodily pain. SF-36 has been used in a number of general practice populations and people from deprived areas have demonstrated poorer scores. Brazier et al. (1992) compared the SF-36 with the Nottingham health profile and found the SF-36 a good instrument for use in a general practice population. In their study of 1980 patients in two Sheffield general practices, they compared SF-36 scores with social class and found health perception decreased with lower social class across all dimensions except for general health perception. Hemingway et al. (1997a) used the SF-36 questionnaire as part of the third phase of the Whitehall II study. It was administered to 5766 men and 2589 women. They found low socio-economic status to be associated with poor health functioning. The same team also used SF-36 to measure change in population health (Hemingway et al. 1997b) and found that socio-economic status was associated inversely with baseline functioning. Jenkinson et al. (1993) used data from the Oxford healthy lifestyles survey to investigate the sensitivity of the SF-36 questionnaire to variations in health between social classes. They conclude that the SF-36 is capable of detecting differences between social classes in terms of self perceived health. These findings are similar to this study in which a statistically significant difference was found between women living in affluent and deprived areas in favour of those living in affluent areas for each of the SF-36 scales, with the exception of bodily pain (Table 6.1, page 162).

The SF-36 questionnaire has also been shown to been useful as a measure of outcome within the NHS. Garratt et al. (1993) studied over 1700 patients in Aberdeen with four common conditions – low back pain, menorrhagia, suspected peptic ulcer, and varicose veins. They found the SF-36 to be acceptable to patients, and have confirmed its psychometric validity and reliability within their patient population. In their discussion they emphasise that they recommend the SF-36 to be used "not as a self contained questionnaire but as part of a more comprehensive portfolio of measures to assess many aspects of patient outcome." This is the way in which SF-36 has been used in this study.

The differences shown in scoring SF-36 between affluent and deprived groups have also been shown in breast cancer studies. Ashing-Giwa et al. (1999) carried out a study describing the quality of life of long term breast cancer survivors in California. They used the SF-36 questionnaire as part of their study. They concluded that differences in quality of life were due to socio-economic and life-burden factors and not to ethnicity. The results from the present study confirm these findings in a UK population. A further study from the US by Woolf et al. (1998) studied functional status in an inner city family practice centre using SF-36 and found a correlation between low socio-economic status and functional status scores. An example from their findings is patients with a yearly income of less than $15,000 had lower mean physical function scores than those reported nationally for patients with hypertension, diabetes, depression, recent myocardial infarction. It is not surprising that the same pattern was found in the group of women with breast cancer in this study. It may therefore be postulated that this difference is not related to breast cancer or the impact of breast cancer on the lives of these women but due to the inherent problems associated with deprivation.

The use of SF-36 in other deprived populations has shown similar results to this study. It is unclear why the result for bodily pain was an exception to the pattern seen in the remainder of the dimensions of the questionnaire and this finding requires further investigation. This was not seen in the Californian study of breast cancer survivors (Ashing-Giwa, Ganz, & Petersen 1999). This study is the first in the UK to use SF-36 to study affluent and deprived populations with breast cancer.

Information issues

The obtaining of information is an important issue because research in the West of Scotland has indicated that the vast majority of cancer patients want to be informed about their illness (Meredith et al. 1996). Most women in the study obtained information from their hospital specialist. However, women from affluent areas were significantly more likely to do so compared with women from deprived areas (Table 6.2). The data regarding information provided by this study related to the sources of information rather than to the amount or quality of the information. The questions in the questionnaire explored whether women from affluent and deprived areas had obtained information relating to breast cancer from the same or different sources, to further the investigation being pursued on the balance of care for women with breast cancer. Therefore, the data on information only covers several aspects of what is an extensive subject.

Few studies have described the sources from which women with breast cancer obtained information. Most have addressed the issue of the actual information received and whether or not perceived information needs were met. Meredith et al. (1996) in a study in the west of Scotland asked 259 cancer patients (including women with breast cancer) about their need to know whether they had cancer, the medical name of their illness, progress through treatment, how treatment works, side effects, chances of cure and treatment options. They found that almost all patients wanted to know about their diagnosis. They related some of their results to deprivation categories. More patients from affluent areas compared with those from deprived areas wanted to know that their illness was cancer. When asked about information about all possible treatments, affluent patients did seem to want more information. Some years ago the GIVIO investigators in Italy (GIVIO Investigators 1986b) assessed the quantity and quality of information received by women with breast cancer from their doctors. They found that the quality of information was directly and independently related to length of patients' education.

There have been some studies which have concentrated on information sources. Ashbury et al. (1998) studied a group of 913 cancer patients in Canada recruited through newspaper advertisements, 64% of whom were women with breast cancer. Their particular interest was to investigate whether the symptoms which patients with cancer experience were being addressed and in the context of their questionnaire study, they asked about helpful sources of information. Nurses (61%), specialists (61%) and other cancer patients (60%) were reported by respondents to be helpful sources of information. This study did not relate the findings to any socio-economic or demographic factors. In Meredith's Glasgow study (Meredith et al 1996) all patients reported a preference for the diagnosis to be given by a hospital specialist. Fallowfield et al (1994, 1995) had previously reported 94% of patients in a sample of 101 expressing a desire for as much information as possible from their Oncologist.

It is unclear why affluent women in this study were more likely than deprived women to report having received information from hospital specialists and breast care nurses (Table 6.2, page 163). Several explanations are possible as the reasons for this apparent difference.

One of the hospitals in the study did not appoint a breast care nurse until the latter part of the second year of the study (T. Cooke, personal communication). The specialists in this particular hospital only saw women from deprived areas, so this may have biased the results. Although this may explain the predominance of affluent women having received information from a breast care nurse, it does not explain the difference with respect to breast specialists. However, specialists working in hospitals serving deprived communities may be more hard pressed and have less time to explore patients' information needs, and less time to reinforce information regarding breast cancer.

An alternative explanation is that it may be that more of the affluent women in this study remembered receiving information from hospital specialists and breast care nurses because it was their personal preference to seek information from these professionals, rather than any failure on the part of the health care professionals with respect to more deprived patients.

Another explanation is to do with recall bias. This questionnaire was sent out several years after diagnosis. Many factors may influence a woman's recall of life events which have taken place in the intervening years, which may be different for different socio-economic groups. In addition the women who replied to the questionnaire were the survivors. Having survived breast cancer may affect the view that one has of the treatment received and the experience of the disease. It is possible that the same questionnaire given to women recently diagnosed with breast cancer would produce different results. The semi-structured interviews reported by Meredith et al. (1996) were conducted within nine weeks of patients being told that they had cancer.

The variety of possible information sources from which women may obtain information regarding their breast cancer can be problematic. Van Wersh et al. (1997) in a study in the Netherlands, highlight the issue of potential gaps in the information women receive due to the multi-disciplinary nature of care. They developed a care protocol in an attempt to overcome these potential gaps. This protocol received positive evaluation, but the main relevance of their paper for this thesis is the reminder of the potential difficulties arising from such a variety of information sources as were identified by the respondents to the questionnaire in this study.

Few women in the current study contacted voluntary organisations (Table 6.2 and 6.5, pages 163 and 166). There may be several reasons for this. BACUP (Slevin et al. 1988), the British Association of Cancer United Patients set an office up in Glasgow after the years this study covers. Their information books were available, but women may not recall some years later the organisation that published the books they read. In asking women these questions there was an awareness that there would be recall bias, but an assumption that this would be the same for women from affluent and deprived areas. For each of the possible media sources suggested (books, magazines, newspapers, TV) the affluent were more likely to have sought information (Table 6.3, page 164). This may be because affluent women are more likely to buy publications in which articles about cancer occur. It was also impossible to know at what stage in their cancer journey women had obtained information about breast cancer. In addition it would be a mistake to assume that the inclusion of questions on media sources as information was a sign of approval of all the information presented by the media regarding breast cancer. A recent study in Glasgow highlights the extensive coverage of 'breast cancer genetics' and the reasons why this is so attractive to the media, despite the relative rarity of these issues in clinical practice (Henderson and Kitzinger, 1999). However, as a potentially powerful source of information on diseases, the media cannot be underestimated, even if the messages may be skewed.

An information source missing from the questionnaire is the World Wide Web. This would of necessity be included in any such questionnaire in the future. As this study population developed breast cancer in 1992 and 1993 this was not relevant as use of the Internet was minimal then. However some work has been carried out in the use of the Internet as a tool for obtaining information (and support and empowerment). Sharf (1997) discusses the 'Breast Cancer List,' an on-line discussion group formed "for the discussion of any issue relating to breast cancer." This article discusses the benefits of the list as a community of individuals interested in breast cancer but acknowledges it is not a representative sample of people concerned with breast cancer. For example, ethnicity and socio-economic status are rarely mentioned within messages. Sharf analysed the content of this list and found that the most common mailings were informational requests and responses. The relevance of this to the current study is perhaps the demonstration of unmet informational needs. As has been discussed with regards to the media above, the information available on the World Wide Web regarding disease is variable. Impicciatore et al. (1997) demonstrate this, using managing fever in children at home as an example. Only four out of 41 web sites provided accurate and complete information on this subject. It is likely that similar findings would be obtained in the case of breast cancer.

This study is the first reported study to investigate the possible differences in information sources due to socio-economic differences. It emphasises the important role which health professionals have as the source of information about breast cancer and its management. Further studies regarding information given to breast cancer patients need to explore whether there are different informational needs in affluent and deprived groups.

Follow up

The data showed that the majority of the respondents were still attending hospital follow up. This corroborated the data that has been presented from the hospital data collection and will be discussed in detail in the general discussion in chapter 7.

Help seeking behaviour

In addition to understanding about the information sources remembered by women, the questionnaire asked about their current behaviour if they became anxious about breast cancer. This question is of course free of recall bias, but only reflects what women imagine they will do if such a circumstance arose. Over 70% of women from both deprived and affluent areas reported they would contact their GP if they became anxious about their breast cancer. It is interesting both that no difference was found between women from affluent and deprived areas in this respect, and that this was the most likely behaviour for all women. This demonstrates that these Glasgow women considered their

GP the first point of contact. Patients clearly viewed their GP as important as their hospital consultant in worrying situations. It may be this is because of the gatekeeper function of general practice in the UK. However respondents were more likely to discuss their anxiety with professionals than with their family and friends. This finding is of particular interest, as prior to this research, the author sent a questionnaire to GPs in the West of Scotland to explore their perceived role in breast cancer care (Macleod et al. 1998). Among other questions, the GPs were asked who (hospital consultant, GP or both) they thought were responsible for different aspects of the care of women with breast cancer. Almost half (48.3%) replied that psychosocial issues were mainly or exclusively the concern of GPs and 86.9% felt that family issues were mainly or exclusively the responsibility of GPs. Although the precise questions to women with breast cancer and GPs in these two data sources (the GP questionnaire and the questionnaire to women in this study) are different, the findings seem to indicate that both GPs and patients viewed the GP's role to be important in the management of breast cancer.

It is also interesting to relate this finding to the data obtained from GP records (chapter 5) which showed increased consultation rates in the first two years after diagnosis. It could therefore be postulated that these additional contacts had been helpful in strengthening the doctor - patient relationship, which then may have resulted in the respondents to the questionnaire stating that their most likely action if anxious about breast cancer would be to speak to their GP. If the increased consultation rate which was seen in the first two years after diagnosis persisted into following years, it may be that these women were seeing their GPs regularly anyway. It may be that this increased contact which resulted in both GPs and women rating contact with GPs important.

Anxiety provoking issues

In order to place the degree of anxiety caused by breast cancer in the context of other aspects of the respondents' lives, they were asked about the issues which caused them most anxiety. Not surprisingly, women living in deprived areas reported a greater degree of anxiety regarding money, other health problems and family problems (Table 6.9). There is controversy about the relationship between psychosocial issues and breast cancer outcomes. The relevance of discussing this here is related to the different experience women form affluent and deprived areas with breast cancer may have.

It is hardly necessary to reproduce here the evidence for women in lower socio-economic groups having lower income levels. The definition used here for socio-economic status included factors which result from or indicate lower income. It therefore makes intuitive sense that there is a relationship between low income and worrying about money. The larger numbers of deprived women reporting worry about money emphasises again the multi-factorial nature of the burdens of deprivation.

Elsewhere in this thesis the importance of co-morbidity has been discussed (pages 92, 128, 182). These arguments are strengthened by the finding that women from deprived areas worry more than women from affluent areas about other health problems.

Pinder at al. (1993) examined the prevalence of psychiatric disorder and breast cancer in 139 women with advanced breast cancer. Clinical depression was significantly more prevalent amongst patients in the lower social classes. These data produce similar results to those obtained by Dean at al. (1987) in a study of women with early breast cancer. They postulate reasons for these findings, and suggest that deprived women may experience increased 'psychosocial adversity' compared to more affluent women and may experience greater financial hardship. The current study supports these findings.

Marshall and Funch (1983) in a small cohort of women with breast cancer (352 women) produced some evidence that both stressful events and the extent of an individual's social network can impact on survival from breast cancer. However, stage at diagnosis was a much more powerful indicator of survival than either of these social aspects. Maunsell et al. (1995) investigated the association between breast cancer survival and social support in 224 women in Quebec who were followed up for 7 years. They found a positive association between social support and survival in this small study. One of the implications of their finding was that the traditional division of research questions into medical and psychosocial aspects may hinder the understanding of breast cancer. In this study these different aspects have been integrated for this reason

Other researchers have emphasised the relationship of socio-economic status and other psychosocial aspects not explored in this study. Bosma et al. (1999) studied the relationship between socio-economic status and perceived control beliefs in 2462 general patients in the Netherlands. They report a correlation between low socio-economic status and perceived low control and between low socio-economic status and mortality. Although the study under consideration did not include locus of control these data from the Netherlands are relevant in that they emphasise the complexity of the issues involved in socio-economic status research and also the importance of an individual's psychological response. Watson et al. (1999) investigated the psychological responses of 578 women with breast cancer and found that a high helplessness / hopelessness score had a moderate detrimental effect.

All these studies confirm the close interaction between physical and psycho-social issues. The complexities of these issues are enormous. Although this is accepted by many authors, there is little literature on the particular psycho-social problems confronted by women who have breast cancer and are of low socio-economic status. In a review of the literature on psychosocial concerns and breast cancer, Leedham and Ganz (1999) do not mention low socio-economic status as a factor for particular concern. As Visser and Herbert concluded in an editorial in 1999, 'more longitudinal studies are needed to unravel the role of psychosocial factors in cancer.'

Lifestyle issues

Women from deprived areas were more likely to have smoked at some time in their lives than women from affluent areas. This is in keeping with known demographic trends for cigarette smoking. It may be that some of the co-morbidity which has been observed in this study may be related to cigarette smoking among the women in the deprived group. It is not possible to tell this from the data which were collected.

More women from affluent areas were in employment compared to women from deprived areas (Table 3.6). However, the diagnosis of breast cancer did not appear to have been a factor causing change in the working situation of women from either affluent or deprived areas. This may be due to the age at which women get breast cancer (commonest age range 55 – 65 years). Other lifestyle changes reported by affluent women might reflect the sources from which they had obtained information about breast cancer.

6.5 Summary

The data presented in this chapter from the postal questionnaire have provided further information regarding the balance of care for women with breast cancer in affluent and deprived areas.

Deprived women had poorer SF-36 scores than women living in affluent areas, in keeping with other literature and therefore helping to validate the results from the questionnaire.

The differences in the information sources reported by these groups of women require further investigation.

Women in both groups claimed they would contact their GP if they became anxious about a breast problem. This emphasises the role of the GP in the management of breast cancer, especially when considered alongside the data in chapter 5 regarding increased consultation rates.

Women in deprived areas experienced greater anxiety about other health problems than women in affluent areas. This fits with the findings of greater co-morbidity among these women. The greater degree of anxiety expressed by women living in deprived areas taken with the poorer SF-36 scores points to greater psychological distress and more social problems. It is likely that these factors impact on the eventual outcomes of women living in deprived areas, whether or not they suffer from breast cancer.

TABLES

Table 6.1: SF 36 scale scores for women from affluent and deprived areas

SF 36 Scale	AFFLUENT *n* Median, (IQR)	DEPRIVED *n* Median, (IQR)	Mann - Whitney test
Physical functioning	*n = 74* 80 (54 - 95)	*n = 95* 61 (20 - 80)	**Z = -3.97** **p = 0.0001**
Role - physical	*n = 75* 100 (67 - 100)	*n = 87* 50 (0 - 100)	**Z = -2.59** **p = 0.0096**
Bodily pain	*n = 75* 46 (44 - 100)	*n = 100* 56 (44 - 100)	**Z = -1.65** **p = 0.09**
Mental health	*n = 75* 76 (64 - 88)	*n = 96* 66 (45 - 84)	**Z = -3.36** **p = 0.0008**
Role - emotional	*n = 74* 100 (67 - 100)	*n = 86* 100 (0 - 100)	**Z = -2.48** **p = 0.01**
Social functioning	*n = 76* 87 (78 - 100)	*n = 99* 75 (50 - 100)	**Z = -2.04** **p = 0.04**
Vitality	*n = 75* 60 (45 - 80)	*n = 96* 50 (30 - 65)	**Z = -2.39** **p = 0.02**
General health perception	*n = 74* 77 (52 - 87)	*n = 88* 59 (35 - 77)	**Z = -3.09** **p = 0.002**

Table 6.2: The information seeking behaviour of women living in affluent and deprived areas from individuals, health care workers and voluntary organisations

Information source	AFFLUENT n (% of affluent group) *total n = 77*	DEPRIVED n (% of deprived group) *total n = 100*	Chi squared test results
Family and friends	23 (29.9%)	16 (16.0%)	**$X^2 = 4.87$, DF = 1 p = 0.027**
GP	44 (57.1%)	54 (54.0%)	**$X^2 = 0.17$, DF = 1 p = 0.68**
Hospital specialist	73 (94.8%)	76 (76.0%)	**$X^2 = 11.55$, DF = 1 p = 0.0007**
Breast care nurse	54 (70.1%)	40 (40.0%)	**$X^2 = 15.86$, DF = 1 p = 0.00007**
Alternative practitioner	2 (2.6%)	2 (2.0%)	**Fisher's exact test p = 0.79**
Voluntary organisations:			
BACUP	12 (15.8%)	7 (7.0%)	**$X^2 = 3.46$, DF = 1 p = 0.06**
Breast Cancer Care	18 (23.4%)	11 (11.0%)	**$X^2 = 4.86$, DF = 1 p = 0.03**
Tak Tent	4 (5.2%)	1 (1.0%)	**Fisher's exact test p = 0.09**

This table shows those who answered yes to the statement: "We would like to know about where you have obtained information relating to your breast problem (e.g.causes, treatment)".

Table 6.3: The information seeking behaviour of women from affluent and deprived areas from the media

Information source	AFFLUENT n (% of affluent. group) *total n = 77*	DEPRIVED n (% of deprived. group) *total n = 100*	Chi squared test results
Magazines	39 (50.6%)	33 (33.0%)	**$X^2 = 5.6$, DF = 1 p = 0.02**
Newspapers	35 (45.5%)	22 (22.0%)	**$X^2 = 10.96$, DF = 1 p = 0.0009**
Books	20 (26.3%)	18 (18.0%)	**$X^2 = 1.76$, DF = 1 p = 0.18**
Leaflets	38 (49.4%)	31 (31.0%)	**$X^2 = 6.16$, DF = 1 p = 0.013**
TV news	35 (45.5%)	26 (26.0%)	**$X^2 = 7.29$, DF = 1 p = 0.007**
TV documentaries	41 (53.2%)	39 (39.0%)	**$X^2 = 3.56$, DF = 1 p = 0.06**
TV drama	13 (16.9%)	13 (13.0%)	**$X^2 = 0.52$, DF = 1 p = 0.47**

This table shows those who answered yes to the statement: "We would like to know about where you have obtained information relating to your breast problem (e.g.causes, treatment)".

Table 6.4: Information obtained from any source for women living in affluent and deprived areas

Information source	**AFFLUENT** **n (% of aff. group)** *total n = 77*	**DEPRIVED** **n (% of dep. group)** *total n = 100*	**Chi squared test results**
Family and friends, hospital specialists, breast care nurses, alternative practitioners, BACUP, Breast Cancer Care, Tak Tent	76 (98.7%)	92 (92.0%)	**$X^2 = 4.05$** **DF = 1** **$p = 0.04$**
Magazines Newspapers Books Leaflets, TV	58 (75.3%)	53 (53.0%)	**$X^2 = 9.27$** **DF = 1** **$p = 0.002$**

This table shows those who answered positively about any of the sources listed. The women who replied no (or didn't reply) are those who did so to every option.

Table 6.5: Advice regarding practical problems seeking behaviour of women from affluent and deprived areas from individuals, health care workers and voluntary organisations

Information source	AFFLUENT n (% of aff. group) *total n = 77*	DEPRIVED n (% of dep. group) *total n = 100*	Chi squared test results
Family and friends	10 (13.0%)	10 (10.0%)	**$X^2 = 0.39$, DF = 1 p = 0.53**
GP	7 (9.1%)	16 (16.0%)	**$X^2 = 1.83$, DF = 1 p = 0.17**
Hospital specialist	25 (32.5%)	36 (36.0%)	**$X^2 = 0.24$, DF = 1 p = 0.62**
Breast care nurse	48 (62.3%)	42 (42.0%)	**$X^2 = 7.20$, DF = 1 p = 0.007**
Alternative practitioner	1 (1.3%)	0 (0%)	**Fisher's exact test p = 0.25**
BACUP	6 (7.8%)	1 (1.0%)	**Fisher's exact test p = 0.02**
Breast Cancer Care	7 (9.1%)	7 (7.0%)	**$X^2 = 0.26$, DF = 1 p = 0.61**
Tak Tent	1 (1.3%)	1 (1.0%)	**Fisher's exact test p = 0.85**

This table shows those who answered yes to the following question: "Where have you obtained advice about practical problems? (e.g.help regarding bras, or prosthesis)"

Table 6.6: Advice regarding practical problems seeking behaviour of women from affluent and deprived areas from the media

Information source	AFFLUENT n (% of aff. group) *total n = 77*	DEPRIVED n (% of dep. group) *total n = 100*	Chi squared test results
Magazines	10 (13.0%)	7 (7.0%)	**X^2 = 1.76, DF = 1 p = 0.18**
Newspapers	5 (6.5%)	2 (2.0%)	**X^2 = 2.31, DF = 1 p = 0.13**
Books	8 (10.4%)	5 (5.0%)	**X^2 = 1.86, DF = 1 p = 0.17**
Leaflets	18 (23.4%)	11 (11.0%)	**X^2 = 4.86, DF = 1 p = 0.03**
TV news	5 (6.5%)	4 (4.0%)	**X^2 = 0.56, DF = 1 p = 0.45**
TV documentaries	8 (10.5%)	8 (8.0%)	**X^2 = 0.33, DF = 1 p = 0.56**
TV drama	3 (3.9%)	3 (3.0%)	**X^2 = 0.11, DF = 1 p = 0.74**

This table shows those who answered yes to the following question: "Where have you obtained advice about practical problems? (e.g.help regarding bras, or prosthesis)"

Table 6.7: Attendance at hospital clinics for women from affluent and deprived areas

Hospital appointment intervals	AFFLUENT n (% of affluent group) *n = 77*	DEPRIVED n (% of deprived group) *n = 99*
< 3 months	2 (2.6%)	4 (4.0%)
3 - 6 months	22 (28.6%)	31 (31.3%)
6 - 12 months	49 (63.6%)	59 (59.6%)
> 12 months	1 (1.3%)	1 (1.0%)
not attending hospital clinic	3 (3.9%)	4 (4.0%)

Chi squared test results: $X^2 = 0.52$ DF = 4 $p = 0.97$

Table 6.8: Most likely action in response to anxiety of women from affluent and deprived areas

Action if anxious re breast problem	AFFLUENT n (% of affluent group	DEPRIVED n (% of deprived group)	Chi squared test results
Keep it to yourself			
	n = 67	*n = 74*	
Yes	6 (9.0%)	13 (17.6%)	**$X^2 = 2.60$**
No	45 (67.2%)	42 (56.8%)	**DF = 2**
Possibly	16 (23.9%)	19 (25.7%)	**p = 0.27**
Speak to family or friends			
	n = 65	*n = 73*	
Yes	33 (50.8%)	39 (53.4%)	**$X^2 = 0.31$**
No	15 (23.1%)	14 (19.2%)	**DF = 2**
Possibly	17 (26.2%)	20 (27.4%)	**p = 0.85**
Speak to your GP			
	n = 72	*n = 87*	
Yes	51 (70.8%)	63 (72.4%)	**$X^2 = 2.73$**
No	13 (18.1%)	9 (10.3%)	**DF = 2**
Possibly	8 (11.1%)	15 (17.2%)	**p = 0.25**
Contact breast care nurse			
	n = 68	*n = 70*	
Yes	25 (36.8%)	26 (37.1%)	**Fisher's exact test**
No	28 (41.2%)	32 (45.7%)	**p = 0.74**
Possibly	15 (22.1%)	12 (17.1%)	
Contact hospital specialist			
	n = 71	*n = 79*	
Yes	43 (60.6%)	53 (67.1%)	**$X^2 = 2.08$**
No	15 (21.1%)	18 (22.8%)	**DF = 2**
Possibly	13 (18.3%)	8 (10.1%)	**p = 0.35**
Contact a voluntary organisation, such as BACUP or Tak Tent			
	n = 63	*n = 67*	
Yes	3 (4.8%)	1 (1.5%)	**Fisher's exact test**
No	53 (84.1%)	55 (82.1%)	**p = 0.41**
Possibly	7 (11.1%)	11 (16.4%)	

Table 6.9: Degree of anxiety in women from affluent and deprived areas

'Very much' anxiety*	AFFLUENT n (% of affluent group)	DEPRIVED n (% of deprived group)	Chi squared test results
Money	n = 71 2 (2.8%)	n = 82 10 (12.2%)	**Fisher's exact test** **p = 0.02**
Job security	n = 71 2 (2.8%)	n = 73 2 (2.7%)	**Fisher's exact test** **p = 0.67**
Breast cancer	n = 74 17 (23.0%)	n = 93 28 (30.1%)	**X^2 = 1.06** **DF = 1** **p = 0.30**
Other health problems	n = 73 6 (8.2%)	n = 86 19 (22.1%)	**X^2 = 5.73** **DF = 1** **p = 0.02**
Family problems	n = 72 5 (6.9%)	n = 80 14 (17.5%)	**X^2 = 3.86** **DF = 1** **p = 0.049**
Relationship problems	n = 71 2 (2.8%)	n = 78 5 (6.4%)	**Fisher's exact test** **p = 0.26**

*This table demonstrates the respondents who responded the question; Do you worry about any of the following? by answering 'very much'.

Table 6.10: Smoking history in women from affluent and deprived areas

Smoking history	AFFLUENT n = 77	DEPRIVED n = 97
Never smoked	38 (49.4%)	30 (30.9%)
Ex - smoker	27 (35.1%)	37 (38.1%)
Current smoker	12 (15.6%)	30 (30.9%)

Chi squared test results: $X^2 = 8.02$. DF = 2, $p = 0.018$

Table 6.11: Reported lifestyle changes since diagnosis of breast cancer in women from affluent and deprived areas

Change to lifestyle	AFFLUENT n (%) *n = 77*	DEPRIVED n (%) *n = 100*	Chi squared test results
Started yoga	0	4 (4.0%)	Fisher's exact test p = 0.07
Taken up more sport	12 (15.6%)	13 (13.0%)	$X^2 = 0.24$, DF = 1 p = 0.62
Avoided animal fats	40 (51.9%)	33 (33.0%)	$X^2 = 6.44$, DF = 1 p = 0.01
Eaten less red meat	44 (57.1%)	42 (42.0%)	$X^2 = 3.99$, DF = 1 p = 0.04
Used relaxation tapes	7 (9.1%)	13 (13.0%)	$X^2 = 0.66$, DF = 1 p = 0.41
Taken evening primrose oil	16 (20.8%)	15 (15.0%)	$X^2 = 1.00$, DF = 1 p = 0.31
Taken vitamins	20 (26.0%)	17 (17.0%)	$X^2 = 2.12$, DF = 1 p = 0.14

Table 6.12: Change in employment status for women in affluent and deprived areas

Change in employment status as a result of breast cancer*	**AFFLUENT** **n (% of affluent group)** *n = 77*	**DEPRIVED** **n (% of deprived group)** *n = 100*
No change	66 (85.7%)	82 (82.0%)
Change	11 (14.3%)	18 (18.0%)

Chi squared test results: $X^2 = 0.44$ DF = 1 p = 0.508

*Missing values were recoded as 'no change' before analysis.

Chapter 7

DISCUSSION

7.1 Introduction

Discussion sections within chapters 4 – 6 have dealt with issues arising from each of these studies. However there were some aspects of the care of affluent and deprived women with breast cancer that were contributed to by more than one of these studies and which are more usefully considered together. This chapter discusses access to health care, the role of co-morbidity in determining outcomes from breast cancer, issues to do with communication and information and data obtained regarding follow up.

Chapter 8 summarises what was been learned from this research about deprivation and breast cancer.

7.2 A critique of the study methodology

This study was designed to describe and compare the care received by affluent and deprived women with breast cancer. Two methodologies were used to achieve this aim: data collection from medical records and a postal questionnaire. These have been described in chapter 2 and sections 4.2, 5.2 and 6.2. References have already been made to particular difficulties encountered in carrying out the study throughout this thesis. In this section these are brought together to provide an overall view of the aspects of the research that proved problematic, together with an assessment of the suitability of the methodology to address the research questions.

One of the strengths of this study is that the study population were obtained form the West of Scotland Cancer Registry. As discussed earlier (page 52), Scottish cancer registration data is of high quality, resulting in confidence that the study population was as complete as possible. The medical records data collection was carried out in two stages – firstly from hospital records and secondly from general practice records. Good access to hospital records was achieved, with almost complete coverage of the study population (Table 3.1). Much of the information collected from hospital records was information that is collected in surgical audit and was therefore available in the records. The general practice data collection proved to be more difficult due to the numbers of practices involved and the variable nature of general practice record keeping (Table 5.1). The variable nature of general practice records, both in content and legibility resulted in it being unlikely that a complete record of the number or the content of the consultations was achieved. In addition, no information was obtained about the contributions to care made by health professionals other than doctors from the records due to the difficulty of obtaining community nursing records. However valuable data were obtained as a result of the GP records data collection which justified the time and effort which the process took. In particular increased contact with GPs after a diagnosis of breast cancer has been shown for the first time. Although carrying out a retrospective study involves difficulties in terms of obtaining incomplete data, a prospective study would have taken many years to produce the data presented in this thesis.

A good response rate to the postal questionnaire sent to patients was achieved (81%). However, these patients were survivors, by definition, and were all at least three and a half years from diagnosis. The questionnaire data (chapter 6) has produced many interesting finding in this population, but care needs to be taken in extrapolating these findings to all women with breast cancer. Indeed it could be postulated that this group of women might have produced different responses had similar questions been asked closer to their diagnosis. It was anticipated when the study was designed that this would be the case but it was expected that useful comparison information would be obtained about survivors. The results from the study have justified this expectation (chapter 6). However the response rate to the questionnaire was high, and again provided valuable information on differences between affluent and deprived women in terms of psychological status and information sources.

One of the main problems encountered in the study was the reduction that took place in the number of cases at each stage of the study. This has been described and discussed in chapter 3 (page 56) and there are understandable reasons for these reductions. It was difficult to predict at the outset to what extent this reduction would take place and in retrospect it was particularly unfortunate that the questionnaire was only sent to just over half of the original study population (Table 3.1, page 59).

In deciding the study population, some pragmatic decisions were taken which were based on the time available for data collection and analysis by a single researcher. In retrospect, it would have been beneficial to have obtained cases over a three year period rather than two years as this would then have included a complete round of breast screening. However, analyses have been carried out (page 74) which indicate that there were similar proportions of screen detected cancers in both the screened and non-screened groups.

Again for pragmatic reasons it was decided to study only the women at either end of the deprivation spectrum, excluding those who lived in areas with deprivation categories of three, four or five at time of diagnosis. Carnon et al (1994) included women from the whole deprivation spectrum their study, and found that those who were excluded from the study described in this thesis fell between the most affluent and the most deprived in terms of outcome. However, the most informative comparisons carried out by Carnon and his colleagues are those which related to the women living in the most affluent and most deprived sectors.

This research was carried out in a single city. Glasgow is a suitable place to carry out research of this kind because affluent and deprived people live close to each other and in many instances attend the same hospitals. However, one of the hospitals only treated women from deprived areas and this has given rise to some possible bias which has been discussed in chapter 4 (page 86). Issues arising as a result of this bias included type of axillary surgery carried out, access to breast care nurses and communication with general practice.

A further advantage of Glasgow as a place to carry out this research is that there is little private care for women with breast cancer in Glasgow, perhaps related to an interest in breast cancer by both University departments of surgery. The potential biasing factor of private care was therefore not an issue in this study. The problem of case record retrieval in the private sector was also avoided. There may however be problems in generalising the findings of this study to areas of the country in which larger proportions of women with breast cancer may be seen in the private sector.

One of the most interesting findings to have emerged from this study is the importance of co-morbidity (section 7.4). The measures of co-morbidity are all indirect measures as it was not anticipated at the outset that this would become such an important issue. If this had been anticipated, direct measures of co-morbidity, such as comprehensive data regarding coexisting illnesses would have been obtained from the medical records. Although major illnesses were documented from general practice records, these were only collected as referred to during the period of the study. In addition, no comment can be made regarding the extent to which the co-morbidity is smoking related. Further work on co-morbidity and breast cancer outcomes is therefore important.

Although difficulties were encountered in carrying out this study, the methods used have both answered the research questions and provided additional material of interest. Issues worthy of further research have been identified.

7.3 Access to care

The study presented in this thesis is the first UK study to compare the care received by affluent and deprived women with breast cancer.

The evidence from the data presented leads to the conclusion that there were no differences between women from deprived and affluent areas in access to health care, or surgical and oncological treatments. Some differences were shown in waiting times for appointments and type of axillary surgery, but these differences could be explained by differences in hospital policy. These data appear to differ from those published by Pollock and Vickers (1998). In their paper, they document admission details for patients with colorectal, lung and breast cancer in South East England between 1992 – 1995. For all three cancers the proportion of patients recorded as ever having surgery was lowest among those from deprived areas. However, as they point out, with no data regarding stage it is difficult to interpret this finding. The study presented here has shown that for women with breast cancer in Glasgow no difference in surgical treatment occurred when operable breast cancer was considered. In particular no evidence was found in this study to support the view expressed by Pollock and Vickers that "primary care is failing patients from deprived areas."

However more women living in deprived areas presented with advanced cancers. It remains unclear why this is the case. No evidence of service delay has been detected from the results here, but are unable to comment on patient delay. Nichols et al. (1981) and Facione (1993) both believed patient delay was an important aspect of overall delay. Further work is needed to explore possible reasons for this.

It can be postulated that if service delay is excluded as a reason to explain more advanced presentation in deprived women then there must either be some patient delay or there may be biological properties within the cancer resulting in more aggressive cancers having a shorter lead time to discovery. No evidence has yet emerged to definitively link deprivation with more aggressive biological breast cancers although work is ongoing (Scottish Cancer Foundation, 2000, personal communication).

There are a number of factors that may lead to delay in breast cancer presentation in deprived areas. Data on GP consultations showed deprived women consulting as frequently as affluent women prior to diagnosis and more frequently after diagnosis. This could lead to the conclusion that there was no difference in access to care between affluent and deprived women. However, there may be a difference between access to care and accessibility of care. A number of factors may interfere with accessibility. These may include ease of transport, childcare, caring for sick or elderly relatives and inflexible employment. It can be postulated that issues such as these are more likely to pose an accessibility problem for women living in deprived areas. An alternative explanation is that public health messages regarding the importance of individual women being breast aware and consulting general practice where concerned (Scottish Intercollegiate Guidelines Network 1998) are failing to reach deprived women. These issues need further research.

7.4 Co-morbidity

There has been an accumulation of evidence throughout this thesis pointing to the presence of greater co-morbidity in women from deprived areas, which may be an explanation for their known poorer outcomes. Analysis of the number of hospital admissions in the 2 years following diagnosis of breast cancer (Table 4.18, page 112) showed that women from both ends of the deprivation spectrum were admitted to hospital equally often with problems related to breast cancer, while admissions to hospital for conditions unconnected with breast cancer were more common amongst women living in deprived areas. This is likely to indicate a greater number of co-morbid conditions in women from deprived areas which may in turn translate into the poorer survival figures which have been reported from all causes. The argument for this is strengthened by the data presented in chapter 5 from the general practice records data collection which showed more consultations with GPs after diagnosis by women living in deprived areas (Table 5.6, page 136), but no more consultations with breast cancer related problems (Table 5.7, page 137). The excess in consultations may be due to consulting about other illnesses than breast cancer.

The data from the questionnaire study sheds further light on these findings. As has been discussed in chapter 6, women living in affluent areas were found to have statistically significant higher SF-36 scores for each of the questionnaire's domains, with the exception of bodily pain (page 146). This finding has been shown to be consistent with other literature, which show higher SF-36 scores in socio-economically-disadvantaged groups (Hemingway et al. 1997b). These arguments are further strengthened by the finding that women from deprived areas worried more than women from affluent areas about other health problems. Therefore, there appears to be greater psychological morbidity in the women from deprived areas in this study.

The link between deprivation and morbidity has been established. Eachus et al. (1996) investigated the link between deprivation and morbidity in 26, 931 patients in 40 GP practices in Somerset and Avon and found a positive association between deprivation and many diseases. Cancers were not included in this self-reported questionnaire study. Nevertheless, the relationship that this study showed between deprivation and morbidity is important, as most previous work has concentrated on mortality. It does not however give any information about co-morbidity.

However, a number of studies have examined the presence of co-morbidity in general practice. Schellevis et al. (1993) studied the extent of co-morbidity in a general practice population of 23, 534 patients in the Netherlands. They discovered co-morbidity to be important quantitatively in patients over the age of 65. Sixteen percent of patients over the age of 65, who suffered from one of five common chronic diseases, also suffered from another one. This happened more frequently than could be expected by chance. In another study, they then examined the relationship between consultation rates and incidence of intercurrent morbidity in 962 patients who had at least one of five chronic diseases (Schellevis et al. 1994). Patients were followed up for a period of 21 months. Consultation rates were found to be higher for patients with co-morbidity than for patients with a single disease and intercurrent diseases were presented more frequently to the general practitioner by patients with co-morbidity than by patients with a single disease. These data have important implications for considering the workload of general practitioners and echo findings from the current study of increased GP consultations after a diagnosis of breast cancer.

Eachus et al. (1999) obtained information regarding socio-economic position within a study designed to investigate the association between the severity of hip pain and disability and several measures of socio-economic status. In their study, co-morbidity was self-reported on a screening questionnaire and analysed by using a summary score. They found evidence of association between increased severity of hip disease with decreasing socio-economic position. Increasing disease severity was also associated with increasing age and greater co-morbidity. This fits with the conclusions from the current study.

Some work has also related breast cancer to co-morbidity. Moormeier (1996) carried out a literature review of aspects of breast cancer in relation to black women. She concluded that the discrepancy in survival between black and white women exists because black women present with more advanced tumours which have different tumour biology and have confounding co-morbid conditions. Confounding co-morbid conditions cited by Moormeimer include diabetes, hypertension, heart disease, lung disease and kidney disease.

Chaturvedi and Ben-Shlomo (1995), using data from the third morbidity study studied the association between GP consultation rates for several common conditions and operation rates. They found an increase in consultations amongst lower social classes for hernia, gallstones and osteoarthritis, but no corresponding increase in operation rates. They suggest that at least some of the influences resulting in poorer access to surgical interventions for disadvantaged people may act after presentation to the health care system. One of the possible explanations of this may be the greater amount of co-existing morbid conditions amongst deprived people. There may therefore be an interaction between co-morbidity and access to care.

The degree to which co-morbidity affects outcomes for people living in deprived areas remains under researched. The only UK work linking co-morbidity and breast cancer is from the study currently under consideration (Macleod et al. 2000). The measures of co-morbidity used in this study were hospital admission, GP consultation rates and degree of anxiety expressed in the questionnaire study regarding other health problems. Although valuable these measures are indirect. Further work needs to be done on directly linking co-morbid conditions to outcomes from breast cancer. In particular the impact of smoking related co-morbidity would be interesting.

7.5 Communication and information

Data gathered from hospital records (page 77) showed that GPs of women in affluent areas received more relevant information than the GPs of women living in deprived areas. In addition, GPs of women from deprived areas waited longer to receive a letter containing a management plan (page 122). It has been postulated earlier in this thesis that these observations may be explained by differences in hospital practices. A study in The Netherlands (van der Kam et al. 1998) carried out a questionnaire study in which 150 GPs gave details about communication from hospital regarding the most recent patient who had been diagnosed with cancer. The median period between initial referral date and receipt of definitive diagnosis from the surgeon was 4 weeks. In the current study the median time from initial consultation with GP to receipt of definitive diagnosis was 26 days for affluent women and 29 days for deprived women. This is not statistically significant. (Table 5.9, page 139). The present study confirms van der Kam et al's view that communication between GPs, patients and specialists is too slow. When considered alongside data from the GP records study (chapter 5, page 121) regarding consultations in general practice, it can be postulated that consultations soon after diagnosis are hampered by this slowness in receipt of information. This does appear to be true for all patients and is likely to be related to systems within secondary care.

Communication with patients and about patients between health care professionals is closely related to information which patients obtain about themselves, their disease and treatment. This has already been discussed in chapter 6 (page 152). The data from the study regarding information sources has highlighted the important part health professionals, especially doctors, play as a source of information for patients about breast cancer. The GP records study has shown increased number of consultations in general practice after diagnosis and data from the questionnaire showed that women would first of all consult their GP if they became anxious about their breast cancer (Table 6.8, page 169). Further work needs to identify whether GPs are able to appropriately meet this need for reassurance and information, and to recognise the specific training needs of GPs in this area.

7.6 Follow up

Information regarding follow up was obtained from each of the three data sources. The data obtained in the hospital records data collection showed deprived women more likely to fail to attend hospital appointments (Table 4.19, page 113). However these numbers were small and when analysis was carried out concerning the total number of times patients were seen in clinic (page 77), there was no statistically significant difference found between the groups. It may be that women living in deprived areas did attend rearranged appointments and therefore were seen in hospital as often as women from affluent area.

The general practice records data collection provided evidence of continuing care in general practice and demonstrated that women from deprived areas consulted more frequently than women from affluent areas after diagnosis, although all women consulted more frequently than previously (page 122). This is perhaps informal follow up but needs to be considered alongside follow-up at hospital.

Data from the postal survey (chapter 6) corroborated evidence that had been obtained earlier, although it related to a later time period. Most women were still attending hospital for follow up regularly at the time of the survey.

Grunfeld and colleagues reported three studies carried out to evaluate a primary care centred system of routine follow up (Grunfeld et al. 1995b, Grunfeld et al. 1999). They found that primary care follow up was possible and an acceptable alternative for both patients and GPs. Their work showed no increase in delay in diagnosing recurrence and no increase in anxiety or deterioration in health-related quality of life. The willingness of GPs to be involved in follow up may be related to the information obtained from the current study, demonstrating the increased contact GPs have with patients with breast cancer. The arguments (Grunfeld et al. 1995c) for shared care are strengthened by the evidence from this study of the extent of continuing care provided by GPs. Grunfeld et al. (1999a) also carried out a study exploring patient satisfaction with follow up in general practice. They found that women with breast cancer were more satisfied with follow up in general practice than by specialists. The information presented in chapter 6 regarding the readiness of women to consult their GP if they became concerned about breast cancer echoes these findings of satisfaction with general practice follow up (Table 6.8, page 169).

This study has provided information on the ongoing role that GPs have in the management of women with breast cancer. Data presented in chapter 5 provided evidence of increased consultations in general practice after diagnosis. In the context of increased consultations in general practice and discussions regarding delay (page 88), it is useful to explore the role of primary care in the management of women with breast cancer. Prior to the start of this study, a questionnaire study was carried out of all the GPs in five West of Scotland Health Boards (Greater Glasgow Health Board, Ayrshire and Arran Health Board, Lanarkshire Health Board, Argyll and Clyde Health Board and Forth Valley Health Board). The aspects of this questionnaire dealing with referral have already been published (Macleod et al. 1998. In addition to information regarding referral practice, data was also gathered on the GPs' views of their role. Forty eight percent felt than management of psychosocial issues was mainly a matter for primary care and 87% felt that the management of family issues was mainly a matter for primary care. As is discussed in chapter 6 these views compare well with women's views of the role of their GP (Table 6.8).

This study is the first to demonstrate an increase in GP consultations following a diagnosis of breast cancer. Future reappraisals of breast cancer follow up (Dewar 1995) ought to include this information when considering the most appropriate follow up for women with breast cancer.

7.7 Summary

A number of interesting issues have arisen from this discussion about the care received by women with breast cancer from socio-economically affluent and deprived areas.

Although more deprived women presented with advanced cancers, it does not appear that this is due to delay caused by the NHS. However the evidence of greater co-morbidity, including psychological co-morbidity among women from deprived areas may help to explain their known poorer outcomes. The study has also highlighted important issues to do with the role of primary care in the ongoing care of patients with breast cancer. Communication between primary and secondary care needs to be improved for all patients. Further work is required to identify the role of primary care in the ongoing care of women with breast cancer.

Chapter 8

CONCLUSIONS

It would appear that explanations for the known poorer outcomes of deprived women with breast cancer from deprived areas are not simply due to an inferior standard of care delivered by the NHS. The hypothesis which was presented at the outset of this thesis (page 38) has not been proved in terms of access to care or surgical and oncological treatment. In other words, this study has not demonstrated any evidence of the Inverse Care Law operating in the care of women with breast cancer in Glasgow (Tudor Hart 1971) at the level of medical treatment.

However, although the NHS gives deprived women an equal chance with affluent women once they present with breast cancer, there are interesting differences between the groups. These differences include information seeking, waiting times, consultation patterns, communication between primary and secondary care, the explanations for which may not differ for breast cancer than for other diseases in which deprived populations have a poorer outcome.

It may be therefore that the reasons underlying the poorer survival for women from deprived areas with breast cancer are not due to their breast cancer or its management, but to other factors which result in deprived women having a reduced life expectancy from all causes compared with affluent groups (Eames, Ben-Shlomo, & Marmot 1993).

The evidence presented in this thesis regarding co-morbidity suggests the importance of understanding more about the interaction of different diseases and psychological problems within individuals in considering outcomes. In addition, further work needs to be done to clarify the reasons for and results of breast cancer presentations among deprived women.

A complex picture has emerged of factors contributing to the outcome of deprived women with breast cancer. In attempting to improve the survival and quality of life in those who have cancer, a greater understanding is needed about the effect of the social class divide.

The implications of the social class divide are in breast cancer are considerable. Carnon at al. (1994) in their Glasgow paper estimated the benefit to survival if all social groups had the same 5 year survival as the most affluent group. They predicted that 475 more women out of a catchment area of 467 000 in the West of Scotland could be expected to survive for 5 years. This exceeds the 25% reduction in mortality that is the aim of the national breast screening programme. This theoretical survival advantage has immense public health and economic implications. It encourages the ongoing study of this subject.

APPENDICES

Appendix 1: Hospital data records form

HOSPITAL RECORDS DATA

Patient /code no	
Postcode of patient at diagnosis	
?Change of address	Yes / No
Referring hospital and number	
BOC Number	
GP name and address Phone number	
Date of diagnosis	
Date of birth	
Menstrual status at diagnosis	Pre- / Peri- / Post- menopausal

Presentation

Screening / Primary care / Secondary care / Other - state

Timing from initial presentation

Date of being seen by GP / screening centre	
Date of referral letter from GP / screen.centre	
Date of initial appointment at hospital clinic	
Date(s) of surgery	

Staging

Early / locally advanced / metastatic

Pathology

Grade(where appropriate)	
Tumour size	
Node status	positive / negative / not done / unknown
Evidence of metastasis	

Initial treatment for early disease

Surgery -	no surgery / to breast / to axilla-clearance/sampling mastectomy / conservation surgery
Surgeon	
No of in-patient days at time of primary surgery	Admission 1: Admission 2:
XRT	no XRT / chest wall / axilla
Seen by oncologist during primary Rx	Medical / Clinical / Neither
Adjuvant treatment	none / chemotherapy / endocrine / both
Primary chemotherapy pre-op	Yes / No
Involvement in Clinical Trial(s)	Yes / No If Yes, Name of trial(s):

Letters from Surgeons to GP

DATE	INFORMATION

Recurrence **YES / NO**

Date of recurrence	
Presentation of recurrence -	local Date: distant Date:
Detection of recurrence	Routine visit / Referred back early by GP / self-referral

Follow-up after initial treatment

Clinic visits in 2 years following end of initial treatment:

	SURGICAL	ONCOLOGY
No of clinic visits		
No of early visits		
No of DNA's		
Discharged from clinic		
Lost to follow-up		
Moved away from area		

Letters

From surgeons:

Following initial clinic visit detailing probable diagnosis	Yes / No
management plan	Yes / No
indication of what patient has been told	Yes / No
Discharge letter from admission for primary surgery stating:	
diagnosis	Yes / No
operative procedure	Yes / No
further management plans	Yes / No
follow-up plan	Yes / No
IF early visit: reason stated	Yes / No
outcome stated	Yes / No
future F/U plan stated	Yes / No
IF referral to other specialist: reason stated	Yes/ No
outcome stated	Yes/ No
future F/U plan stated	Yes/ No
Information regarding duration of endocrine therapy	Yes / No / N/A
Side-effects of Tamoxifen stated	1 / 2 / 3 / 4 / None
Tamoxifen stopped due to side effects	Yes / No

Letters from Oncologists to GP

DATE	INFORMATION

From Oncologists:

Letter following 1st visit	Yes / No
Management plan clear - re XRT	Yes / No
chemo	Yes / No
endocrine therapy	Yes / No
prognosis	Yes / No
what patient knows	Yes / No
If XRT: GP informed at start of treatment	Yes / No
and end of treatment	Yes / No
complications - skin reaction	Yes / No
lymphoedema	Yes / No
If Chemo: GP informed at start of treatment	Yes / No
expected adverse effects	1 / 2 /3 /4 / 5
complications	Yes / No
end of treatment	Yes / No
Information regarding duration of endocrine therapy	Yes / No / N/A
Side-effects of Tamoxifen stated	1 / 2 / 3 / 4
Tamoxifen stopped due to side effects	Yes / No
IF early visit: reason stated	Yes / No
outcome stated	Yes / No
future F/U plan stated	Yes / No
IF referral to other specialist: reason stated	Yes/ No
outcome stated	Yes/ No
future F/U plan stated	Yes/ No

Admissions

Breast cancer related problem:

	Admission 1	Admission 2	Admission 3	Admission 4
Date				
Nature of problem				
Hospital				
Duration of stay				
Discharge letter				

Other problems (not related to breast cancer) resulting in hospital admission

Dates	Cause of Admission

IF DECEASED

Date of death	
Cause of death	1a b c 11
Time from Dx of breast cancer to death	

DEFINITIONS

Menstrual status
Post - menopausal: 12 months since last period

Date of diagnosis
Date of definitive surgery, where possible. If no surgery, date of histological confirmation.

Surgery to axilla
Clearance or sampling: what surgeon says it is

Date of recurrence
Date of objective confirmation of recurrence - histological, if possible; or positive bone scan etc

Local recurrence / distant spread
Local = recurrence in breast initially involved with tumour, and ipsilateral axilla
Distant = all other sites, including ipsilateral supraclavicular fossa

Letter after primary surgery
GP should be informed of the following information as a minimum (i.e.YES will be entered if the following is stated in the GPs letter)

Diagnosis	breast cancer
Operative procedure	has the patient had a mastectomy
further treatment plan	referral to Oncology
F/U plan	time of first clinic visit

Letters during chemotherapy
Letter at start and end of treatment counted; whether there are letters after each pulse not taken into account

Chemotherapy treatment - expected adverse effects
1 alopecia
2 infertility
3 marrow suppression
4 mouth problems
5 nausea and vomiting

Endocrine therapy - expected adverse effects

1 endometrial cancer
2 flushings
3 vaginal dryness / discharge
4 weight gain

Clinic visits
Start at visit 1 AFTER initial treatment
If several initial clinic visits (e.g. with haematoma), count as 1 visit.

Appendix 2: Letter to GP, and reply form

Date

Drs name & address

Dear Drs

Breast cancer care - research project

I am writing to ask for your help with a project about breast cancer. This will not involve any of your time and is merely a request to examine a few of your case records.

I am engaged in a research project exploring the paradox of why, although breast cancer is commoner among affluent women, survival is poorer amongst deprived women. In particular I am looking at whether the patterns of care women receive is different in the extremes of the deprivation spectrum.

I am studying the women in the most affluent and most deprived groups in Glasgow who were diagnosed as having breast cancer in 1992 and 1993 and am trying to build up a picture of the total care these women received. In order to do this, I have begun by studying their hospital records for details about their care. To complement this hospital records data collection I would like to look at the other aspects of their care, and in particular at the important contribution of primary care. Although I understand that general practice records may be incomplete, and do not necessarily reflect the total care a patient has received from primary care, I believe that there is information to be gained from them which may be a useful indicator of care e.g. number of consultations in primary care, letters received from hospital specialists, referrals to other agencies.

Needless to say, we have ethical approval for this study. The analysis of the data will be entirely anonymous so far as the clinicians involved are concerned, and will be related to variables such as deprivation status.

Later on in the study, we plan to send questionnaires to the women concerned, to ask them about their use of services and current health status. Copies of the questionnaires and interview schedules will be available, if desired.

I understand that the following are patients of yours. I would therefore be very grateful if I could make an arrangement with your Practice to see their case records.

Patient 1
Patient 2
Patient 3

I enclose a form for reply and a pre-paid envelope. I would be grateful if you would complete this and return it to me. I will then be in contact with the Practice to arrange a time which would be suitable to come. If you would like to discuss this with me, please contact me on 331-2351 or 332-8118.

With thanks for your help.

Yours sincerely

UNA M. MACLEOD

Cancer Research Campaign Breast Cancer Care Research Project

Practice: Drs name & address

Patient 1

May case record be examined? Yes / No / Moved practice / Deceased

May patient be contacted
by questionnaire? Yes / No / Moved practice / Deceased

Patient 2

May case record be examined? Yes / No / Moved practice / Deceased

May patient be contacted
by questionnaire? Yes / No / Moved practice / Deceased

Patient 3

May case record be examined? Yes / No / Moved practice / Deceased

May patient be contacted
by questionnaire? Yes / No / Moved practice / Deceased

Contact person at Practice:

Signed: _ Date:_ _ _ _ _ _ _ _ _ _ _ _ _ _

Please return in the enclosed envelope to
Dr Una M.Macleod, CRC Research Fellow in Primary Care Oncology,
University of Glasgow, Department of General Practice,
Woodside Health Centre, Barr Street,Glasgow, G20 7LR

Appendix 3: Reminder to GPs

GP name & address

13th January, 1997

GP name & address

Dear

Breast cancer care - research project

You may recall that I wrote to you some months ago asking for your permission to see the case notes of the following patients:

«Patient1»
«Patient2»
«Patient3»

This is to help us form a picture of the total care which women with breast cancer receive from various members of the health care professions, as part of a 3 year study looking at the patterns of care for women with breast cancer. Although I understand that GP records are not necessarily a complete record of a patient's care in primary care, yet I believe that we can obtain useful information from them, e.g. how much information GPs receive from hospitals about their patients' care, how often women with breast cancer consult their GPs.

I have had a very encouraging initial response with over 70 % of GPs replying. I am keen to try to maximise this and I would be very grateful, therefore, if I could make an arrangement with your Practice to see the above records. Of course, the information is confidential and will not be analysed by clinician.

I enclose a form for reply, and a pre-paid envelope. The form also asks whether you feel the women concerned are suitable for being sent a postal questionnaire. More information is available from myself on 331-2351, if desired.

With thanks for your help

Yours sincerely

UNA M. MACLEOD

Appendix 4: GP data collection form

DATA FROM GP RECORDS

Study ref no **Address**

GP practice no.

Date(s) initially seen by GP with breast problem	
Date referral made to hospital clinic	

Problem list	YES / NO
Problem list with breast cancer in it	YES / NO

BEFORE DIAGNOSIS

No. of consultations in 12 month period before diagnosis (3 - 15 months)	
No. of consultations with breast problem	
?consultations for repeat prescriptions only	
?consultations for sick line only	

AFTER DIAGNOSIS

No. of contacts with GP in first 12 months ***after*** Dx	
No. of contacts with GP in 2nd 12 months ***after*** Dx	
No. of surgery consultations	
No. of home visits	

No. of consultations regarding breast cancer	
No. of consultations with psychological component	

Referral to psychologist / psychiatrist / counsellor with problem related to breast cancer.	
Referral to psychologist / psychiatrist / counsellor with other problem	

LETTERS

Date of initial hospital letter	
Date of letter stating diagnosis	
Date of letter stating plan of treatment	

Other hospital letters (in first 2 years after Dx):

No. From surgeons	
No. From oncologists	
Mention of psychological state	

LETTERS FROM HOSPITAL

DATE	**FROM**	**REASON** (e.g.clinic, disch, report of results)	**INFORMATION** (include Dx, Rx, Ix,info given to pt, psychosoc, review plans)

Details of letters from breast screening centre

Relevant past medical history - details of major illnesses or operations

History of medication related to breast cancer (e.g. Tamoxifen) or anti-depressant or anti-anxiolytic medication

Drug	**Date commenced**	**date stopped**

Notes
To include details missing from hospital records form e.g. menopausal status

Appendix 5: Letter sent to GPs prior to questionnaire being sent to women

Date

GP name & address

Dear Dr

BREAST CANCER CARE STUDY

You will recall I wrote to you some months ago requesting to see some case records. I was very grateful to be able to see these notes and this has helped me take my study forward.

I have now reached the questionnaire phase of this study, and as previously indicated intend sending out questionnaires to the following patients in your practice:

Patient 1
Patient 2
Patient 3

I will send them out in the week beginning 9th June, 1997, and would be grateful if you could contact us if some development has occurred which would make it inappropriate to contact these patients. Please 'phone Karen on 353 1684.

Thank you once again for your help.

With kind regards.

Yours sincerely

Una M Macleod

Appendix 6: Questionnaire to women

Glasgow Primary Care Breast Study

UNIVERSITY
of
GLASGOW

Thank you very much for your help with our research .

Please read through the questions, and put a tick in the box closest to your answer.

The questionnaire should take no more than 20 minutes to complete.

If you have any queries about this questionnaire, or are unsure of what any of the questions mean, 'phone Dr Una Macleod on 353-1684 between 9 am and 5 pm.

When you have completed filling in the questionnaire, please send it in the prepaid envelope provided to

Dr Una Macleod
Department of General Practice,
University of Glasgow,
Woodside Health Centre,
Barr Street,
Glasgow, G20 7LR

ABOUT YOU

First of all, we would like to know some details about yourself.

Please will you tell us some details about your family and home.

Do you have any children? ☐ Yes ☐ No

If YES, how many children do you have? ☐

What are their ages?

Please list everyone who currently lives in your house? We DO NOT need to know their names just how they are related to you, and their age.

Age in years	Relationship to you (e.g. husband, daughter, friend, lodger, etc)
1.	
2.	
3.	
4.	
5.	
6.	

SF-36 HEALTH SURVEY

questions ask for your views about your health and how you feel about life in l. If you are unsure about how to answer any question, try and think about your l health and give the best answer you can.

general would you say your health is:

(circle one)

Excellent...1

Very good...2

Good..3

Fair...4

Poor...5

mpared to one year ago how would you rate your health in general now?

(circle one)

Much better now than one year ago 1

Somewhat better now than one year ago.........................2

About the same as one year ago..............................3

Somewhat worse now than one year ago.........................4

Much worse now than one year ago..........................5

3. The following questions are about activities you might do during a typical day. Doe health now limit you in these activities. If so, how much?

(Circle one number on ea

ACTIVITIES	**Yes, Limited A Lot**	**Yes, Limited A Little**	**No, Limi At**
a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing **several** flights of stairs	1	2	3
e. Climbing **one** flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. Walking **more than a mile**	1	2	3
h. Walking **half a mile**	1	2	3
i. Walking **100 yards**	1	2	3
j. Bathing and dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work other regular daily activities as a result of your physical health?

(Circle one number on ea

	YES	**N**
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Were limited in the **kind** of work or other activities	1	2
d. Had **difficulty** performing the work or other activities *(e.g. It took extra effort)*	1	2

ring the past 4 weeks, have you had any of the following problems with your work or regular daily activities as a result of any emotional problems (such as feeling depressed ious)?

(Circle one number on each line)

	YES	NO
down on the amount of time you spent on work or other activities	1	2
omplished less than you would like	1	2
dn't do work or other activities as carefully as usual	1	2

ring the past 4 weeks, to what extent has your physical heath or emotional problems red with your normal social activities with family, friends, neighbours or groups?

(Circle one)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

w much bodily pain have you had during the past 4 weeks?

(Circle one)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

8. During the past 4 weeks, how much did pain interfere with your normal work (inclu work both outside the home and housework)?

(Cir

Not at all ....
A little bit ....
Moderately ....
Quite a bit ....
Extremely ....

9. These questions are about how you feel and how things have been with you during tl month

For each question, please indicate the one answer that comes closest to the way you have be feeling.

How much time during the past month

(Circle one number on each

	All of the time	**Most of the time**	**A good bit of the time**	**Some of the time**	**A little of the time**	**N of ti**
a. Did you feel full of life?	**1**	**2**	**3**	**4**	**5**	
b. Have you been a very nervous person?	**1**	**2**	**3**	**4**	**5**	
c. Have you felt so down in the dumps that nothing could cheer you up?	**1**	**2**	**3**	**4**	**5**	
d. Have you felt calm and peaceful?	**1**	**2**	**3**	**4**	**5**	
e. Did you have a lot of energy?	**1**	**2**	**3**	**4**	**5**	
f Have you felt downhearted and low?	**1**	**2**	**3**	**4**	**5**	
g. Did you feel worn out?	**1**	**2**	**3**	**4**	**5**	
h. Have you been a happy person?	**1**	**2**	**3**	**4**	**5**	
i. Did you feel tired?	**1**	**2**	**3**	**4**	**5**	

uring the past 4 weeks, how much of the time has your physical health or emotional ms interfered with your social activities (like visiting with friends, relatives, etc.) ?

(circle one)

All of the time 1

Most of the time..2

Some of the time..3

A little bit of the time.. 4

None of the time 5

lease choose the answer that best describes how true or false each of the following ents is for you.

(Circle one number on each line)

	Definitely true	**Mostly true**	**Don't know**	**Mostly false**	**Definitely false**
em to get ill more easily n other people	**1**	**2**	**3**	**4**	**5**
m as healthy as anyone I ow	**1**	**2**	**3**	**4**	**5**
xpect my health to get rse	**1**	**2**	**3**	**4**	**5**
health is excellent	**1**	**2**	**3**	**4**	**5**

INFORMATION AND HELP

We would like to know about where you have obtained <u>information</u> relating to yo breast problem (e.g. causes, treatment)

(Please circle for each o

	YES	**NO**
Family and friends	**1**	**2**
Your GP	**1**	**2**
Hospital specialist	**1**	**2**
Breast care nurse	**1**	**2**
Alternative practitioner *e.g. homeopath*	**1**	**2**
BACUP	**1**	**2**
Breast Cancer Care	**1**	**2**
Tak Tent	**1**	**2**
Magazines	**1**	**2**
Newspapers	**1**	**2**
Books	**1**	**2**
Leaflets	**1**	**2**
TV news	**1**	**2**
TV documentaries	**1**	**2**
TV films, plays, soap operas	**1**	**2**
Other (please state below)	**1**	**2**

Which of these have you found most helpful?

e have you obtained advice about practical problems? (e.g. help regarding bras, or esis)

(Please circle for each one)

	YES	**NO**
and friends	**1**	**2**
GP	**1**	**2**
al specialist	**1**	**2**
care nurse	**1**	**2**
ative practitioner *e.g. homeopath*	**1**	**2**
P	**1**	**2**
Cancer Care	**1**	**2**
nt	**1**	**2**
ines	**1**	**2**
apers	**1**	**2**
	1	**2**
s	**1**	**2**
ws	**1**	**2**
cumentaries	**1**	**2**
ns, plays, soap operas	**1**	**2**
(please state below)	**1**	**2**

Which of these have you found most helpful?

Do you still attend a hospital clinic about your breast problem?
Please tick yes or no. ☐ **Yes** ☐ **No**

If Yes, how long is there between your appointments?
Please tick the box which best applies to you.

☐ less than 3 months ☐ 3-6 monthly ☐ 6 months to 1 year
☐ more than 1 year ☐ other - please state

If you become anxious about your breast problem, which, if any, of the following you most likely to do? Please answer <u>each</u> one

(Please circle for eac

	YES	NO	POSSIB
Keep it to yourself	1	2	3
Speak to family or friends	1	2	3
Speak to your GP	1	2	3
Contact breast care nurse	1	2	3
Contact hospital specialist	1	2	3
Contact a voluntary organisation, such as BACUP or Tak Tent	1	2	3

Which, if any, of these has been the most helpful in the past?

Do you worry about any of the following?

(Please circle for eac

	Very much	Somewhat	A little	Not at all
Money problems	1	2	3	4
Job security	1	2	3	4
Breast cancer	1	2	3	4
Other health problems	1	2	3	4
Family problems	1	2	3	4
Relationship problems	1	2	3	4

Which of these things worry you most?

LIFESTYLE

u smoke?
tick the box which best applies to you.

never ever smoked ☐ No, used to, but stopped ☐ Yes

If stopped, how many years is it since you stopped?

u taking any medicines for your breast m? ☐ Yes ☐ No

If Yes, please list names of medicines

you taken or done any of the following as a result of diagnosis of your breast m?

(Please circle for each one)

	YES	NO
yoga	1	2
up more sport	1	2
d animal fats	1	2
ess red meat	1	2
laxation tapes	1	2
Evening Primrose Oil	1	2
vitamins	1	2

WORK AND INCOME

f our key interests is to compare any differences women in different social groups xperience. In order to do this it is necessary to ask you a few questions about your nd income.

ouse you live in rented or ? ☐ Rented ☐ Owned ☐ Other

Please tick the one which applies most to you.

How many rooms are there in your house? *(excluding kitchen and bathroom)*

Please put number in box. ☐

How old were you when you completed full time education, (including college, if applic
Please put age in box. ☐☐ Years

Do you work? ☐ Yes ☐ No

If Yes, *which of the following applies to you?*

☐ Full Time ☐ Part Time ☐ Occasional

How long have you worked at this job? ☐☐ Years
Please put number of years in box.

We are interested in finding out if your breast problem has affected your work.
Please tick yes or no for each question.

Have you changed your job because of your breast problem?	☐ Yes	☐ No
Have you reduced your hours because of your breast problem?	☐ Yes	☐ No
Have you stopped working because of your breast problem?	☐ Yes	☐ No

How many people in your house have a paid job (including yourself)? ☐

Which of the following most closely describes the total income for your household over year?
Please tick one box.

☐ Less than £5,000 ☐ £5,000-10,000 ☐ £10,000-20,000

☐ £20,000-30,000 ☐ £30,000-40,000 ☐ More than £40,000

Who in the household contributes most to this income?
Please tick one box.

☐ Yourself ☐ Husband/Partner ☐ Some other person

How many people in your house own a car? ☐
Please put number in box.

For Office Only
☐☐

Appendix 7: Letter with questionnaire

Date

Ref: «studno»

«title» «name» «surname»
«address»
«address1»
«address2»
«postcode»

Dear «title» «surname»

I am writing to ask for your help with a study which I am carrying out in Glasgow. I know from hospital records that you have attended one of the Glasgow hospitals for treatment of a breast problem.

I am studying the different experiences which women with breast problems have and the treatment they receive. I enclose a questionnaire which asks about your home, family, feelings and views about your treatment, and about how you are now. I hope you will help by taking a few minutes to read through this, answer the questions and send it back to me in the enclosed pre-paid envelope.

The aim of our research is to find out information which I hope may improve the care of all women with breast problems. It is only if we understand better how women themselves feel about their treatment and experiences that we can try and influence things to maintain the good aspects and improve the not so good aspects of that care.

All the replies will be treated in confidence and will be analysed in a way in which no one will be identified. If you have any questions you would like to ask about the questionnaire or the study, please contact me on 353 1684.

Thank you for your time and help.

Best wishes.

Yours sincerely

Dr Una M Macleod

Encl.

Appendix 8: Reminder letter regarding questionnaire

Date

Ref: «studno»

«title» «name» «surname»
«address»
«address1»
«address2»
«postcode»

Dear «title» «surname»

You may remember that I wrote to you a couple of weeks ago asking for a few minutes of your time to fill in a questionnaire. If you have returned this within the last few days, please ignore this reminder.

The aim of my research is to find out information which I hope may improve the care of all women who have had breast problems. It is only if we understand better how women themselves feel about their treatment and experiences that we can try and influence things in order to maintain the good aspects and improve the not so good aspects of that care.

I must emphasise again that all replies are confidential and the analysis is entirely anonymous.

If you have any questions you would like to ask about the questionnaire or the study, please contact me on 353 1684. I do hope you will be able to help us by filling in this questionnaire as we really value your opinions.

With thanks and best wishes

Yours sincerely

Dr Una M Macleod

Encl.

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