THE PROMOTION OF BREAST SELF EXAMINATION IN THE CONTEXT OF THE DIAGNOSIS AND MANAGEMENT OF BREAST DISEASE

BY

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SUMMARY

The incidence and mortality rates from breast cancer continue to increase in the United Kingdom, and the disease is the most common cause of death in women aged 35 to 54 years. Various aetiological factors have been identified, but the known risk factors are not sufficiently predictive to form the basis of programmes for the primary prevention of breast cancer.

A range of studies are currently evaluating the benefits of screening by clinical examination and mammography to increase the likelihood of early diagnosis and treatment. This report describes a study which examines the alternative approach of an education programme designed to promote breast self-examination (BSE) among women aged 15 to 64 years, and which, at the same time, documented the diagnosis and management of breast disease in a circumscribed community in Daventry, Northamptonshire.

The education programme was carried out over 6 months by a full-time research health visitor. Women were taught within established work or leisure groups, with additional open meetings in the health centre. The teaching consisted of a set of slides, which were presented by the health visitor, and followed by an open-ended discussion. A teaching model was available for women to practise their BSE technique. As well as teaching the method of BSE, the education programme stressed that most breast problems are not due to cancer, that earlier diagnosis improves the chance of curing breast cancer and that BSE both increases the likelihood of early diagnosis and gives reassurance that everything is all right. Publicity was provided

through posters, leaflets, an article and advertisements in the local newspaper and by word of mouth. The leaflets explaining BSE were distributed at each talk, and the health visitor was available in the health centre at certain times for women who wanted an individual consultation.

Using the age-sex register as an age-stratified sampling frame, postal questionnaires were sent to 600 women before the education programme and to the same 600 and to a new sample of 600 women afterwards. Before the programme, most women (87%) had heard of BSE, although only 13% said that they practised it regularly each month. Those women who had heard about BSE from, or been taught BSE by, a health professional were more likely to report practising it. Other factors which increased the level of reported practice were uptake of cervical cytology and a history of breast cancer in a relative or close friend.

After the programme only 2% women reported that they had not heard of BSE, and 23% now said that they practised it every month. About one-fifth of the sample had attended a talk given by the health visitor, over half of these at their place of work. Almost all of those who used the practice model reacted favourably to it. Very few women expressed anxiety about the programme itself or about BSE, although there were various indications of underlying fears about breast cancer, which probably stem from direct experience of the disease rather than from health education. The GP consultations were monitored, and there were no instances of women attending because of unreasonable anxiety caused by the programme. The number of women consulting with breast symptoms did increase slightly

during the programme, but there was no evidence that this resulted from ill-founded worries.

Data were collected during the programme and in the 6 month periods immediately before and immediately afterwards on all women consulting their GP with breast symptoms. A total of 239 women, age range 13 to 90 years, were seen by the 9 general practitioners, with the only woman partner seeing the greatest number of patients. About one-third of women presenting with either a breast lump or pain had waited for one month or more before consulting their GP. Although 20% women were referred to hospital, only 4% were found to have primary breast cancer. Thus, the breast disease seen in general practice is almost entirely benign and often appeared to represent physiological variation. The women who had primary breast cancer were diagnosed by the GP in two-thirds of cases. Diagnostic difficulty and delay in general practice and hospital tended to occur in those women without the typical symptom of a painless lump. The follow-up arrangements in general practice for women referred to hospital and for women who were asked to re-attend their GP for subsequent review of their symptoms appeared rather haphazard.

These data on GP workload indicate that to improve the management of breast cancer by reducing the delay in diagnosis it may be necessary to make several changes. Both women and their doctors need to recognise the potential significance of symptoms other than the classical painless lump. GPs may have to accept a greater number of women consulting with what prove to be minor breast

symptoms, and a larger proportion of women may need to be referred to hospital. All women who are found not to have breast cancer require reassurance about this, and about the value of their consultation. At the same time, review and follow-up procedures should be improved to ensure that symptomatic women are monitored and that adequate assessment and support is given to those women who require treatment for breast cancer. Any changes in practice should be carefully evaluated.

Although the programme to promote BSE achieved some modest changes, the scope of such programmes is probably limited. Several specific problems were identified - for example, the value and difficulty of involving health professionals, the continuing gap between knowledge and behaviour in BSE and the uncertainty about the benefits afforded by BSE. Health education at a more general level faces a variety of difficulties, some of which are discussed, and BSE must be considered within this context. It is suggested that any teaching about BSE should be coupled with education about the benefits of reducing diagnostic delay. Wherever possible, this teaching should be given within routine health care, with the health professionals being provided with the appropriate expertise, literature and materials. BSE would thus become part of a wider strategy designed to promote the secondary prevention of breast cancer.

INTRODUCTION

This is the report of a study carried out in Daventry, Northamptonshire, to evaluate a programme to promote breast self-examination.

The extent of the problem of breast cancer is summarised in Chapter 1, together with a discussion of current knowledge about the epidemiology and management of the disease. Strategies for the prevention of breast cancer, including breast self-examination, are reviewed in Chapter 2 ,and Chapter 3 considers some of the problems associated with breast self-examination in particular, and health education in general.

The methodology of the Daventry study is presented in Chapter 4, and the extent of the programme in Chapter 5. Two sets of evaluative data were collected. First, data on the management of breast symptoms in general practice during the 18 months of the study and these data are summarised in Chapter 6. Second, population-based data were collected before and after the programme to assess women's knowledge, attitudes and behaviour with respect to breast disease and breast self-examination. These data are presented in Chapter 7.

Finally, in Chapter 8 the results are discussed in the context of published work in this area. The implications for health service practice and research are considered.

C H A P T E R 1

Breast cancer: the size of the problem and the epidemiology and management of breast cancer

INTRODUCTION

In 1979, the most recent year for which data are available, over 12,000 women died in England and Wales from breast cancer: almost half were under the age of 65 years (OPCS, 1980b). It has been estimated, from cancer registry data, that in a high incidence country 1 in 14 women will develop breast cancer at some stage in their lives and that the incidence may increase further (Zdeb, 1977). This chapter discusses first the mortality and incidence data for breast cancer, in the UK and internationally, and the available data on secular trends (Section 1.1), and, second, a review of the epidemiological literature on breast cancer (Section 1.2). The chapter ends with a summary of the current strategies available for the management of breast cancer (Section 1.3).

1.1 SIZE OF PROBLEM

1.1.1 UK MORTALITY DATA

The mortality data for women in England and Wales over the last 20 years show that the number of deaths from breast cancer has increased (Table 1.1). In 1957 there was a total of 8,612 deaths which, by 1977, had increased to 11,819 deaths. Table 1.2 shows the mortality rates from breast cancer by 10 year age-groups for women resident in England and Wales during the same years. The rate for the total population increased by 26% over the 20 year period, and again the increase was seen in each age-group, particularly in those aged 55-64 years where the mortality rate increased by almost one-third.

TABLE 1.1

NUMBER OF DEATHS OF WOMEN FROM BREAST CANCER IN ENGLAND AND WALES DURING 1957, 1967 AND 1977

(General Register Office, 1958 and 1968; OPCS, 1980b)

Age Group	1957 (% of each age group)	1967 (% of each age group)	1977 (% of each age group)
15-24	5 (< 0.1)	5 (< 0.1)	4 (< 0.1)
25-34	96 (1)	121 (1)	139 (1)
35-44	631 (7)	697 (7)	611 (5)
45-54	1760 (20)	1835 (18)	1879 (16)
55-64	2102 (24)	2654 (26)	2928 (25)
65-74	2068 (24)	2459 (24)	3114 (26)
75-84	1540 (18)	1834 (18)	2298 (19)
85+	410 (5)	626 (6)	846 (7)
TOTAL	8612 (100)	10231 (100)	11819 (100)

TABLE 1.2

MORTALITY RATES OF WOMEN FROM BREAST CANCER IN ENGLAND AND WALES DURING 1957, 1967 AND 1977 (PER 100,000 WOMEN)

(General Register Office, 1958 and 1968; OPCS, 1980b)

Age Group	1957	1967	1977	% Change 1957-1977
15-24	0.18	0.14	0.11	
25-34	3.16	4.18	4.03	+28
35-44	19.55	23.17	22.23	+14
45-54	53.77	58.24	64.37	+20
55-64	76.66	86.68	100.24	+31
65-74	102.94	107.90	120.84	+17
75-84	153.54	152.96	161.95	+5
85+	222.83	230.15	233.70	+5
TOTAL	47.18	52.82	59.40	+26

Breast cancer is the commonest cause of death in women aged 35-54 years and the second commonest (second to accidents) in those aged 25-34 years.

1.1.2 UK INCIDENCE DATA

There have been similar increases reported in the numbers and the rates of breast cancer registrations in the Birmingham and South Metropolitan Regions of England (Adams & Spicer, 1965; Armstrong, 1976). In England and Wales almost 20,000 new cases of female breast cancer were notified to the cancer registries during 1974 - over half were in women aged less than 65 years (OPCS, 1980a). The standardised registration ratio, set at 100 in 1968, had increased from 96 in 1965 to 124 by 1974. Data from the South Thames (Table 1.3) and West Midlands (Table 1.4) Cancer Registries confirm that the earlier reported increases in breast cancer registrations continue in most age-groups. The increases appear to be greatest in women aged 45-54 years.

1.1.3 INTERNATIONAL TRENDS

There is a large international variation in the incidence and mortality rates of breast cancer. The highest rates are found in Northern Europe and North America, intermediate rates in Southern Europe and South America and the lowest rates in Africa and Asia (UICC, 1966; UICC, 1970). Studies on Japanese migrants to Hawaii or mainland USA have shown that their rates of breast cancer approach those in US women after two or three generations, suggesting the relatively greater importance of environmental factors than genetic

TABLE 1.3

INCIDENCE OF BREAST CANCER IN SOUTH THAMES REGION IN WOMEN

(i) Numbers of Newly-Diagnosed Cases Registered During 1961-1975 by Age-Group

	25-34	35-44	45-54	55-64	65-74	75+
1961-65	44.4	298.0	588.2	670.8	605.0	566.4
1966-70	54.8	296.2	628.6	747.8	650.8	581.4
1971-75	58.6	283.8	624.2	692.4	694.4	592.2

(ii) Incidence Rates of Breast Cancer Registered During 1961-1975 by Age-Group per 100,000 Women

	25-34	35-44	45-54	55-64	65-74	75+
1961-65	10.8	63.7	124.5	153.5	187.0	263.2
1966-70	13.5	72.3	138.1	161.3	178.4	223.1
1971-75	13.5	75.7	146.0	162.2	184.4	217.2
Percentage change 1961-65 to 1971-75		+19	+17	+6	-1	-18

(derived from South Thames Cancer Registry data)

TABLE 1.4

INCIDENCE OF BREAST CANCER IN WEST MIDLANDS REGION IN WOMEN

(i) Numbers of Newly-Diagnosed Cases Registered During 1961-1975 by Age-Group

	25-34	35-44	45-54	55-64	65-74	75+
1961-65	38.2	220.2	399.0	405.8	340.4	259.2
1966-70	34.0	233.0	437.4	461.6	397.0	306.8
1971-75	46.0	218.4	441.0	502.2	437.6	317.4

(ii) Incidence Rates of Breast Cancer Registered During 1961-1975 by Age-Group per 100,000 Women

	25-34	35-44	45-54	55-64	65-74	75+
1961-65	11.5	63.2	124.6	146.8	179.1	227.0
1966-70	10.8	71.7	137.3	158.0	196.5	249.2
1971-75	13.7	72.0	155.8	172.6	197.8	236.3
Percentage change 1961-65 to 1971-75		+14	+25	+18	+18	+4

(derived from West Midlands Cancer Registry data)

differences (Buell, 1973; Haenszel & Kurihara, 1968).

Data from the USA indicate that the mortality from breast cancer increased between 1950 and 1971, with the greatest increase of 11% occurring in those aged 55-64 years (Armstrong, 1976). For example, data from the Connecticut cancer registry show increases in the incidence of breast cancer which, between 1960 and 1971, were as high as 38% in those aged 45-54 years. Similar increases in incidence have been reported from Finland (Teppo et al, 1974), Iceland (Bjarnason et al, 1974) and West Germany (Hamburger Krebsregisters, 1973).

It might be predicted that the evolution of population screening programmes would increase the apparent incidence of breast cancer. However, these increases in incidence were noted before screening was made widely available and appear to be paralleled by increases in mortality. It seems probable, therefore, that there has been a genuine increase in the incidence of breast cancer in certain Western countries, with a concomitant increase in mortality.

1.2 EPIDEMIOLOGY OF BREAST CANCER

Two substantial reviews of the epidemiology of breast cancer are available (MacMahon et al, 1973; Kelsey, 1979). The major findings and hypotheses are summarised in this section.

1.2.1 SEX

Less than 1% of the deaths from breast cancer occur in men (OPCS, 1980b), and the epidemiological literature relates almost exclusively to women. The

following summary includes data on women only.

1.2.2 AGE

The age-specific incidence and mortality of breast cancer both increase with age. Using data from the UK, USA, Denmark and Japan, Lee et al (Lee et al, 1976) showed that since the 1930s the greatest increases in incidence with age occurred in women under the age of 50 years. The relationship between incidence of breast cancer and age varies internationally, depending on the overall incidence rates of breast cancer in each country. In high incidence countries the incidence rates of breast cancer continue to increase over the whole life span (see, for example, Tables 1.3 and 1.4). Where the incidence rates of breast cancer are at an intermediate level the incidence rates tend to increase to the age of 50 years and then level off (UICC, 1966). In countries where the risk of breast cancer is low the incidence rates decline after the age of 50 years (UICC, 1966). These different patterns of age-specific incidence rates are corroborated by data from Iceland which show that, as the incidence of breast cancer increased from 1930, the shape of the age-specific incidence curve changed from that of a low-incidence country, through that of a country with an intermediate level of risk to that of a high risk country (Bjarnason et al, 1974).

1.2.3 REPRODUCTIVE FACTORS

One of the most consistent findings in the epidemiological studies of breast cancer has been the protective effect of an early first-term pregnancy. For example, one study (MacMahon et al, 1970) which set the risk of

developing breast cancer at 1.0 for nulliparous women, found that women who had delivered their first child before the age of 20 years had a relative risk of around 0.5, whilst for those whose first full-term pregnancy occurred over the age of 35 years the relative risk increased to about 1.5. Women with a first full-term delivery between 30 and 35 years appeared to have a similar risk to nulliparous women. These findings have been replicated in a variety of countries (Kelsey, 1979).

There is also agreement that to exert a protective effect the pregnancy must continue to term - indeed, there are suggestions that abortion, spontaneous or induced, may increase rather than decrease the risk (for example, Valaoras et al, 1969; Yuasa & MacMahon, 1970; Lin et al, 1971; Pike et al, 1981). The protection derived from a relatively early pregnancy appears to last throughout life (MacMahon et al, 1970). There has been some controversy as to whether parity exerts an effect independent of age at first birth. Although some authors have concluded that high parity does not provide any additional protection (MacMahon et al, 1973), there is some more recent evidence that women of very high parity may be at lower risk than would be predicted simply on the grounds of their age at first birth (Tulinius et al, 1978; Thein-Hlang et al, 1978; Adami et al, 1978). Breast feeding has been considered to provide protection against breast cancer. However, when the effect of parity is controlled, a history of breast feeding does not appear to offer any additional protective effect (MacMahon et al, 1970).

The protection afforded by an early first birth may be accounted for in two ways. First, there may be a common factor which is causally related both to the development of breast cancer and to a delayed first pregnancy. An obvious candidate would be the occurrence of anovulatory cycles, which would subject breast tissue to high levels of oestrogen without intermittently elevated progesterone levels, and would also tend to delay the first pregnancy (Sherman and Korenman, 1974). Secondly, an early first birth might exert a direct protective effect by altering breast tissue to make it less susceptible to tumour initiation (MacMahon et al, 1973). This theory has been extended to explain the increased risk, relative to nulliparous women, of women whose first pregnancy occurs over the age of 30 years. By this age there are more likely to be transformed tumour cells in the breast at the time of pregnancy and these cells might be promoted by the stimulation of breast tissue which occurs during pregnancy (MacMahon et al, 1973).

The significant influence of reproductive status has led to the hypothesis that patterns of fertility may be the explanation for the observed secular trends in the incidence of breast cancer. Several authors have observed that the increased incidence appears to be partly cohort-specific (Armstrong, 1976; MacMahon, 1958; Bjarnason et al, 1974), and MacMahon (MacMahon, 1958) and Armstrong (Armstrong, 1976) compared cohort-specific mortality and incidence rates with cohort-specific fertility rates. Although the earlier study failed to show any association which would explain

the increase in breast cancer (MacMahon, 1958), Armstrong (Armstrong, 1976) concluded that cohort-specific decreases in fertility rates paralleled the cohort-specific increases in breast cancer rates, and "may, at least in part, have been responsible for them". However, changes in fertility could not explain the cross-sectional increases in breast cancer rates which began in the 1960s.

1.2.4 ENDOGENOUS HORMONES

The obvious importance of reproductive status in the aetiology of breast cancer provoked considerable interest in the role of endogenous hormones. At the same time research in animals suggests that the administration of either naturally-occurring or synthetic oestrogens can lead to the development of breast cancer in mice, rats, rabbits, hamsters and dogs (summarized by IARC, 1974).

Both early menarche and late menopause have been shown to be associated with an increased risk of breast cancer - that is, either that the age at menarche and menopause are individual risk factors, or, perhaps more probably, that the greater the number of menstrual cycles the higher the risk of breast cancer (Kelsey, 1979). Artificial menopause also reduces the risk of breast cancer, and the lower the age of oophorectomy, the lower the risk - for example, women who have their ovaries removed before the age of 35 years have only one-third of the risk of women who undergo a natural menopause aged 45-54 years (Kelsey, 1979).

The role of endogenous hormones has been summarized

by Kirschner (Kirschner, 1977). Most attention has been focussed on the role of oestrogens, although their relationship with breast cancer is clearly not straightforward - for example, oestrogen levels are high during pregnancy, which, on the whole, is associated with a decreased risk of breast cancer. One hypothesis has centred on the oestriol ratio (the ratio of oestriol to oestrone plus oestradiol), which appears to be higher in young Asian women than in their North American counterparts (MacMahon et al, 1974). There have been criticisms of and counter-arguments for this hypothesis (Wotiz et al, 1978), although probably the consensus view would be that the oestriol ratio may be a useful marker of risk but that some explanation of its apparent association with breast cancer is required (MacMahon et al, 1973; Kelsey, 1979). In post-menopausal women most oestrogen is in the form of oestrone (Rader et al, 1973), which is known to be carcinogenic in animals (IARC, 1974), and there has been some interest in the possible role of oestrone in the aetiology of breast cancer. There is an association between obesity and the increased production of oestrone (Grodin et al, 1973) and thus oestrone might form a link between post-menopausal obesity, diet and breast cancer.

There have been suggestions that other hormones, such as progesterone, androgens and prolactin, may be involved in the aetiology of breast cancer, but very little supporting evidence has been adduced.

1.2.5 EXOGENOUS HORMONES

Because of the indications of an association between

endogenous hormones and breast cancer, there has been some anxiety that the use of oral contraceptives (OCs), particularly in young women, and hormone replacement therapy (HRT) may increase the risk of breast cancer. Although the results of published studies of OC use are reassuring, three studies have shown an increase in breast cancer risk in two sub-groups of women - those who had taken OCs for a relatively long period of time and who had previous, biopsy-proven benign breast disease (Brinton et al, 1979; Paffenbarger et al, 1977) and those who had taken OCs before their first pregnancy (Paffenbarger et al, 1977; Pike et al, 1981). Thus the negative studies should be interpreted with some caution, since long-term users and those who took OCs before their first pregnancy are the very groups for whom sufficient data may not yet be available. On the other hand, several studies have demonstrated a reduced incidence of benign breast disease in women who have used OCs for 2 or more years (Kelsey, 1979), and benign breast disease has itself been shown to be associated with breast cancer (see Section 1.2.6).

The position is similar with regard to HRT. The majority of case-control and cohort studies have not demonstrated any increased risk, although it has been noted that some are difficult to interpret because of methodological problems (Kelsey, 1979). However, two studies have shown an increased risk of breast cancer, one 10-15 years after the first use of HRT (Hoover et al, 1976) and the other when large cumulative doses of oestrogen were used (Ross et al, 1980). The negative studies should therefore be interpreted with some caution until further

studies are completed.

1.2.6 BENIGN BREAST DISEASE

A diagnosis of fibrocystic disease of the breast has been shown consistently to be associated with an increased risk of subsequent breast cancer, with most studies indicating a two-to-four-fold relative risk (Kelsey, 1979). It is uncertain whether fibrocystic disease and breast cancer share common aetiological factors or whether the former does in fact predispose to the latter.

1.2.7 FAMILY HISTORY

There is considerable evidence that women with a family history of breast cancer in a first degree relative have two or three times the risk of developing breast cancer as have all other women (Kelsey, 1979). This effect seems to be greater when the index case develops breast cancer before the menopause, and when she has bilateral disease (Anderson, 1971; Anderson, 1972; Anderson, 1974).

1.2.8 SOCIAL CLASS

Middle class women are more likely to develop breast cancer than are working class women, with the risk estimated as about twice as great in the highest social class as in the lowest (Coharte, 1955; Graham et al, 1960). Although this may reflect a direct or indirect causal relationship, these differences may be partially or completely explained on the basis of confounding variables. For example, middle class women have traditionally been older at the birth of their first baby, and age at first birth is known to be one of the most important predictive factors.

1.2.9 NUTRITION

There has been interest in nutrition as an aetiological factor in breast cancer, both in its own right and via the intermediary of body-build. The data on body-build are conflicting, with no clear indication as to which indicators are most closely associated with breast cancer risk; no consistent association has been found in pre-menopausal women and two studies have shown a negative association between large build and the risk of breast cancer (Kelsey, 1979).

Nutrition may be of importance in two ways. First, obesity increases the conversion of androstenedione to oestrone (Grodin et al, 1973); thus a diet which contained excess calories would predispose to obesity and cause elevated levels of oestrone, which has been implicated in the aetiology of breast cancer (see Section 1.2.4). Second, there is evidence from animal experiments that a high-fat diet can predispose to breast cancer, and that this increased risk of breast cancer is not attributable to increased calorie intake (Carroll, 1975; Gammal et al, 1967). Epidemiological data on human populations have shown an association between national breast cancer mortality rates and the per caput consumption of fats and oils (Armstrong and Doll, 1975; Drasar and Irving, 1973). The Japanese migrant studies show an increase in breast cancer incidence associated with an increase in fat consumption (Buell, 1973). Both breast cancer rates and fat consumption are low in Seventh Day Adventists (Phillips, 1975) and breast cancer rates have increased in Iceland as the diet has become Westernised (Bjarnason et al, 1974).

However, these data show associations rather than causal relationships, and case-control studies of nutrition and breast cancer have been only slightly suggestive of a link (Kelsey, 1979).

1.2.10 IONISING RADIATION

There are three main sources of data about the effect of radiation on human breast tissue - the long-term follow-up of survivors of the atomic bombs in Hiroshima and Nagasaki (McGregor et al, 1977), the observations on women who underwent repeated fluoroscopies during therapeutic pneumothorax for pulmonary tuberculosis (Boice and Monson, 1977) and the follow-up of women who received radiation treatment for post-partum mastitis (Shore et al, 1977). These studies all suggest that there is a linear, non-threshold, dose-response relationship between the radiation of human breast tissue and the subsequent development of breast cancer. Using these data the National Academy of Sciences has estimated that, for a breast dose of 1 rad, six new cases of breast cancer will occur per million women per year, after a lag period of 10 years (BEIR, 1972).

1.2.11 OTHER FACTORS

Conflicting results about the possible association of breast cancer with reserpine and with hair dyes have been obtained, but there is no clear evidence of any causal relationship. (For a review see Kelsey, 1979.)

1.3 THE MANAGEMENT OF BREAST CANCER

In the management of breast cancer, there are four main strategies which are used either curatively or palliatively - surgery, radiotherapy, endocrine therapy

and cytotoxic therapy. In addition, other forms of treatment may be employed, often to counteract the adverse effects of other therapies - for example, physiotherapy, the provision of a suitable prosthesis for women who have had a mastectomy, psychological and social support and drugs, in particular analgesics and anti-emetics.

It is estimated that, in 1977, 145 per 100,000 women in England and Wales were admitted to hospital with the diagnosis of breast cancer (DHSS/OPCS/WO, 1980). The mean length of stay was 14.9 days, and, on average, almost 1500 beds were occupied each day. Patients with breast cancer also account for a significant proportion of out-patient resources, especially when they attend for courses of radiotherapy or cytotoxic therapy. Over the 2 year period 1971-1972 it has been estimated that about 2 per 1,000 women in England and Wales consulted their general practitioner at least once with symptoms resulting from breast cancer (RCGP/OPCS/DHSS, 1979).

The diagnosis of breast cancer will almost inevitably lead to considerable physical, mental and emotional difficulties for the woman and for her family. Apart from the fears of illness and death, the treatment may cause many additional problems, but offer no guarantee of success. The treatment is also expensive to the woman and her family, and because of the high incidence of breast cancer and the complexity of its treatment, considerable NHS resources are also used.

Thus, strategies to improve the outcome for women with

breast cancer can be justified on humanitarian and economic grounds. However, despite extensive basic medical and applied research, and the provision of appropriate resources to allow the full implementation of apparent advances in medical care, the outlook for a woman with newly-diagnosed breast cancer remains uncertain. The prognosis has been found to be related to the size of the tumour, the involvement of the overlying skin or underlying chest wall, the involvement of axillary or supraclavicular lymph nodes and the presence of distant metastases. These factors have been used to develop a system of staging the disease, the most widely used being the American TNM system (STEER, 1973) and the International TNM system (UICC, 1972). The underlying principles of the TNM systems are the same, each being based on the tumour size and local involvement of skin or chest wall (T), the presence or absence of involved lymph nodes (N) and the presence or absence of distant metastases (M). The extent of the breast cancer can be assessed both clinically and pathologically.

Using TNM staging, it has been found consistently that patients with Stage I disease have the best prognosis, those with Stage II and Stage III disease have intermediate prognoses and those with Stage IV disease have the worst outcome. Similarly when the disease is staged by the histology of the axillary nodes, the survival is best in those women without histological involvement of the axillary nodes and worst in those with four or more nodes showing evidence of metastatic disease (Henderson and Canellos, 1980).

However, the relationship between stage at presentation and prognosis is not straightforward. For example, 25-30% of women who appear to have Stage I disease die within 10 years of diagnosis, even though there seems to have been complete local control of their disease (Fisher et al, 1975a). This presumably reflects the fact that the disease has in fact already spread to distant sites at the time of diagnosis, although this spread may not be detectable using conventional tests. Although on the whole survival rates decrease and recurrence rates increase with larger lesions or increased node involvement, women with tumours larger than 6 cms but no histological node involvement, had a recurrence rate of 24% at 5 years, compared with 44% in women with smaller tumours of 1-2 cms diameter but with histological evidence of nodal involvement (Fisher et al, 1969; Packard et al, 1977).

The effect of delay between the first symptom being noted and the provision of definitive treatment on outcome is complex. When delay occurs, the cancer is likely to be more advanced, both in terms of tumour size and axillary node involvement (Robbins and Bross, 1957; Bloom, 1965; Fisher et al, 1977b). However, this does not appear to consistently worsen the patient's chances of survival (Bloom, 1965; Zelen, 1968; Dennis et al, 1975). One study reported similar outcomes for women who watched their tumours for more than 1 year before seeking treatment and those who presented promptly (Bloom, 1965).

Follow-up studies indicate that about three-quarters of those women who are diagnosed as having breast cancer die with evidence of persistent disease (Adair et al, 1974;

Brinkley and Haybittle, 1975; Mueller et al, 1978). By 20 years after their diagnosis, the total mortality rate of women diagnosed as having breast cancer is the same as that of an age-matched control group, although some still die with breast cancer (Brinkley and Haybittle, 1975). However, the majority of patients will die within 20 years of their breast cancer being diagnosed and at a much higher rate than a group of age-matched controls.

Despite the substantial body of research designed to elucidate the optimal treatment programme for each woman with newly-diagnosed breast cancer, no clear consensus has emerged. There are major problems in the design, analysis and interpretation of these studies which in many cases make it difficult to evaluate the findings. The data on outcome imply that there are variations in the host-tumour interaction. These variations, which may reflect different degrees of aggression in the tumour or defence in the host (Carter, 1974; Mackay, 1974) emphasise the importance of either allowing for a theoretical prognosis without treatment or including a control group who receive conventional treatment in any trial of therapy for breast cancer. However, given the present incomplete state of knowledge on tumour characteristics and outcome, this may present problems. For example, patients with Stage I disease may really comprise a spectrum from those with aggressive disease (limited local growth but early distant metastases) to those with limited-potential disease (limited local growth, which may have been present for some time, and no distant metastases) (Zelen, 1968). If these patients are considered

as a homogeneous group, some will undoubtedly receive inappropriate treatment; moreover, the results of any trial including such a mix of patients would be very difficult to interpret fully. Despite interest in the development of a histological grading system which would be predictive of outcome, the U.S.National Surgical Adjuvant Breast Project was unable to define a suitable system (Fisher et al, 1975b).

A second problem in evaluating research in the management of breast cancer lies in the measurement of outcome. Studies of procedures such as mastectomy, with a specifically curative intention, tend to measure outcome in terms of death/survival, although survival may often be disaggregated into survival with and without recurrence. If the procedure is being assessed in terms of cure, a follow-up of not less than 20 years is obviously mandatory, although interim survival rates can also be calculated. Those forms of therapy which are intended to palliate advanced or recurrent disease are more appropriately evaluated in terms of a response to treatment - this may be either objective, for example a reduction in tumour size, or subjective, for example a reduction in the pain caused by a bony metastasis.

Third, it may be difficult to make comparisons between studies. This may be due to minor differences in treatment regimen, for example the dose of radiotherapy, or due to variations in the criteria for inclusion in the study, or due to the proportion of women who are not treated exactly as defined in the protocol. These problems are compounded by the fact that the control group will vary considerably

from study to study. As a "no treatment group" would be considered unethical, the comparison group is usually given what is considered by that particular centre to be the optimal, conventional treatment - and this will vary from centre to centre, and over time.

Finally, there are difficulties in recruiting sufficient numbers of women into each study to ensure that small differences in the effectiveness of two methods of treatment would be detected. It has been estimated that 600 patients would have to receive each type of treatment to demonstrate with certainty (90% power, $p< 0.05$) that one treatment will induce a 10% better outcome than another. When considering breast cancer a 10% difference in outcome may be a relatively large variation, and it may be necessary to include even larger numbers of women into each treatment group (Boag et al, 1971; Baum et al, 1972). Thus, multi-centre collaborative studies, with all their difficulties, become the only method able to assemble enough cases to investigate potential advances in breast cancer therapy.

To quote Henderson and Canellos: "...the over-interpretation of small, uncontrolled, and poorly-designed studies or the extrapolation from the experience of an individual practitioner will usually be misleading. The development of co-operative groups of physicians....means that most physicians may participate actively in ongoing therapeutic trials, an alternative preferable to anticipating future developments on the basis of insufficient data" (Henderson and Canellos, 1980).

Despite the gaps in knowledge about the management of

breast cancer, particularly at the level of defining the most appropriate treatment for an individual woman, some conclusions can be drawn (Henderson and Canellos, 1980):-

... the place of radical mastectomy in the management of breast cancer has been seriously questioned. A large randomised study of women without axillary lymph node involvement found no difference in terms of either survival or local recurrence between those treated by radical mastectomy and those who received a simple mastectomy, with or without radiotherapy (Fisher et al, 1977a). Another study of women with Stage II disease also failed to show any difference in survival between the group treated by radical mastectomy and the group treated by simple mastectomy plus radiotherapy (Lythgoe et al, 1978). It seems therefore that less mutilating and disabling operations are at least as effective as radical mastectomy in terms of survival and local recurrence for women with Stage I or Stage II disease.

... although radiotherapy at the time of simple mastectomy may reduce local recurrence, there is no evidence that it improves survival (Cancer Research Campaign Trial, 1976; Fisher et al, 1977a; Lythgoe et al, 1978).

... in place of the classical methods of curative treatment (radical mastectomy or simple mastectomy with radiotherapy) alternatives such as tylectomy (Atkins et al, 1972; Hayward, 1977) and primary irradiation without surgery (Proznitz et al, 1977; Harris et al, 1978), have been demonstrated to merit further consideration and evaluation.

... endocrine therapy (the addition of oestrogens, androgens, progestogens or corticosteroids or the ablation of the ovaries, adrenal glands or pituitary gland) is not the only option, nor necessarily the most effective one, for women with advanced disease. The oestrogen-receptor assay has made it feasible to select those women who are most likely to respond to the various strategies of hormonal manipulation and to maintain their response. The preliminary results of studies of the anti-oestrogens, such as tamoxifen, and aminoglutethimide, which suppresses corticosteroid synthesis, appear promising (Henderson and Canellos, 1980) and, if maintained, these drugs may play an increasingly important role in women with relatively advanced disease.

... combination chemotherapy has also shown evidence of early benefit in the management of advanced breast cancer, particularly in younger women and in those who are less responsive to endocrine therapy (Nemoto et al, 1978; Priestman et al, 1978). Two randomised studies of adjuvant chemotherapy in early breast cancer, although with involved axillary nodes, show chemotherapy to be associated with increased survival and decreased relapses at 4 years follow-up, although these improvements are seen only in pre-menopausal women (Bonadonna et al, 1978; Fisher et al, 1979).

There has been a tendency to evaluate the treatment of breast cancer only in relation to its effect on the progress of the tumour. The effects on the woman herself are rarely considered, although it is a commonplace to doctors that women can be very upset and disturbed, both

physically and psychologically, by their treatment. For example, cytotoxic therapy has extensive side-effects - in particular, anorexia, nausea and vomiting and hair loss, which, although very unpleasant for the woman, may not even be noticed by her doctors (Palmer et al, 1980). Mastectomy also causes physical and psychological sequelae. In Manchester 152 women with breast cancer treated by mastectomy were randomly allocated to either normal care or normal care plus counselling and monitoring (Maguire et al, 1980). About 40% of women had significant psychological problems, such as anxiety, depression and sexual difficulties 3 months after surgery, although by 18 months the psychological morbidity in the group who received counselling was only one-third that of the control group. The nurse, who had received suitable training, was able to identify most of the psychological morbidity diagnosed by the psychiatrist who evaluated her work, but general practitioners and social workers had detected only one-fifth of the psychological problems. Similar findings have been reported from elsewhere (Baum and Jones, 1979).

Thus, following the diagnosis and treatment of breast cancer there appears to be significant morbidity, some of which may be attributable to the treatment rather than the disease. There is also evidence of difficulties in social relationships (Maguire et al, 1980), although relatively little work has been carried out in this area - for example, the reactions of the women's sexual partners to their illness remain an enigma. However, the data which do exist suggest that in future the evaluation of therapeutic

interventions in breast cancer should include measurement of their effect on the woman herself and, possibly, on her family and close friends.

The complexity of the treatment of breast cancer, and the evidence of continuing problems relating to both the disease and its treatment, reinforce the importance of inter-specialty collaboration to provide the optimal management for each woman. The various modalities of treatment are traditionally each seen as the province of a different medical specialty and thus the joint assessment and follow-up of these women should be routine. In addition the psychiatric team should be more involved, either directly, or indirectly,by educating and training other health care workers to identify and either treat or refer women with psychological problems. The primary care team should also be trained to recognise and manage the well-described problems which the woman with breast cancer is likely to encounter.

C H A P T E R 2

The prevention of breast cancer: reducing delay in treatment, screening and breast self-examination

INTRODUCTION

Despite the apparent advances in the management of breast cancer, the prognosis for a woman with the disease is much the same now as it was 40 years ago (Baum, 1976). Considerable attention has therefore been devoted to the possibilities of prevention. Although epidemiological studies have indicated a variety of factors which appear to increase an individual woman's likelihood of developing breast cancer (summarised in Chapter 1), the opportunities for primary prevention are limited. For example, the promotion of adolescent pregnancies might reduce the incidence of breast cancer but, at the same time, would have other far-reaching, and probably unacceptable, consequences. Other risk factors, such as a family history of breast cancer or a personal history of benign breast disease, are not capable of modification. The evidence of increased risk associated with the consumption of certain dietary components or drugs is not yet strong enough to justify primary preventive action.

Secondary prevention seems to offer the greatest possibilities for reducing the mortality and morbidity associated with breast cancer. There are essentially two objectives: first, to detect the cancer as early as possible, and, second, having detected it to reduce the delay before treatment. Three strategies for secondary prevention will be considered - reducing the delay (Section 2.1), screening for breast cancer (Section 2.2) and the promotion of breast self-examination (Section 2.3).

2.1 REDUCING THE DELAY

2.1.1 THE EXISTENCE OF DELAY

There is often some delay between noting the first symptoms of breast cancer and receiving definitive treatment - sometimes this delay may be considerable. For example, in a study of 162 women aged 16-50 years with newly-diagnosed breast cancer (Adam et al, 1980 (appended)) four events were defined - the woman (i) first suspecting an abnormality; (ii) consulting her general practitioner; (iii) first attending a hospital out-patient clinic and (iv) receiving definitive treatment. When the time intervals between these events were analysed, delays were found to occur in each. Delay, arbitrarily defined as a time interval of more than 2 weeks, was experienced by 41% of women during the first interval, 25% of women during the second interval and 35% of women during the third interval. Perhaps more worrying was the finding that 10%, 6% and 8% of women waited more than 12 weeks in the three time intervals respectively.

The explanations given by the women for any delay which occurred were based on rationality and logic rather than ignorance and fear, although obviously fear may have played a larger role than they wished to disclose. For example, the delay on the part of the women was accounted for most commonly by their assumption that the symptoms were not serious or were due to something other than cancer, or by their domestic responsibilities which made it inconvenient to be ill. The delays occurring within the health service were found most likely to be due to

diagnostic or administrative problems, and were particularly common where the symptoms were not typical of cancer or where there was a history of benign breast disease.

These findings are in accord with those of previous studies of women with breast cancer (Bywaters & Knox, 1976; Bywaters, 1977), and with a more recent report (MacArthur & Smith, 1981). Contrary to many assumptions the woman herself is by no means entirely responsible for any delay which she experiences in obtaining treatment, a finding common to other areas of medical practice (see, for example, Chalmers et al, 1972; Holliday & Hardcastle, 1979). Moreover, even that part of the delay which might be attributable to the women will not necessarily be eliminated merely by providing them with more information about breast cancer. This may not determine their subsequent behaviour, as even knowledgeable women may provide good reasons for their decision not to seek treatment immediately. There are also problems about finding the most appropriate information to provide both for the woman and for health professionals - for example, the emphasis on cancer presenting as a painless lump seems to have inhibited the suspicion of cancer when the symptoms do not fit this stereotype.

2.1.2 THE BENEFITS OF REDUCING DELAY

Apart from these difficulties it is necessary to consider whether minimising delay reduces the morbidity and mortality from breast cancer. The data on this are conflicting and difficult to interpret, partly because

most studies calculate the length of survival from date of diagnosis rather than date of first symptoms and partly because the criteria for inclusion vary from study to study. A recent report (Elwood & Moorehead, 1980) of 1591 women with breast cancer diagnosed in British Columbia during 1945, 1950, 1955, 1960, 1965, 1970 and 1975 reported that long-term survival was greater in patients with a shorter delay between the appearance of symptoms and diagnosis. However, when the data were analysed within groups by clinical stage at presentation, there were no consistent or statistically significant differences in survival between the long and the short delay groups. If, as this indicates, delay is correlated with stage at presentation, then the criteria for patient slection might account in part for the results of previous studies which have shown either no association between delay and survival (Park & Lees, 1951; Bloom, 1965; Dennis et al, 1975; Fisher et al, 1977b) or better survival in the long delay group (Lewis & Reinhoff, 1931; Berkson, 1962).

However, other studies have reported an improvement in survival when delay is reduced (Treves & Holles, 1958; McWhirter, 1957; Sheridan et al, 1971), and it has even been suggested that delay time may be used, in conjunction with other measures, to assess the prognosis for a woman with breast cancer (Charlson & Feinstein, 1974). However, although the conclusion that a reduction in delay improves the long-term survival remains controversial, those involved in cancer education have based their strategies

on the assumption that a reduction in delay is beneficial.

2.1.3 THE EXPLANATIONS FOR DELAY BY THE WOMAN

Cancer education has traditionally given considerable priority to breast cancer. The potentially sinister nature of the painless lump has been stressed, and women have been encouraged to check their breasts regularly and report any changes to their doctor without delay. Although there is some evidence of an increase in the proportion of women with clinical Stage I disease at presentation (Elwood & Moorehead, 1980; de Bono & Pillers, 1978), it appears that there has been very little reduction of delay since 1960 (Elwood & Moorehead, 1980). The characteristics of women who delay have been extensively studied, and recently summarised (Ray, 1980). For example, the women are more likely to be older, working class, of lower educational status, to be anxious, depressed or express feelings of hopelessness, to deny the possibility of cancer and to express fears of mastectomy, malignancy and hospitalisation.

The underlying reasons for delay in presentation are complex and as early as 1955 it was possible to conclude that ignorance was not the only explanation (Paterson, 1955). In addition, delay by the woman is only part of the problem - other significant delays occur between her first medical consultation and definitive treatment. These delays will only be alleviated by educating the health professionals and by changing the organisation of services. Meanwhile, although the evidence

that early diagnosis and treatment improve long-term survival is by no means conclusive, women with breast symptoms are encouraged to present as early as possible. In addition to this, breast screening and breast self-examination (BSE) are advocated.

2.2 SCREENING FOR BREAST CANCER

During the 1950s techniques for the screening of asymptomatic women for breast cancer were developed. Three modalities have evolved - clinical examination, mammography and thermography. So far only one randomised study of breast screening has been reported - the Health Insurance Plan (HIP) study in New York. This study (Shapiro et al, 1973) which was started in 1963, randomly allocated 62,000 women aged 40-64 years who belonged to the HIP pre-paid, group practice plan into one of two groups. The first group received their normal medical care, the second group, in addition to this, were invited to attend for a screening examination, which was repeated three times at annual intervals. The screening examination consisted of an interview with the patient followed by clinical examination and mammography.

A report of 9 years follow-up (Shapiro, 1977) shows that the mortality from breast cancer was reduced by about 30% in the group of women who had been screened (91 deaths in the screened group compared with 128 deaths in the control group). However, there was no difference in mortality in women aged 40-49 years. The difference was most marked in women aged 50-59 years, although still present to a lesser extent in those aged 60 years and over. When

the impact of screening is measured in terms of case-fatality rates similar results are obtained - screening appears to be most effective in those aged 50-59 years. When the case-fatality rates are considered separately among women with breast cancer detected by different screening modalities, the prognosis is best for those women diagnosed by mammography only, next best for those women diagnosed by clinical examination only and worst for those women in whom the cancer was detected by both mammography and clinical examination. Clinical and pathological staging indicated that the women who had been screened were more likely to present at an earlier stage than were the control group.

Screening by mammography and clinical examination therefore appears to reduce by about one-third the mortality attributable to breast cancer in women aged 50 years and over. The results of the HIP study also lend support to the hypothesis linking a reduction in delay in obtaining treatment with improved outcome. However, in considering any screening programme it is necessary to take into account the relative costs and benefits of screening.

The criteria for the validation of a screening programme have been defined (McKeown, 1968). These include (i) the biological criteria, such as an understanding of the natural history of the disease, the availability of suitable screening tests and the application of effective treatment, and (ii) the economic criteria, which are usually expressed in terms of whether

the screening programme justifies priority over other possible expenditures. It is also essential to appreciate and define the potential risks of a screening programme - risks of both over-diagnosis and under-diagnosis. In summary there should be "evidence that (screening) is effective, and that it deserves priority over competing medical measures" (McKeown, 1968).

2.2.1 THE PREVALENCE OF BREAST CANCER AT FIRST SCREENING EXAMINATION

Published papers have reported a wide variety of prevalence rates of breast cancer at the first screening examination (Table 2.1). Although the characteristics of the women vary by age, method of referral and risk status, they are all supposedly asymptomatic and it is surprising to find a 10-fold difference in detection rates. One obvious explanation for this is that screening clinics are being used by women who are already symptomatic, but are apparently reluctant to use the more conventional referral networks. For example, in one study 3 of the 6 women "found" to have breast cancer knew that they had a lump in the breast (Thomas, 1975), and in another 11% of the invited women had symptoms of breast disease (George et al, 1976). Screening, a very resource-intensive activity, may not be required to diagnose these symptomatic women; the provision of more acceptable pathways into the health care system may be all that is required.

TABLE 2.1

PREVALENCE OF BREAST CANCER AT FIRST SCREENING EXAMINATION

Study	Characteristics of women screened	Modalities used	Rate of breast cancer detection per 1000 women screened
Sydney (Croll et al, 1977)	25+ years; well women, doctor-referred.	M	2.2
HIP, New York (Shapiro et al, 1973)	40-64 years; invited.	CM	2.7
Edinburgh (Edinburgh Breast Screening Clinic, 1978)	40-60 years; invited.	CMT	2.8
Sweden (Jakobsson et al, 1975)	35+ years; invited.	CMT	4.2
Sweden (Lundgren & Jakobsson, 1976)	35+ years; invited.	M	5.7
Manchester (George et al, 1976)	All ages; self-referred.	CM	6.6
BUPA (Bailey et al, 1976)	All ages; self-referred, fee paying.	CT(M)	6.9
Gateshead (Stark, 1976)	35-75 years; self-referred.	CMT	7.6
Manchester (George et al, 1976)	50+ years; invited.	CM	9.6
Guildford (Thomas, 1975)	35+ years; identified as high risk	CM	10.8
West London (Chamberlain, 1975)	40+ years; self-referred (1000) + identified as high risk (200)	CM	12.0
Gateshead (Stark, 1976)	35-75 years; identified as high risk	CMT	24.5

C = clinical examination; M = mammography; T = thermography

2.2.2 THE SAFETY OF MAMMOGRAPHY

The only appreciable hazard in screening for breast cancer comes from mammography (Bailar, 1977). Early mammography, such as that used in the HIP study, necessitated the use of high doses of radiation. In the Breast Cancer Detection Demonstration Programme established by the American Cancer Society and the National Cancer Institute in 1973, the average X-ray dose was 3.1R per examination, with a range of 0.27 to 18.0R (Thier, 1977). More recent studies have achieved lower doses - for example, in Manchester it was possible to reduce the radiation to less than 1R per examination using modern low-dose systems (George et al, 1976).

No direct evidence about the possible carcinogenicity of mammography is available yet. However, the data described in Section 1.2.10 indicate that there probably would be some finite risk of radiation-induced cancer, particularly in younger women. This albeit indirect evidence about the risks of mammography is likely to remain the best source of data at least for some time (Bailar, 1977). Populations of women who had received mammography would have to be followed for at least 20 years (assuming a 10 year latent period) and allowance would have to be made for selection biasses. With an appropriate design it should be possible at a population level, to determine the risk of mammography-induced cancers.

Using the available cited data on women exposed to radiation, the National Academy of Sciences has estimated that, for a breast dose of 1 rad, six new cases of

breast cancer will occur per million women per year, beginning after a lag of 10 years. Screening would have to be repeated regularly and the risk of repeated mammography is believed to be additive (BEIR, 1972). In terms of the individual woman who underwent mammography, this risk attributable to diagnostic radiation would increase her lifetime risk of breast cancer from 7% to 10% with thirty screening examinations, each with a dose of 1 rad, assuming that the risk applied throughout life. This estimated increased risk may, if known, be acceptable to many women. However, the possibility that mammography may cause as well as diagnose cancer should be explained. It seems premature to conclude that "no breast cancer has ever been shown to be due to a screening examination" (BUPA Health Promotion Centre, 1980).

2.2.3 THE POSSIBLE OVER-DIAGNOSIS OF BREAST CANCER

The debate about the real value of detecting lesions which are less than 1 cm in diameter resembles that about cancer of the cervix, where there still remains some doubt about the significance of in situ lesions. Screening enables the diagnosis of breast cancer to be made at a very early stage - the cancer may be invasive but less than 1 cm in diameter, may be in situ, or may be considered to be of borderline malignancy. For example, by June 1976, 1810 breast cancers had been detected in the 280,000 women participating in the Breast Cancer Detection Demonstration Programme (Thier, 1977). Of these, 592 were in situ or invasive lesions less than 1 cm diameter, and, at independent pathological review, 66 lesions were re-interpreted as benign and 22 others as "borderline". At re-review, some

lesions were re-classified for a second time, and the difficulties in accurately discriminating benign from malignant were emphasised. The inclusion of such lesions among cases of breast cancer results in two problems - first, in the context of the evaluation of screening their inclusion may apparently improve the breast cancer case-fatality rates among screened women; and second, there are serious difficulties in determining the most appropriate treatment and in providing the woman with a likely prognosis.

2.2.4 THE POSSIBLE OVER-DIAGNOSIS OF BENIGN BREAST DISEASE

A definitive diagnosis of breast cancer can be made only by the histological examination of a biopsy specimen, and thus women who have signs suggestive of breast cancer at screening will be referred for a diagnostic biopsy. The biopsy rates have varied in the different studies of screening, as has the ratio of benign to malignant lesions found at biopsy. For example, biopsy rates between 2.3% in Edinburgh (Edinburgh Breast Screening Clinic, 1978) and 9.8% in West London (Chamberlain et al, 1975) have been reported, with most programmes admitting between 2% and 3% of women for biopsy. The percentage of biopsies which are considered to demonstrate malignancy also varies - in Edinburgh (Edinburgh Breast Screening Clinic, 1978) 13% biopsies were malignant, in the HIP study 20% (Shapiro et al, 1971), in Manchester 33% in invited women (George et al, 1976), whilst in Gateshead 58% women referred for biopsy were found to have malignant disease (Stark, 1976).

These differences are hardly surprising given not only the different clinical practices in each screening clinic, but also the different characteristics of the

women who attended for screening (Table 2.1). However, all the studies demonstrate that screening for breast cancer will also detect benign breast disease, much of which would not otherwise be diagnosed or require treatment. Since the diagnosis involves not only a biopsy, usually under general anaesthetic, but also the anxiety that the lesion may be malignant, the costs of diagnosis to the woman may be considerable. There are, of course, also resource implications for the health service.

2.2.5 THE ACCEPTABILITY OF SCREENING

There are several plausible reasons why women might decline invitations to attend for breast screening, ranging from fear and embarrassment, to a scepticism about the balance of benefits and costs involved. The acceptance rates have varied in the different studies - for example, in Manchester 54% of the invited women attended for screening (George et al, 1976), 65% in the HIP study (Shapiro et al, 1973) and 82% in Edinburgh (Edinburgh Breast Screening Clinic, 1978). This last, remarkably high, acceptance rate has been attributed to the fact that each woman received an invitation letter signed by her own general practitioner, and "many women said they came only because their doctor asked them to"; however this cannot be the only explanation as the same method of invitation was used in Manchester. It is also encouraging that 84% of the Edinburgh women who attended the first screening examination returned one year later for re-screening. Reports from Sweden indicate even higher acceptance rates of screening invitations of 78% (Jakobsson et al, 1975) and 88% (Lundgren & Jakobsson, 1976).

There is some evidence that women with certain characteristics may self-select themselves for screening - either by accepting rather than refusing an invitation to attend, or by referring themselves. For example, a greater proportion than would be expected of those attending for screening have symptoms. In one study the women who attended for screening tended to be younger, were more likely to be middle class, more likely to have experienced other preventive health care (cervical screening and chest X-ray screening) and to be more optimistic about the curability of cancer (Hobbs et al, 1980). Some of the self-selection which occurs, for example the increased uptake of screening by middle class women, may operate to encourage those who would be defined as being at "higher risk" to be screened.

2.2.6 RESOURCE IMPLICATIONS

To be effective in reducing the morbidity and mortality associated with breast cancer, screening must be made available on a total population basis. Although certain risk factors have been defined, none of these is specific enough for the screening of only high-risk populations to be feasible (Shapiro et al, 1973). It has been estimated that at 1975 prices a screening programme including mammography would cost £12M annually for England and Wales (Knox, 1975). A simulation model has suggested that the programme would produce a 12% reduction in mortality from breast cancer on the assumption of a 50% uptake, and 30 successive annual screening examinations. Thus the cost per "life saved" would be £8,000.

The resource implications of breast screening include staff requirements. Screening is not only labour-intensive, but has traditionally been performed by the most expensive and scarce type of health personnel - doctors. The clinical examination has been carried out by surgeons, and the mammograms have been read by radiologists. In addition, screening clinics have employed nurses, to assist with the clinical examinations, and radiographers to take the X-rays. Some studies have considered the extended role of non-medical staff in breast screening. For example, in Manchester comparisons were made between nurses and surgeons in performing clinical examinations, and radiographers and radiologists in reading the mammograms (George et al, 1976; George et al, 1980a). The non-medical team of nurse and radiographer were as successful in detecting breast abnormalities as the medical team of surgeon and radiologist. Unfortunately nurses and radiographers are also expensive and in short supply. In addition, it may not be necessary to include a routine clinical examination. Experience in Sweden indicates that screening may be performed successfully by mammography only (Lundgren & Jakobsson, 1976).

Apart from the resources required for screening, additional resources are required for the follow-up of those women found to have abnormalities. This will include referral to a clinician, possible biopsy and appropriate treatment. In the first year of a screening programme this will have considerable implications, although the evidence suggests that subsequently the extra workload would be reduced (George et al, 1980b).

There are other dilemmas in breast screening which remain unresolved. How often screening should be performed, at what age it should start, whether different screening programmes for higher risk and lower risk women should be developed, what false negative rate could be expected, and, ultimately, what the benefits of the optimal screening programme might be. The HIP study has indicated some reduction in the mortality attributed to breast cancer, this benefit being limited to women aged 50 years and over. However, the screening was performed almost 20 years ago and it seems likely that more up-to-date programmes, using increasingly sophisticated equipment, might achieve a greater benefit. Several studies now in progress should clarify at least some of these issues, although it may be another 10 years before definitive results are available. Meanwhile the evidence does not support the introduction of a national programme of breast screening and the objectives in the management of breast cancer should be to increase the efficiency and effectiveness of the treatment of women with symptoms.

2.3 THE PROMOTION OF BREAST SELF-EXAMINATION (BSE)

BSE has been advocated as a means of promoting the early detection of any breast abnormality, both as an adjunct to screening and as a technique in its own right. Although several different methods of BSE are taught, the underlying principles are similar. The breasts are first inspected in a mirror and then palpated systematically, including the axillary tails and axillae. The examination is designed to allow each woman to learn what is normal for her, and, having done this, to be able to detect any

slight changes. It should be repeated at monthly intervals, and, in women who are still menstruating, should be performed soon after the end of each period, when the breasts are least likely to be lumpy.

American studies have shown that about three quarters of breast cancers are detected by the women themselves (Lesnick, 1977; Maharry, 1980), and on the basis of this, and the uncertainties about screening, BSE has been promoted with considerable enthusiasm. It has been characterised as the epitome of the perfect screening procedure - "simple, self-generated, inexpensive, non-invasive and non-radiative" (Moore, 1978). Despite this advocacy, there is little evidence of any benefit resulting from its correct practice.

2.3.1 PRACTICE OF BSE

This professional belief in the value of BSE does not appear to be shared by the target population - women. Several surveys of the prevalence of BSE practice have been carried out, and the results are fairly consistent. In 1974 the American Cancer Society interviewed 1007 randomly-selected women aged 18 years and over (American Cancer Society, 1974). Although 77% women had heard of BSE, only 18% said they had examined their breasts each month during the year before the survey. The Manchester Study of the feasibility of breast screening (Hobbs et al, 1977) found by interview that 16% of 350 women practised BSE, although 54% had heard about it. Only 10% of 1000 consecutive women attending the Breast Clinic in Toronto said that they practised monthly BSE (Mahoney, 1977), although a further 70% said that they had tried but discontinued it, because

"they found so many lumpy areas that they became confused, frustrated or terrified". In New Zealand a sample of 1450 women aged 15 years and over were randomly selected for education about BSE (Richards, 1977). Before the study they were interviewed and 16% said that they examined their breasts at least once every month. In Australia the prevalence of monthly BSE practice in women aged 18 years and over was found to be 21% (Hill et al, 1980).

Higher levels of BSE have been achieved in certain populations. In Canada, the Canadian Cancer Society has, since its inception in 1938, been actively concerned with public education about cancer, and has used regular polls to evaluate changes in knowledge, attitudes and behaviour. Polls conducted in 1960 (Phillips & Taylor, 1961) and 1971 (Phillips, 1974) showed that the proportion of women "practising BSE regularly or occasionally" increased over the 11 years from 20% to 38%. A further poll in 1975 showed that 36% women said they practised BSE monthly and a further 27% occasionally (Phillips & Brennan, 1976). These relatively high levels of BSE practice, and the increase over the past 20 years, are attributed, at least in part, to the health education programme. In Holland, a study of 344 women aged 35-64 years attending for breast screening showed that 34% reported the practice of monthly BSE (van den Heuvel, 1977). Highly health-conscious groups of women may also have a higher prevalence of BSE practice. For example, a study of 177 women aged 30-74 years who belonged to a Common Health Club in Sonoma County, California ("a membership controlled, low-cost, comprehensive

educational and motivational system for individuals to assess their own health status") showed that 53% said that they practised monthly BSE (Rodnick & Bubb, 1978).

Women attending breast clinics may also be more likely to describe themselves as regularly practising BSE. In a study of 150 consecutive women who attended the Breast Disease Clinic at PMI-Strang Clinic in New York from July 1 1969, 37% claimed that they practised regular BSE, although a few of these carried out the examination less frequently than monthly (Thiessen, 1971). However, in another study (Hill et al, 1980) the prevalence of BSE practice in a group of women with breast cancer was slightly lower (17%) than in a random sample of the population (21%), possibly because of the confounding effect of age.

Various factors have been found to correlate with whether women are aware of, and practise, regular monthly BSE. There is some evidence that the prevalence declines with age (Rodnick & Bubb, 1978; Hill et al, 1980), although this may of course be a cohort rather than an ageing effect. Increased educational status is also associated with increased BSE practice (Phillips & Brennan, 1976). One study of about 600 randomly selected women living in the North West of England developed a five-point scale of current awareness of BSE - from 0 = "no awareness of BSE", to 4 = "taught how to do BSE and received leaflet" (Haran et al, 1979). Greater awareness was reported by those women who had previously undergone cervical cytology and chest X-ray screening. Although the more aware women

tended to view breast cancer as "the most worrying illness", they were also more optimistic about the chances of cure. Breast size also appears to influence the practice of BSE - in one study women with "small" and "large" breasts were less likely to practise BSE than those with "medium-sized" breasts (Thiessen, 1971).

2.3.2 THE BENEFITS OF BSE

Several studies have noted an association between the regular practice of BSE and a shorter delay in presenting with symptoms of breast disease. For example, in one Canadian study of women presenting at a cancer treatment centre, the mean delay between first noting symptoms and presentation was 3.1 weeks in those who said they practised BSE regularly, 6.0 weeks in those said to be practising occasionally and 25.6 weeks in those who said they never practised BSE (Phillips, 1975). Women who practise BSE regularly might receive definitive treatment for breast cancer earlier for two reasons - they might detect the abnormality earlier or they might then consult a doctor more quickly.

Little research has been done to confirm or refute this hypothesis. Two papers published in 1978 considered the association between the practice of BSE and the clinical and pathological stages of breast cancer at presentation. The first considered 335 patients with histologically confirmed breast cancer during 1975-1977 in Vermont (Foster et al, 1978). 25% women reported that they practised BSE monthly, 28% occasionally and 47% never - BSE practice became less common with increasing age. There

was a significant association between the reported frequency of BSE and the diagnosis of breast cancer at earlier clinical and pathological stages. Of the women who said that they practised BSE regularly each month, 55% presented with clinical Stage 0 or I cancer, 40% with Stage II and only 5% with Stage III or IV. In comparison, amongst women said to be practising BSE occasionally, and women who said they never practised BSE, findings of cancer stages were 35% (0 or I), 50% (II), 15% (III or IV) and 19% (0 or I), 44% (II), 38% (III or IV) respectively. When assessed by a pathologist, the lesions of women who said they practised monthly BSE were found to be most likely to be smaller, without histological involvement of the axillary nodes.

There are several difficulties in interpreting this study. First, women who have the symptoms and subsequent diagnosis of breast cancer may feel that they should report practising monthly BSE (Thiessen, 1971). However, the prevalence of BSE practice is not significantly higher than that found in the general population (American Cancer Society, 1974). Second, the study did not include an assessment of how well each woman carried out BSE, nor, indeed, any attempt to validate their reports as to whether or not they did. Third, there is no analysis of how the symptoms were found in each case - for example, whether those women who practised BSE detected the change during routine BSE or accidentally, or whether the methods of discovery differed between the practitioners and non-practitioners of BSE. Thus, although the study allows some assessment of the stage of the cancer at presentation in women who say they do or do not practise

BSE, it is not capable of establishing any causal relationship between the optimal practice of BSE and the early diagnosis of breast cancer.

The second study was of 293 women who were diagnosed as having primary breast cancer in North Eastern New York and Western Massachusetts during 1975-1977 (Greenwald et al, 1978). In this study the data were analysed by the initial method of detection of the abnormality. Overall 28% women were said to be practising BSE at the time of discovering their symptoms, 14% on a monthly basis and 14% less frequently, which again is consistent with the findings in randomly-selected populations of women. Of those women who said that they practised BSE, only 69% discovered their symptoms through BSE - a further 20% discovered their symptoms by accident and 11% were diagnosed at a routine physician examination. Thus there is the suggestion that, if these women really were practising monthly BSE, they may not have been carrying out the examination correctly.

Nevertheless, the cancers which were detected either by BSE or by routine physician examination were at a significantly earlier clinical stage than those detected accidentally. Of those cancers identified initially by BSE, 38% were clinical Stage I, 53% Stage II and only 9% Stage III or IV, compared with 27%, 49% and 24% respectively for those found by accident. Differences in a similar direction were found when pathological stage at diagnosis was examined, although these did not reach statistical significance. This study does provide data on the method of detection of breast cancer symptoms. However, again

there was no attempt to validate the women's reports of their practice of BSE, nor to assess their technique, although the results do cast some doubt on the efficacy with which BSE is practised.

The two studies (Foster et al, 1978; Greenwald et al, 1978) appear to be consistent in showing that cancers are diagnosed at earlier clinical and pathological stages in women who report that they practise BSE. Moreover, the cancers were at an earlier stage when found by routine BSE than by accident in women who said that they practised BSE (Greenwald et al, 1978). Unfortunately, neither study was designed to enable the consideration of whether the practice of BSE reduces the mortality and morbidity from breast cancer. So far there is no evidence about this, although various studies currently in progress should provide some information. Meanwhile, despite caution in some quarters (Thiessen, 1971; Moore, 1978), the enthusiastic advocacy of BSE continues.

2.3.3 TEACHING BSE

There have been numerous reports of educational programmes designed to encourage BSE, and almost all have shown that such programmes can increase the prevalence of reported BSE, at least in the short-term. Education about BSE has been carried out in a variety of ways - one-to-one teaching by health professionals, the use of leaflets, illustrated talks to small groups of women and the use of the mass media.

In Canada there have been extensive educational programmes about BSE with a steady increase in the reported

prevalence of BSE practice (see Section 2.3.1). These programmes have been based predominantly on the use of films with accompanying leaflets, although some women have been taught BSE by their doctors. In an assessment of the BSE technique of a self-selected group of women, those who had received medical instruction in addition to seeing the film and leaflet were less proficient at the inspection part of BSE, but better at performing a complete examination, using the flat of the fingers and knowing the best time to practise BSE (Phillips & Brennan, 1976). Unfortunately, these women were not a random sample and the numbers are not given, but there is the suggestion that one-to-one teaching rather than instruction via the mass media may result in a better technique of BSE.

An Australian study (Hill et al, 1980) of a 12 month programme carried out through television advertising and local doctors, found an increase in the prevalence of reported BSE from 21% to 34%. The level of BSE reported by women with newly-diagnosed breast cancer also increased from 17% to 23%, but remained lower than that in a random sample of the population, probably because of the different age structure. A programme in Merseyside was based on a "BSE Teaching Kit" which comprised a filmstrip, teaching notes/commentary and leaflets (Hobbs, 1971a). Teaching was available to women's groups and also to women at work and was provided by a panel of speakers, many of whom were doctors. A postal questionnaire was sent to the women one year after they received the education and amongst the 41% who replied, the prevalence of BSE was 48%. (No pre-education data are available for comparison.)

Women attending the Breast Clinic at St.Michael's Hospital in Toronto (Mahoney, 1977) underwent clinical examination, mammography and thermography. If their breasts were considered to be normal, they received instruction in BSE from the doctor, and at the same time were assured that "what they feel is normal". 533 women have been followed up at a subsequent examination and 70% reported that they were practising monthly BSE - an increase from only 10% at the initial consultation. Even among women in the Californian Common Health Club with the high initial prevalence of monthly BSE practice of 53%, one-to-one instruction at the time of cervical cytology increased the prevalence to 78%, the increase occurring across the age-groups (Rodnick & Bubb, 1978).

In Finland 56,000 women aged 20-80 years were enrolled in a study to encourage BSE (Gastrin,1976; Gastrin, 1980). The programme included "person-to-person education and instruction", supplemented by the use of mass media (the "Mama Programme"). Before the programme only 2% of women reported that they practised BSE regularly; since the start of the programme "67% of the 2900 women in one area have examined themselves regularly each month". The later report of this study (Gastrin, 1980) also considered the incidence and mortality from breast cancer among the women who were involved in the educational programme. There has been an increase in the numbers of women with newly-diagnosed breast cancer which coincided with the start of the programme. These women were younger and there were fewer cancers with axillary node involvement than would have been expected. The mortality was lower than that predicted for the number

of women with incident breast cancer (15 deaths observed, 29 deaths expected). However, no histological details are given, and this apparent improvement in outcome may reflect the increased diagnosis of borderline or in situ cancers.

However, one campaign in New Zealand did not increase the practice of BSE (Richards, 1977). A "Cancer Week" was held by the Cancer Society of New Zealand using publicity in magazines and newspapers, a demonstration film which was shown on television and was also available to groups, a "cancer pamphlet" and the involvement of some doctors and nurses in one-to-one instruction. Comparison of data collected from a random sample of women before and after the programme showed only a small increase in knowledge about BSE, and only a small reduction in the number of women who felt that they had insufficient information or confidence to carry out BSE (41% to 35%). Not surprisingly only 15% women said that they were practising BSE at least once a month after the programme, compared with 16% beforehand. This lack of effect may be attributable to the structure and conduct of the educational programme. For example, emphasis on cancer ("Cancer Week" and "Cancer Pamphlet", for example) has been considered to be potentially non-productive, or even counterproductive, in the promotion of BSE (Hobbs et al, 1977). There is also some evidence that confining the educational programme to one week limits its effectiveness.

Following Hobbs' work in Merseyside (Hobbs, 1971a; Hobbs, 1971b; Hobbs, 1973), she and her colleagues have

defined five prerequisites for teaching BSE (Hobbs et al, 1977):-

... Stressing the greater likelihood of non-malignant than malignant causes for changes in the breast

... making clear the advantages of treating cancer while still at an early stage

... explaining the "lumpy" nature of the normal breast

... seeking to teach established groups, so that group support is available for developing a regular health habit

... offering personal counselling and follow-up if needed

In this same article the authors concluded by pointing out the considerable deficiencies in our knowledge about BSE. Despite the number and variety of educational programmes to encourage BSE, there remains uncertainty about the best approach - or approaches, since different women probably require different educational strategies. Unfortunately, few of the studies have even considered inter-woman variation, but have rather tended to assume that the target group is homogeneous. Still less is there any clear idea of the costs, risks and benefits of the promotion of BSE. For example, not one of the studies reviewed above included data on the resources required for the programmes which they have attempted to evaluate. Moreover, although BSE is commonly assumed to be harmless, presumably because it does not incur the overt risks of medical technology, an experienced clinician has written that "patients have a certain fear, dislike or dread of BSE" (Moore, 1978).

Whether or not a procedure which apparently induces such emotions can nevertheless be regarded as harmless, it would seem prudent at least to look for the possible adverse effects of programmes to promote BSE.

These studies have been carried out on the premise that the early detection and treatment of breast cancer improves the outcome. It seems to be argued that BSE must be a good thing because, if practised regularly, it will promote the early detection of symptoms. Some limited data on the second part of this assumption are now available (Foster et al, 1978; Greenwald et al, 1978), but, nevertheless, the underlying basis for the promotion of BSE remains founded in belief rather than knowledge. The next chapter discusses the contradiction between this lack of evidence of the benefits of BSE and the enthusiasm with which it is advocated.

C H A P T E R 3

The renewed interest in health education: some problems, with specific reference to breast self-examination

INTRODUCTION

"Health education concerns all those experiences of an individual, group or community that influence beliefs, attitudes and behaviour with respect to health, as well as the processes and efforts of producing change when this is necessary for optimal health" (WHO, 1969). It is, therefore, one aspect of preventive medicine.

During the past decade there has been an increasing interest in the potential of health education to alleviate or eliminate many health problems, especially those which are not susceptible to medical treatment either now or in the immediate future. This chapter summarises recent developments in health education (Section 3.1) and examines the motives behind them (Section 3.2). These developments have revealed several problems within health education. These problems stem partly from the conflicting motives of, and partly from the unrealistically high expectations held by, the advocates of health education (Section 3.3). Breast self-examination (BSE) has its own, specific problems which are discussed in more detail in the final section (Section 3.4).

3.1 THE RENEWED INTEREST IN HEALTH EDUCATION

3.1.1 HEALTH EDUCATION VERSUS TREATMENT OF DISEASE

Health education, as defined above (WHO, 1969), represents the legacy of Hygeia, the Greek goddess of health. Although health promotion has been seen as one strategy for improving health since then, its importance relative to the diagnosis and treatment of disease has fluctuated. There is apparently no historical documentation

of this, but it might be possible to correlate increased therapeutic optimism with a decreased interest in health education and vice versa. For example, during the 19th Century, health education was an important component of the evolving specialty of public health and, towards the end of the century, of health visiting. In the mid-20th Century, the wave of major therapeutic advances distracted attention away from health education, towards curative medicine.

More recently the balance has shifted again, as the limits of therapeutic progress have been appreciated. Many diseases remain resistant to medical or surgical treatment. The accumulating evidence shows that their aetiology often lies in unhealthy behaviour which is potentially preventible. Therapeutic successes have only been achieved at the cost of increasing dependency on health professionals, iatrogenic disease and a continued expansion of spending on health. Critiques of modern health care, with its emphasis on acute, curative medicine, have emerged in several Western countries (see, for example, Illich in the USA (Illich, 1974; Illich, 1976), Lalonde in Canada (Lalonde, 1975) and Mahler on behalf of the WHO (Mahler, 1975)). In the UK the most influential writer has undoubtedly been McKeown, in particular the Rock Carling Memorial Lecture of 1976 (McKeown, 1979). More recently, these critiques have been made accessible to a much wider audience in the UK by Kennedy in the Reith Lectures of 1980 (Kennedy, 1980).

3.1.2 THE RESPONSE OF GOVERNMENT

In England and Wales, as in other Western countries, the important role of health education has been endorsed by central government. A range of reports have been published on priorities in health and personal social services (DHSS, 1976b; DHSS, 1977e; DHSS, 1981), prevention and health (DHSS, 1976a; DHSS, 1977b) and follow-up reports about specific areas of prevention (DHSS, 1977c; DHSS, 1977d; DHSS, 1978). The Social Services and Employment Sub-Committee of the Expenditure Committee of the House of Commons began a special enquiry into preventive medicine in November 1975, reporting in April 1977 (Expenditure Committee, 1977) and many of their 58 recommendations related specifically to health education. The government responded in a White Paper (DHSS/DES/SO/WO, 1977) which aimed to set the "Sub-Committee's recommendations in the broader context of the Government's total policies and plans on prevention". This White Paper did not reject any of the Sub-Committee's proposals about health education.

Similarly, the Royal Commission on the National Health Service (Royal Commission on NHS, 1979) included a chapter on "Good Health" which emphasised the value of health education, and recommended its extension and development in areas of proven effectiveness. Many independently-produced reports on specific aspects of health or causes of ill-health have stressed the need for health education. These are too numerous to list, but see, for example, the Report of the Committee on Child Health Services (DHSS/DES/WO, 1976), "Smoking or Health" (Royal College of Physicians, 1977), "Health Education and Self Help" (Farrell & Robinson,

1980), "Inequalities in Health" (DHSS, 1980), and the three reports published recently by the Royal College of General Practitioners (RCGP, 1981a; 1981b; 1981c). Indeed, so far has this trend gone, that it is now unusual to consider any health-related issue without invoking the role of health education. In what might be considered to be parallel sets of documents, the Department of Education and Science (DES, 1977) and the Scottish Education Department (SED, 1974), together with independent committees (for example, Advisory Committee on Alcoholism, 1979; DHSS, 1977a; Violence to Children Select Committee Report, 1977), have all recommended an increase in the quality and quantity of health education provided in schools.

3.1.3 THE GROWTH OF THE HEALTH EDUCATION PROFESSION

Health education is also seeking such marks of professionalism as academic credentials. A variety of courses are now available leading to the Certificate, the Diploma or an MSc. in Health Education. Two of the Masters Courses in Community Medicine are open to health education officers, and health education is included in the curricula of other health professionals. The volume of research which relates either directly or indirectly to health education continues to grow.

Although health education officers had been in post before the reorganisation of the NHS in 1974, both their existence, and the resources with which they were provided, depended on the interests and attitudes of the Medical Officers of Health. Their position, and the funding of the area health education departments, became relatively

more secure after 1974, although the 1982 NHS restructuring is likely to cause disturbances. With this recently increased security and professionalisation has come a greater consensus about the role of the health education officer, which is seen primarily as to co-ordinate all those involved in health education, namely all practitioners of health or education. The Health Education Council can be seen to have a similar function but at a national level, as well as to stimulate research in health education.

Health education currently occupies a significant place within the health and education services and is evolving a professional identity. It is seen as the potential solution to some of the more difficult problems in health care, and derives support from central government and a range of independent committees and advisory bodies. Indeed, the extent of the support for health education may prove to be one of its major problems, particularly if these aspirations are not matched with appropriate resources. Further difficulties might result from the different motivations of those who advocate health education.

3.2 THE MOTIVES BEHIND THE RENEWED INTEREST IN HEALTH EDUCATION

Both the consumers and providers of health care and health education have displayed this renewed interest. However, although each different group advocates health education, their motives and objectives can be very different; and may even conflict.

3.2.1 MOTIVE 1 : ECONOMIC

The expenditure on health care in Western countries continues to increase (Abel-Smith, 1976). Thus one

obviously attractive argument for effective prevention and health education would be based on the economic savings which might be expected to accrue because of the reduced incidence of disease. (Interestingly, health education designed for the public has not used this argument about indirect savings to the individual or society, although some programmes have emphasised the direct savings to the individual who, for example, gives up smoking.)

The DHSS, however, is clearly ambivalent about the economic consequences of allocating greater resources to preventive medicine. It has been emphasised in some government documents that prevention is not necessarily cheaper (see, for example, DHSS, 1976a; Expenditure Committee, 1977). On the other hand, a further DHSS document also published in 1976, stated that "preventive medicine and health education are particularly important when resources are tightly limited, as they can often lead to savings in resources in other areas" (DHSS, 1976b).

This confusion about the economic consequences of programmes of prevention and health education extends beyond the DHSS. The difficulties in assessing the costs and benefits of opportunities in prevention have been summarised (Warner, 1979) as due to:-

(i) the lack of precise or definitive empirical evidence on the association between specific preventive activities and health status, often largely attributable to the lag between the preventive action and the appearance of any change in health

status, and the difficulties in quantifying many of these changes

(ii) the nature of any economic benefits, which are deferred and therefore difficult to attribute to specific action.

The cost-benefit assessment of prevention and health education will be largely determined by the assumptions in their calculation. In particular it will depend on which costs and benefits are included (whether these should include benefits to the individual, to society, or to both, and whether account should be taken of both pecuniary and non-pecuniary benefits) and on the length of time over which they are measured (many preventive activities may result in long-term, rather than short or medium-term benefits). Further complexities in assessing economic costs arise from uncertainty about the extent to which health education is or may be provided within the existing framework of health care. For example, one of the recent reports from the Royal College of General Practitioners concludes that the promotion of health and prevention of disease "require a higher proportion of the general practitioner's attention and time than they appear to receive at the moment" (RCGP, 1981a). The report details various opportunities, but then emphasises (in the only paragraph in bold italic print) that, although prevention is an integral part of primary care, "it is unlikely to be achieved on a national scale unless additional incentives are offered". Thus, even if prevention and health education can, at least to some extent, be absorbed by the existing staff, extra costs may still be incurred.

Although some types of primary prevention, particularly those which can be applied at a community level, may be judged to have greater benefits than costs (Warner, 1979; Scheffler & Paringer, 1980), many activities remain of doubtful financial benefit. However, apart from the possibility that direct economic benefits may accrue from increasing the expenditure on health education, there may be other, more subtle, changes. As well as encouraging more prevention and health education, individual responsibility for health has been advocated as the only possible solution to the increasing cost of health care. For example, "but now the cost of individual responsibility in health has become prohibitive. The choice is in fact, over the long range, individual responsibility or social failure" (Knowles, 1975), "much of the responsibility for ensuring his (sic) own good health lies with the individual" (DHSS, 1976a), and indeed the very title of the document - "Prevention and Health: <u>everybody's</u> business" (my emphasis). In discussing this document elsewhere, another DHSS publication emphasises the need "to bring home to everyone how much they can do to improve their own health and that of their family" (DHSS, 1976b).

The notion of individual responsibility has been criticised, perhaps most extensively by Crawford (Crawford, 1977). He characterises the ideology as one of victim-blaming, in which individuals are seen as guilty, by virtue of at-risk behaviour, of causing their own ill-health. The notion of individual responsibility fulfils the dual functions of justifying the control of public expenditure on health-related services, and of diverting attention from

society's role in the production of morbidity and mortality. Thus the advantages of the deliberate promotion of individual responsibility might, at least partially, explain the recent government enthusiasm for prevention and health education. The economic benefits will not necessarily be direct, but may occur indirectly through an alteration in the expectations of health care consumers. This critique has been applied specifically to health education, which is seen as over-emphasising individual change (Brown & Margo, 1978).

This reasoning is exemplified in some recent, influential medical reports. For example, Clarke & Whitfield have described the phenomenon of self-destruction (Medical Services Study Group, 1978). In a series of 250 deaths among medical in-patients aged under 50 years, they found that "in no fewer than 98 cases the patients contributed in large measure to their own death". These self-destructive acts included self-poisoning (8 cases, of whom 7 had a history of psychological problems), excessive alcohol consumption (6 cases), smoking (38 cases), overweight (12 cases), delay in seeking medical treatment (9 cases) and inadequate compliance with medical advice (37 cases). Two case histories are detailed to demonstrate that not only did these patients die through their own shortcomings, but that in the process they consumed inordinate quantities of NHS resources. However, since one patient had "irretrievable brain damage", and the other was in an intensive care unit, it seems unlikely that they were in a position to demand that expensive investigations and a teaching hospital bed be provided for them. The apparent ingratitude of the

patients is also highlighted: one who died of self-poisoning "had had every conceivable treatment for schizophrenic depression", and others were considered to demonstrate "fecklessness or a psychopathic attitude to life and to doctors in particular".

Another report of a confidential enquiry, that of maternal deaths in England and Wales during 1973-75 (DHSS, 1979), includes similar assumptions. In apportioning the responsibility for the total of 230 avoidable factors which were judged to be present in 140 (60%) cases of maternal death, the responsibility was considered to lie with 48 (21%) women themselves. During the antenatal period one-third of the avoidable factors were "the responsibility of the patient or her relatives". Ten deaths resulted from illegal abortion, and in all cases the avoidable factor was ascribed to the patient - an interesting professional decision when the geographical (Maresh, 1979), and social (DHSS, 1980) inequalities in obtaining an abortion are now well established.

Thus the economic motive may be an important argument in favour of increased resources for health education, although, at the present time, there may be relatively weak evidence that a direct financial benefit would result. The justification may be less concerned with substituting prevention for cure, than with engendering new attitudes about individual responsibility for health, and culpability for illness.

3.2.2 MOTIVE 2 : MEDICAL DISILLUSIONMENT WITH THERAPEUTIC PROGRESS

Medical education since the Second World War has emphasised the medical role in diagnosis and cure, and has not trained doctors to see themselves as being concerned primarily with the prevention of disease and the promotion of health. Inasmuch as the latter was considered to be useful, it was usually judged to be the responsibility of others - those outside the spheres of primary and secondary health care, for example, the legislators, health education officers, teachers and the medical and nursing staff employed in the community health service.

However, this view of the relative importance and status of different forms of medical intervention is no longer appropriate (see Section 3.1.1). Perhaps the first signal of change to come from within the medical establishment was the publication by the Royal College of Physicians in 1962 of "Smoking and Health", and in 1971 the Royal College of Physicians established Action on Smoking and Health (ASH). Subsequent reports from expert advisory committees have reinforced this shift. For example, the Report of the Committee on Child Health Services (DHSS/DES/WO, 1976) recommended that the primary health care team should play a greater role in promoting better health amongst children; one means of accelerating this would be the relocation of the clinicians working in the community health service from clinic to primary care premises. A report from the Royal College of Psychiatrists (RCPsych, 1979) has defined the extent of problem drinking, and identified the different types of prevention available,

many of which involve the medical profession. The recent trilogy from the Royal College of General Practitioners (RCGP, 1981a; 1981b; 1981c) advocates a similar increase in the practice of prevention by their members, with the recruitment of additional primary care health workers, whose work would be entirely preventive and educational.

"Doctors have been saying for years that the causes of many of the killing diseases of middle life are not mysteries, but are contributed to by over-eating, excess alcohol and tobacco" (Medical Services Study Group, 1978). What seems to be changing is that, no longer are doctors merely making these rather obvious and unoriginal assertions but, faced with the limited therapeutic measures available, are acknowledging the importance of their own involvement in attempting to reduce preventible mortality and morbidity.

3.2.3 MOTIVE 3: LIMITING THE POWER OF THE MEDICAL PROFESSION

Perhaps the most vocal proponent of this motive for the promotion of prevention and health education is Illich (Illich, 1974; Illich, 1976). His opening sentence, "The medical profession has become a major threat to health", sets the tone of his argument, which develops an analysis of the sickening qualities of a professional and physician-based health service (Illich, 1974). As well as the inevitable tendency of medical intervention to cause iatrogenic disease, and to deflect interest from the social causes of much ill-health, he identifies the way in which individuals are deprived of the ability to maintain their

own health or to shape their environment. To reverse these trends, Illich stresses the need for individuals to be "self-governing" rather than "administered", and to assert their rights to cope autonomously with pain, sickness and death.

This considerable over-simplification of Illich's critique may appear to imply some similarities between him and the advocates of individual responsibility for the maintenance of health. Superficially it seems that similar arguments are used. However, the contexts within which the changes are proposed are obviously radically different. The promotion of individual responsibility is seen very much as a pragmatic adjunct to the existing health service within the present framework of society. Illich advocates a reclamation not only of health but also of all other areas of life, and a fundamental re-ordering of the levels of power within society. This emphasis on the dangers to health of medicalisation, or medical imperialism, exemplified by Illich, has been expanded by other writers, most notably Marxist sociologists such as Navarro (for example, Navarro, 1976) and Waitzkin (for example, Waitzkin,1979).

3.2.4 MOTIVE 4: THE GROWTH OF HEALTH CONSUMERISM

The previous three motives are attributed mainly to professionals - the politicians and civil servants, the doctors and the academic observers of medicine. At the same time there has been a large popular, albeit middle-class movement towards a greater awareness about health and participation in health promotion, with parallels seen in other spheres of life. The health service has been

criticised, both in terms of the quality of specific services and the management of patient-professional interaction, and in terms of the sole claims to expertise which tend to be made by health professions.

The women's movement has played a prominent role in articulating these criticisms, and, not surprisingly, many have focussed on obstetric care. The management of antenatal consultations, with their emphasis on doctor rather than patient convenience, and the conduct of the delivery and post-natal care have been systematically attacked. There has also been a questioning of the basis on which obstetric care is provided, namely that pregnancy and childbirth are primarily medical events, that the women are therefore defined as patients and the doctors and midwives are experts, who will automatically be in the best position to make decisions (see, for example, Oakley, 1980). Obviously, the merits and otherwise of both the pattern of care and these criticisms can be debated, although it is difficult to dispute many of the specific points made by the critics. However, what is perhaps interesting is that such a substantial literature is emerging.

The authors include social scientists and workers in pressure groups, but much of the evidence is produced by individual women detailing their own experiences. Certain popular publications have traditionally maintained an interest in health - especially women's magazines, although many newspapers also have health correspondents or medical columnists. The newer magazines have maintained this interest, although they tend to adopt a rather more campaigning style and to be less dependent on experts

(see, for example, Spare Rib or Mother Jones). Books on health intended for the lay public have rapidly increased in number, with similar indications of a change in emphasis. The newer books tend to be more explicit, provide more detailed explanations (including interpretations of relevant medical jargon), to consider health within a broader context and to encourage a rather more critical attitude towards health care (see, for example, McKeith, 1977; Stimson & Stimson, 1978; Boston Women's Health Book Collective, 1978; Vickery et al, 1979; Guillebaud, 1980; Open University, 1980). Many are written by non-experts, from the consumer's point of view. These changes, and the apparent commercial success of publishing books about health and health care, indicate a considerable interest among the lay public and a growing sophistication in their understanding of and participation in health care.

3.2.5 CONFLICTING MOTIVES?

There are doubtless other motives which also underlie the new enthusiasm for health education. The WHO definition of health education (WHO, 1969) is so broad that it is open to a variety of interpretations. Draper and his colleagues have defined three types of health education (Draper et al, 1980):-

I Education about the body and how to look after it

II Information about health services and the "sensible" use of resources

III Education about the wider environment in which health choices are made, and the potential influence of this environment on health.

Few people would disagree with the inclusion of Type I health education in any comprehensive programme. This is the most conventional form of health education, and is the cornerstone of most departments of health education. Type II health education may raise more problems. Programmes which encourage "sensible" use of health services (for example, instructions about when to consult the general practitioner) may find favour with the providers of the service. On the other hand they may be opposed by the consumers, who might argue that it is not always possible for a lay person to know whether a consultation is necessary; generalised instructions may result in a potentially harmful delay in obtaining medical advice. The public may, however, welcome advice on how to improve the communication between them and their general practitioners. Unfortunately, doctors and other primary health care staff may resent such advice and feel that it stimulates unwarranted criticism of them.

However, the most serious disagreements would probably occur over Type III health education, with its implications of the need for political change at either the macro or the micro level. The providers of health care tend to see health education, at least to some extent, as a means of making health care more effective and efficient. The consumers, and those who wish to limit the powers of the medical profession and to alter some of the underlying structures of health care, may see health education as one means of achieving far-reaching change. Thus the relative importance attributed to Type III health education

will differ greatly between these groups and others. Those who accept the three types of health education tend to dismiss much current health education as, at best, somewhat naive and, at worst, dangerously misleading. Those who see a more limited role for health education are suspicious of what they see as attempts to politicise health and the transmission of information. As has been described, health education is invested with a range of different and conflicting aspirations, clearly all of which cannot be realised, even if unlimited resources were available. There are other problems too.

3.3 OTHER PROBLEMS OF HEALTH EDUCATION

3.3.1 LACK OF A THEORETICAL BASE

Health education has remained largely outside both medical and educational research until relatively recently. This was partly structural, in that health education departments were based in local authorities outside not only primary and secondary health care, but also the education department, and should have been alleviated by their place within Area Health Authorities since 1974. However, there are other problems which have contributed to the intellectual isolation of health education.

First, its identification by the medical profession as a low-status component of health care. It was not practised by those who were involved in medical education and research, but by individuals who, whilst they may have been skilled practitioners of health education, often did not define their role as including its evaluation and development. Second, health education may have to operate

in areas where there is no clear medical consensus. Smoking may be relatively straightforward, but areas such as nutrition, exercise and the avoidance of stress are fraught with disagreements among the experts. Although these disagreements may be of no practical importance, the health education practitioner may be reluctant to enter such an apparently complex and technical field, and, at the same time, be too professionally isolated to be able to consult colleagues for advice.

Third, health education must draw not only on medical knowledge, but also on the knowledge of other disciplines. Very few of the staff working in health education have an adequate education in and experience of the social sciences. Until recently the undergraduate medical curricula have not included these subjects and the medical staff who are involved with health education are therefore also unable to contribute any expertise or sources of information.

It is not surprising that health education has remained intellectually stunted; what is more worrying is that this has only recently been seen as a problem. There are difficulties at various levels within a health education programme:-

... in defining precise objectives for the health education programme

... in interpreting the current state of relevant knowledge

... in developing an appropriate form of transmitting information, appropriate in terms of content and medium

... in evaluating the effects of the health education programme

... in defining the context within which the programme is carried out, to allow an understanding of its broader implications

... in using the results and experience of the programme towards the creation of a theoretical model of health education, which can explain the findings and be used to generate new hypotheses.

To overcome these difficulties would be ambitious for a well-established discipline; it is unrealistic for health education. Although, for example, considerable attention has been paid to the media used (indeed, the sophistication of the media sometimes appears to be far beyond that of the message), other aspects have remained almost totally undeveloped. Many of the staff may be skilled educators, technicians or organisers, but they lack experience in the other essential disciplines or in research. Despite the high aspirations for health education, the resources which are specifically allocated for it are small. Together with these resource problems, both human and financial, is the fact that health education is potentially one of the most difficult areas of health care in which to work. It requires an understanding of health in its broadest sense, a knowledge of and contact with a wide range of disciplines, and an ability to use these qualities in developing an intellectually acceptable area of practice.

3.3.2 INADEQUATE EVALUATION OF HEALTH EDUCATION

The evaluation of health education programmes is important both in measuring the effectiveness of a specific

programme and in providing information which can be used in the more general evolution of health education practice. There are signs of an increased interest in evaluation - for example, two recent reviews of the literature, one commissioned by the Scottish Health Education Unit (Tones, 1977) and the other by the Health Education Council (Gatherer et al, 1979), were published almost simultaneously. It is perhaps cynical to suggest that this new interest results from the necessity of some measure of effectiveness, if health education is to compete successfully with other areas of health care for finite resources.

The evaluation of health education is fraught with difficulties. This, together with the common assumption that health education is likely to be both harmless and worthwhile, probably deterred would-be evaluators. One recurrent problem has been the decision as to exactly which measure should be used in evaluation. Many studies have considered that the evaluation should be in terms of the appropriate behavioural change, but, as there appear to be several stages between receiving a piece of information and acting upon it (Fishbein & Ajzen, 1975; Fishbein, 1976), this method might not identify the precise explanation of any failure to achieve the required piece of behaviour.

In the model described by Fishbein & Ajzen (Fishbein & Ajzen, 1975), beliefs represent knowledge of an object or activity - for example, "BSE is rather time-consuming" or "BSE may reduce deaths from breast cancer". Attitudes are subjective judgements, such as "BSE is a good idea" or

"BSE is unnatural". An individual may have many beliefs about BSE, and these, together with her attitudes to related factors, will determine her attitude to BSE. For example, if she holds the two beliefs above, and has favourable attitudes to reducing deaths from breast cancer and preventive health care, then she will probably have a favourable attitude towards BSE.

Similarly there is not a direct relationship between one attitude and behaviour. Although a woman may have a positive attitude to BSE, if she feels that it is unnatural she may not practise it. There is also the importance of the subjective norm, her judgement of whether or not other significant people would think that the behaviour should be performed. This may be relatively important in influencing a woman's decision about the practice of BSE.

In 1974, Jones and Grahame wrote (Jones & Grahame, 1974): "In general, (health education) is more characterised by its good intentions and energy than by its scientific and intellectual rigour and objectivity. Uncritical and unsupported presumptions abound, principles often prove to be prejudices and there is little factual evidence to support activities and claims". These criticisms were reiterated by Green (Green, 1976): "...health education has had too little evaluation....". However, neither analysis considered that the fault lay mainly with the health educators, who had suffered from being denied the multidisciplinary expertise which was required.

Although there are still major difficulties both

in the evaluation of health education and in using the results to make comparisons with other forms of health care, there are signs of an improvement. As described in Section 3.1.3, the experienced practitioners are now being joined by colleagues, in both health education and community medicine, who have received a broader training, including some exposure to research methodologies. They are also supported by the provision of research grants by the national health education bodies and by full-time research staff, working in University departments and in health education research units. It seems likely that the quantity and quality of evaluative work should improve progressively over the next few years.

3.3.3 INCOMPLETE UNDERSTANDING OF HEALTH BEHAVIOUR

In order to develop optimal health education programmes, it is necessary to know and understand the existing health beliefs, attitudes and behaviour. Unfortunately very little work has been done on lay versions of health and health behaviour in Western societies. Health professionals tend to assume that they are wholly responsible for providing health care, whereas in the majority of episodes of illness official health practitioners are not consulted (Hannay, 1979), and health care is provided by relatives and friends, usually female. Studies of antenatal care have shown that working class women have extensive lay networks of information and advice (McKinlay, 1972).

A recent study of the health attitudes of second generation Social Class IV and V women in Aberdeen

demonstrated the existence of complex theories about health and illness (Blaxter & Paterson, 1980). Of particular interest to health educators was the very negative definition of health which many of the grandmothers (women in their 40s and 50s) used. Health was seen as the ability to "carry on" (a phrase which recurred), and being healthy was not so much the absence of symptoms as the refusal to admit to their existence. The implications of this definition are considerable, as it suggests that these women would be unlikely to seek advice for the very early symptoms of disease and would probably be reluctant to attend for screening. Health apparently figured relatively low in their hierarchy of problems - illness in themselves was an inconvenience rather than anything more serious. As other areas of their life seemed to present more immediate difficulties, conventionally defined health-threatening behaviour might, within their framework, be health-promoting (by helping them to cope or carry on, which they deemed to be healthy). Eating a nutritionally poor, but undemanding, diet, collapsing in a chair for 10 minutes rather than going for a jog, even a cigarette may all be re-defined as coping or healthy behaviour.

Unfortunately very few studies have looked in similar detail at the layer of beliefs, attitudes and behaviour which predate and possibly counteract health education. Meanwhile, health educators tend to assume that if they transmit a belief or attitude with sufficient authority they will be believed. The mirror-image of this apparent denigration of pre-existing patterns of lay health behaviour is the

attribution of scientific validity to official Western health care practices, and the notion of their intrinsic rationality. This is frequently equally unjustified as the example of breast cancer shows. The assumptions are made that:-

... any woman who suspects that she has a breast abnormality should consult her doctor.

The rational justification for this is that there is evidence that early diagnosis of breast cancer improves the prognosis. However, as discussed in Section 2.1.2, the evidence is contradictory, and, although early diagnosis is usually encouraged, the case is far from clear-cut.

... The application of a suitable range of investigations should establish a precise diagnosis.

Again this assumption will not hold for many women. There may be a delay while the general practitioner considers whether or not referral to hospital is necessary, investigations such as mammography and needle biopsy are not always accurate and there is also the problem of over-diagnosing cancer (see Section 2.2.3).

... These investigations can be used to define the optimal treatment for each individual woman.

As discussed in Section 1.3, there are still uncertainties about the relative values of the individual components of the treatment for breast cancer, and of the various packages of treatment. Those women who are referred to consultants practising frozen section biopsy,with immediate mastectomy if the histological examination indicates malignancy, do not receive careful investigation and assessment, before the definition of optimal therapy. In any case it is

probably unusual for the women's own views and preferences to be taken into account, or for her even to be informed of the different options.

These obvious deficiencies in the rational model of the treatment for breast cancer should lead to a rather more open attitude towards those women whose behaviour does not conform to the current medical expectations - for example, women who delay, or who question their treatment. However, the general acceptance among doctors that there is a sensible and correct way to behave at various stages in each woman's breast cancer career allows them to criticise those women who do not follow this pre-defined pathway. Illness-promoting behaviour is defined to encompass the failure to conform to medical norms of treatment, however arbitrary these may be. The limited achievements of medicine in the management of women with breast cancer can then be, partly at least, attributed to the women themselves.

3.4 SPECIFIC PROBLEMS OF PROMOTING BREAST SELF-EXAMINATION

The general problems which apply to health education have been discussed at length. Each is relevant to a consideration of the promotion of BSE. In addition there are specific problems associated with BSE.

3.4.1 THE ANXIETIES WHICH SURROUND BSE

BSE carries a high emotional charge for two main reasons: first, because of its associations with breast cancer and second because of the nature of the examination itself. The popular literature provides an indication of the importance to women of their breasts, and of their

fears of breast cancer. One recently published book, "Breasts" (Ayalah & Weinstock, 1978) includes photographs of the breasts of 36 women, and their descriptions of "their breasts and their lives". "The breast book: what every woman needs to know about beauty and the bust" (Harris, 1980) gives an alternative, male view. Another paperback, entitled "Breast Cancer" was published in 1979 (Faulder, 1979) and written for a lay audience. It is difficult to imagine similar books on stomachs and stomach cancer; lungs and lung cancer; or even vaginas and vaginal cancer or testes and testicular cancer.

Breast cancer is a relatively common disease, and therefore the majority of women will know of at least one woman who has had the disease, frequently with fatal consequences. This tends to promote a not unrealistic fear of breast cancer - the incidence and mortality rates are high, and the treatment may involve several unpleasant components. It is hardly surprising that women may allege that they would rather not know that they had breast cancer, and would therefore feel that BSE would stimulate rather than allay their anxieties.

At the same time BSE may engender its own anxieties, separate from those relating to breast cancer. It is not an easy examination to perform, and women may worry that they are not practising BSE correctly. If carried out thoroughly, BSE should be slightly uncomfortable, which again may cause anxiety. In premenopausal women, normal breast tissue may feel lumpy, and this may be alarming for the woman who thinks that any lump is a serious sign. Some women find BSE unacceptable because they are reluctant

to touch their breasts, which are one of the main erogenous zones and thus have various taboos associated with them.

These anxieties may be overlooked, or at least underestimated by the common-sense practicality of health education. The apparent advantages which health educators see in BSE should over-rule such emotional and irrational objections. Similar exasperation is expressed in other areas of preventive medicine - for example, over the failures of individuals to take up services such as cervical screening or dental treatment. This reinforces the importance of understanding lay attitudes and beliefs about both health and the value of various types of interventive behaviour. It also emphasises the need to see women as individuals rather than as a homogeneous entity. Different women will have different anxieties and will require a different approach in the teaching of BSE - all women will require the opportunity to express and discuss their own worries.

3.4.2 THE DEMANDS OF BSE

As well as requiring competence in performing the examination and the ability to cope with any anxieties provoked, BSE also demands that a woman be prepared to devote a certain amount of time to herself, regularly once a month, for an activity which will almost always be apparently non-productive. At the same time she will not receive any positive feedback; in this respect BSE is very different from health checks which are performed by a professional, when expert reassurance is given, often accompanied by praise for such responsible behaviour. In

BSE the woman can only reassure herself that all is well.

The problem for women in justifying what appears to be the self-indulgence of time for themselves is compounded by the fact that many may fear that others may express their scorn or disapproval of BSE. The attitude of her sexual partner may be particularly important, and, if this is anticipated to be negative, may lead the woman to practise BSE secretly, thus imposing another layer of problems.

Educational programmes about BSE have traditionally taught a standard and rather ritualised method of performing the examination. This includes the two stages of inspection and palpation, each of which is to be carried out in what, whilst it is described as a quick and simple way, appears to be a somewhat troublesome and fussy procedure. Little attention has been given to methods of BSE which could be incorporated easily into everyday life - for example, during a bath or shower, as BSE may actually be easier when the breasts are wet and soapy. Again, the health education about BSE has always been directed exclusively at women. Yet by involving partners, either to encourage or to participate, it may be possible to depict BSE not as an isolated, even secret activity, but as something which can be carried out as a joint activity (compare, for example, the way in which many couples now practise contraception jointly). The involvement of the sexual partner might also overcome the problem that many women are reluctant to spend time on themselves. It could be argued that an individual is more likely to take care of their partner's health than of their own.

3.4.3 DOUBTS OF THE EFFECTIVENESS OF BSE

As has been described in Section 2.3, there is still only fragmentary evidence which demonstrates any benefit resulting from the regular practice of BSE. There are obvious explanations for this, and BSE remains a difficult topic for research. Nevertheless, the unjustifiable enthusiasm for BSE in some quarters is somewhat worrying. For example, "a programme of self-examination.....is effective" (Gastrin, 1980), "instruction in breast self-examination as part of the screening procedure is very important" (Strax, 1976) and "the logic of breast self-examination is obvious;....all women should be taught how to make best use of these natural advantages" (Kirkland, 1978).

As Moore has said "to cast any doubt on the goodness and worthiness of BSE somehow appears sacrilegious, taking a dour scientist's view of this tender, humane, consumer-generated, self-help activity" (Moore, 1978). Criticism of BSE may appear to be based on unreasonable demands for evidence of benefit. The criticism by doctors of self-help programmes may, in addition, appear to be a form of medical imperialism. However, assumptions that BSE is harmless may not be reasonable. The advocacy of BSE may stimulate considerable anxiety in those women, who, whilst accepting the rational arguments in favour of BSE, are unable, because of conflicting beliefs and attitudes, to practise it. At the same time, the ethical position of those who advocate an unproven procedure, such as BSE, might appear somewhat dubious. Unfortunately, these difficulties remain for those who wish to attempt an evaluation of BSE, as, in order to evaluate it, it is necessary to persuade women that it is worthwhile.

C H A P T E R 4

A description of the methodology of a study of breast self-examination and the management of breast disease in Daventry, Northamptonshire

INTRODUCTION

This chapter discusses the background to the study (Sections 4.1 and 4.2), its objectives (Section 4.3) and design (Sections 4.4 to 4.9).

4.1 RATIONALE FOR THE STUDY

The idea for a study of breast self-examination (BSE) based in Daventry, Northamptonshire, originated in 1976. Following national publicity about the apparent benefits of screening for breast cancer, a local women's group wrote to the Northampton Community Health Council enquiring whether local breast screening facilities would be made available. The enquiry was referred to the District Community Physician (Dr.Gordon Pledger) with whom the author was working.

By 1976 there was growing interest in the potential for the early detection of breast cancer. Data from the Health Insurance Plan study indicated that women over the age of 50 years appeared to derive some benefit from annual screening by clinical examination and mammography (see Section 2.2). The Health Departments (HD) and Medical Research Council (MRC) had established a joint working party to study the service and biomedical aspects of a national screening programme; four designated centres - Bath, Ealing, Edinburgh and Manchester - had undertaken separate research projects (MRC,1976). Plans were being developed for a long-term HD/MRC multicentre study which was intended to evaluate screening (using clinical examination and mammography) by monitoring long-term breast cancer morbidity and mortality. In this new study, two centres

(Edinburgh and Guildford) were to offer screening programmes, whilst another two (Huddersfield and Nottingham) would provide education about BSE. These four centres would be compared with each other, and with a further four control centres (Bristol, Dundee, Stoke-on-Trent and Oxford) in which routine health education and health care only would be available.

In view of these comprehensive research programmes it seemed premature for Northampton to establish a breast screening service, either as part of the ordinary health care provision or as a research project designed to evaluate its effectiveness. Meanwhile, the Clinical Medical Officers in Northampton Health District were anxious about the value of their teaching BSE to women attending Family Planning and Cervical Cytology Clinics. Many routinely examined the breasts of the women whom they saw in these clinics, and some also took the opportunity to teach BSE. The Clinical Medical Officers were uncertain whether this was an effective use of their time, and, if it was, they wished to know the best way of teaching BSE.

The literature provided very little guidance on this latter point (see Section 2.3), and we felt that, whilst it was inappropriate for us to attempt to evaluate the effectiveness of BSE (the HD/MRC multicentre study was intended to do this), it might be possible to conduct a relatively small, local study which would evaluate one method of teaching BSE.

4.2 DAVENTRY

It was decided to base the study on Daventry, previously a market town, but recently expanded through an over-spill arrangement with Birmingham; during the 1970s the population was estimated to be growing at about 2% per annum (OPCS, 1979). In the 1971 Census the population of Daventry Metropolitan Borough was 11,595 (5,815 women), and of Daventry Rural District was 18,625 (9,445 women). These populations, together with those from other parts of Northampton, were combined into Daventry County District in 1974 and by 1976 the population was estimated at about 54,000 (28,000 women).

4.2.1 HEALTH SERVICES IN DAVENTRY

Acute hospital care for those resident in Daventry County District was provided almost exclusively by hospitals in Northampton, mainly by Northampton General Hospital. This hospital included all the basic District General Hospital specialties, and also provided a radiotherapy service. Primary care services were distributed throughout the district but the vast majority of the population who lived in the town of Daventry itself (about 20,000) were registered with one of the nine general practitioners (GPs) practising from Daventry Health Centre. This was a purpose-built Health Centre on the outskirts of Daventry (in the grounds of Danetre Hospital, which provided care primarily for the elderly). The Health Centre provided accommodation for GPs, and for all the other members of the primary health care team.

4.2.2 BREAST CANCER IN DAVENTRY

Collecting quantitative data on breast cancer in

Daventry involved the usual problems of small numbers. The difficulties were compounded because of local government re-organisation in 1974 and the creation of Daventry County District.

Mortality data are analysed by County districts. Table 4.1 shows the numbers of deaths and the mortality rates from breast cancer in Daventry County District between 1974 and 1978. The rates appear to be relatively low compared to both the county district and health area throughout the 5 years. Table 4.2 shows the numbers of deaths in Daventry County District within 10 year age-groups. The mortality statistics are not available for either the town of Daventry, or the Health Centre catchment area, only.

Cancer incidence data and hospital activity analysis (HAA) data are coded by the old local government areas - Daventry Metropolitan Borough and Daventry Rural District. Table 4.3 shows the new cases of breast cancer notified to the Oxford Cancer Registry during 1974 to 1977. A mean of 14.8 new cases were registered each year, with approximately half aged under 65 years and half aged 65 years and over. One third were resident in the Metropolitan Borough and two-thirds in the Rural District.

Table 4.4 shows the numbers of women resident in Daventry Metropolitan Borough and Daventry Rural District discharged from hospitals in the Oxford Region with a diagnosis of breast cancer. On average there were 26 women discharged each year, of whom 10 had had mastectomies. However, hospital discharge data, although useful for monitoring trends over time, may not be very helpful in

TABLE 4.1

NUMBERS AND RATES OF DEATHS FROM BREAST CANCER IN WOMEN IN DAVENTRY COUNTY DISTRICT, NORTHAMPTON HEALTH DISTRICT AND NORTHAMPTONSHIRE 1974-8

Numbers of deaths	1974	1975	1976	1977	1978
Daventry County District	6	7	6	10	13
Northampton Health District	55	57	58	56	73
Northamptonshire	120	110	124	109	126
Mortality rates per 100,000 women					
Daventry County District	23	26	22	36	46
Northampton Health District	43	44	44	42	54
Northamptonshire	47	43	48	42	48

(derived from SD 25 data)

TABLE 4.2

NUMBERS OF DEATHS FROM BREAST CANCER IN WOMEN IN DAVENTRY COUNTY DISTRICT BY AGE GROUP 1974-8

	1974	1975	1976	1977	1978
25-34	-	-	1	-	-
35-44	-	1	-	-	-
45-54	1	2	1	3	3
55-64	2	-	1	-	2
65-74	1	2	-	3	3
75+	2	2	3	4	5
Total	6	7	6	10	13

(derived from SD 25 data)

TABLE 4.3

NEW CASES OF BREAST CANCER IN WOMEN NOTIFIED TO THE OXFORD CANCER REGISTRY DURING 1974 TO 1977

	Daventry Metropolitan Borough			Daventry Rural District		
	Under 65 years	65 years and over	Total	Under 65 years	65 years and over	Total
1974	2	3	5	7	1	8
1975	2	3	5	2	4	6
1976	4	-	4	5	2	7
1977	-	6	6	10	8	18
Total	8	12	20	24	15	39

TABLE 4.4

NUMBERS OF WOMEN RESIDENT IN DAVENTRY METROPOLITAN BOROUGH AND DAVENTY RURAL DISTRICT DISCHARGED FROM HOSPITAL WITH THE DIAGNOSIS OF BREAST CANCER 1974-8

Daventry Metropolitan Borough	1974	1975	1976	1977	1978
Women discharged with diagnosis of breast cancer	8	17	22	8	6
Women discharged with diagnosis of breast cancer and having had mastectomy	6	6	3	3	4
Daventry Rural District					
Women discharged with diagnosis of breast cancer	13	10	13	19	16
Women discharged with diagnosis of breast cancer and having had mastectomy	8	2	5	11	3

(derived from Hospital Activity Analysis data)

assessing the extent of a disease - especially one where the treatment is so complex. Women undergoing surgery for breast cancer will almost certainly be admitted to hospital, but will not appear in HAA data if this is a private hospital. However, many women will also receive radiotherapy and/or chemotherapy, often as an out-patient in which case it will not be recorded in HAA statistics. Thus the picture can only be partial.

The numbers of deaths from, and cases of, breast cancer were obviously not large enough to use as a means of evaluation, and this was not the intention of the study reported here. Daventry was selected as the study area, both because it was considered to provide the appropriate size of target group for our educational programme, and because of the structure of health service provision, particularly the primary care services, which would make data-collection relatively easy.

4.3 OBJECTIVES

The research project was intended to evaluate a 6 month educational programme in BSE. The objectives of the study were:-

... to design and conduct an educational programme

... to measure the reported changes in knowledge and attitudes which were achieved by the educational programme

... to measure the reported changes in behaviour which were achieved by the educational programme

... to monitor the effects of the programme on the diagnosis of breast disease and on the related NHS workload

... to look specifically for any adverse effects of the programme, particularly increased anxiety

... to cost the programme

4.4 STAFF

Two alternative methods of conducting the educational programme were considered. One approach was to work through the appropriate groups of health care professionals - in particular, GPs, Clinical Medical Officers and health visitors. Alternatively, it was possible to obtain research funds to recruit a specific individual, who would help to develop and would provide the programme, and also would assist with the evaluation of the project. The second alternative was chosen because it was considered that education about BSE might be seen by health service staff as an additional, possibly unmanageable workload. There seemed little point in carefully evaluating a programme which was not adequately conducted.

A health visitor seemed to be the most suitable type of individual to recruit. He or she would have training in and experience of health education, and would also be competent to assist with the evaluation. There also seemed to be advantages in appointing a woman to carry out an educational programme aimed exclusively at women. The study was funded by a grant from the Oxford Regional Health Authority (Locally Organised Research Scheme), which provided the health visitor's salary for 2 years plus the costs incurred in running and evaluating the programme.

The application for a research grant was submitted in August 1977, and approved to start on April 1 1978. On the advice of the Northampton District Nursing Officer,

the post of a Research Health Visitor was advertised within the district. We were concerned that whoever was appointed should not be professionally disadvantaged by moving into what might be seen within nursing as a slightly unusual post,and ensured that her grading and salary would be equivalent to those of a conventional health visitor.

The Research Health Visitor took up her appointment on April 1 1978. The staff at Daventry Health Centre had offered to provide an office for the duration of the study, and she was based there throughout. Immediately before her appointment she had worked as a health visitor in the Health Centre, and so knew both the Health Centre staff and Daventry itself.

4.5 TIMETABLE

The programme and its evaluation were planned as follows:-

Start date	End date	Activity
April 1 1978	September 30 1978	Baseline data collection (i) GP data (ii) population data
October 1 1978	March 31 1979	EDUCATIONAL PROGRAMME
April 1 1979	September 30 1979	Follow-up data collection (i) GP data (ii) population data

4.6 EDUCATIONAL PROGRAMME

The literature on BSE provided very little guidance on the optimal way in which to teach women, and moreover, very little of the work has been done in the UK. Expertise has obviously developed in certain areas, for example film-making, but to a much lesser extent in the development of whole programmes suitable for specific audiences. The programme reported here was developed with the assistance of Patricia Hobbs (Unit for Epidemiology and Social Research, Manchester), and in line with the five prerequisites for teaching BSE described by her and her colleagues (Hobbs et al, 1977):-

... stressing the greater likelihood of non-malignant than malignant causes for changes in the breast

... making clear the advantages of treating cancer while still at an early stage

... explaining the "lumpy" nature of the normal breast

... seeking to teach established groups, so that group support is available for developing a regular health habit

... offering personal counselling and follow-up if needed.

4.6.1 TARGET GROUP

In common with all the reported studies of BSE, it was decided to teach women only. Many studies of breast screening or BSE have been confined to middle-aged women, often women aged 40 years and over or 45 years and over. The rationale for this is obvious, as the incidence of breast cancer increases steeply with age. The absolute

numbers of cases of, and deaths in, women aged less than 45 years are small in proportion to the totals (the most recent figures available show that 13% new cases in 1974 (OPCS, 1980a), and 7% deaths in 1979 (OPCS, 1980b) were in women aged under 45 years). It is argued that younger women have little to gain from learning and practising BSE; the only effect may be to produce unnecessary and unproductive anxiety.

In our study, however, it was decided to provide the educational programme for women aged 15-64 years. There were several reasons for including younger women. First, although the numbers of cases of and deaths in women aged 15-44 years appear small in absolute terms, breast cancer is one of the major causes of morbidity and mortality amongst what is a predominantly healthy group of women (see Section 1.1). Second, there is some evidence that the acceptance of breast screening and the practice of BSE both decline with age (see Sections 2.2 and 2.3). This may be an aspect of ageing, as women's breasts perhaps become of less interest to them; or alternatively it may reflect a cohort effect, and those younger women who currently practise BSE will continue to do so as they age. Either way, younger women might be predicted to be more open to teaching about BSE. Third, even if the older women are seen as the primary target, they will be reached not only directly by the professional educators, but also by informed relatives and friends, some of whom may be younger. Fourth, by setting the lower age limit at 15 years, we included fifth and sixth formers at school - an audience which could be

encouraged to discuss BSE with older women, particularly their mothers. Finally, as discussed in Section 3.4.1, there is considerable concern and anxiety amongst women of all ages about breast cancer. The education was intended not only to promote BSE, but also to encourage symptomatic women to report their symptoms to their doctor. Thus, a significant component of the education was designed to provide reassurance, and we felt that this should be available to women across the age range.

The target group was primarily women living in the town of Daventry, almost all of whom would be registered at the Health Centre. This group was defined, because the evaluation was based first on a questionnaire to a sample of women drawn from the Health Centre age-sex registers, and second on the workload of the GPs who worked there. However, a few groups living in the surrounding villages heard about the programme and expressed interest, and so the teaching was provided for them also.

Women were taught within established groups, either at work, or in leisure groups. Every employer in Daventry, who was thought to employ five or more women, was contacted by letter. This offered the presentation, by the Health Visitor, of an educational programme lasting 30 to 40 minutes. It was suggested that the groups should be limited to not more than twenty women, although the sessions could be repeated. The time should be arranged to suit the convenience of the employer and employees. These employers were mainly shop owners and shop managers, factory owners and factory managers and the public services. A list of

local groups and organisations was obtained from the public library, and the secretaries were contacted, to ask if they would include the presentation in their winter programme 1978/79 (the letters were sent in April-June 1978, when it was expected that groups would be arranging their autumn and winter meetings). They were also asked to suggest any other groups which might be interested, and it was again stressed that the date and time should be at their convenience.

In addition to women in the workplace and in leisure groups, modified versions of the programme were given to two other groups. Fifth and sixth form girls in the two upper schools in Daventry were taught about the normal and abnormal breast and the role of BSE, as one part of a session on health promotion. Women attending for ante-natal care at the Health Centre were also taught about BSE, but this time information was also given about the breast in pregnancy and breast feeding.

Finally, three evening meetings were held in the Health Centre. These meetings were open to anyone.

4.6.2 PUBLICITY

There was no local radio in Daventry and thus the main methods of formal publicity were the local newspaper, posters and leaflets.

The editor of the local newspaper was contacted before the beginning of the programme, and publicity was discussed. On the one hand there was a need to ensure that women in Daventry knew that the education was taking place, but at the same time this must not be achieved by creating

unnecessary fear or anxiety. It was agreed that a draft article would be provided for the paper, and that the proofs would be checked for accuracy before publication. In the event the draft was published unmodified as a centre spread, in the second week of the programme. The advertisement section of the local paper was used to publicise the three open meetings in the Health Centre.

It was decided to use a poster and leaflet with the same photograph and which would obviously be associated with each other, as this might make each of them more noticeable. A variety of leaflets were available through the Health Education Council, none of which seemed suitable; moreover, there were no matching posters. J.Walter Thompson Ltd., a large London advertising agency, was approached, and they agreed to pay the development costs of a leaflet and poster. An additional grant from the Health Education Council covered the printing costs (copies of the leaflet and poster are appended).

Before the posters were printed, enquiries about the possibilities of renting poster hoardings were made. Unfortunately, these hoardings were owned by agencies which sub-let them to companies. There are only a very limited number of hoardings in Daventry, and, at the time of the study, they were all sub-let on long leases, mostly to the tobacco industry. Despite discussions with these companies, none was willing to allow the use of their space, even for a brief period. The local bus company also refused to allow us to use advertising space on their buses. There had recently been some complaint about an advertisement for a Family Planning Clinic, which was displayed on several buses,

and they were concerned that BSE might be seen as a similarly problematic issue.

Poster display therefore relied on the goodwill of the managers of various public institutions (for example, those owned by the Health Service and by Local Government), and of shop owners and managers who were asked to display posters. Unfortunately, this precipitated a further problem. The posters, despite having been designed by one of the leading UK product-sellers, did not turn out to be entirely appropriate for our market. Although not intended to be a wholly realistic portrayal of BSE, the design did show the vague but unmistakeable outline of a nipple. This led to the poster being met with some reservations. Apart from providing general publicity, the poster was also intended to be used to advertise meetings. To this end a plain white strip had been left at the bottom, on which to write the date, time and place of the meeting. With some ingenuity, this strip could be removed and stuck diagnonally across the poster, thus rendering it acceptable. In addition, the Northamptonshire Area Health Education Department produced some alternative posters which were also used. However, the impact of the poster was almost certainly compromised, and it was unfortunate that the difficulties were not anticipated.

The leaflets were provided for women to take away after the teaching (extra copies were available, and they were encouraged to take them for friends), and were also used for general publicity. Supplies were available for all staff in the Health Centre, both to provide a source of information for the women and also to encourage the staff to discuss BSE with their patients.

4.6.3 EDUCATIONAL PRESENTATION

Before deciding what form our presentation should take, all the available films on BSE were studied. The original intention had been to use a film, which would be followed by discussion, but this was altered for two reasons. First, there were some reservations about each film, and none was considered adequate without some additional covering explanations. Second, the Research Health Visitor (in keeping with many educators) did not consider the film/discussion format to be suitable for the target groups, but advocated a loosely-written script, which she could vary to suit the individual group, and which would be illustrated with slides.

Patricia Hobbs and her co-workers in Manchester were in the process of developing a new set of teaching slides with a commentary and were willing to provide copies of these, which were then modified both in content and emphasis. The information we intended to convey could be summarised as:-

... most problems with the breast are not cancer

... the chances of curing cancer are better the earlier it is treated

... the chances of finding cancer earlier are better if you practise BSE

... BSE is quick and simple, and reassures you that everything is all right

... if in doubt, see your doctor as soon as possible.

The talk included information about the normal breast and the possible causes of breast problems. The benefits

of the early diagnosis and treatment of breast cancer were discussed, and then the practice of four quadrant BSE described. Women were encouraged to ask questions both during the talk and at the end, when the discussion continued as long as they wished. The messages and the method of BSE were emphasised by the information in the leaflet.

Further reinforcement was provided by the use of the teaching model manufactured by Spenco Ltd. The model is made of the same material as breast prostheses, and contains 6 lumps, of different shapes, sizes and consistencies, placed at different depths in the breast. Four of these models were available at the end of the discussion, to enable the women to practise their BSE technique.

4.6.4 FOLLOW-UP

The Research Health Visitor was available in the Health Centre on the same two half days each week, for advice, counselling or further teaching if required. This opportunity for one-to-one contact was explained at each educational session, and in the newspaper article. The reception staff at the Health Centre agreed to offer appointments to women who came in or telephoned at other times of the week.

4.7 POSTAL QUESTIONNAIRE

Two postal questionnaires were used to collect population-based data, both before (May 1978) and after (May 1979) the educational programme. The Health Centre age-sex registers were used to select a random sample,

stratified by 5 year age groups, of 600 women aged 15-64 years. Each woman received up to three copies of each of the two questionnaires, which they were asked to return in pre-paid envelopes to the Department of Social and Community Medicine, University of Oxford. The covering letters were signed by the research workers, but explained that the study was being done in conjunction with the woman's own GP.

The first questionnaire collected basic demographic information about the woman, and details of her previous health, her knowledge about BSE, and her knowledge and attitudes about breast disease. The follow-up questionnaire, which was sent out after the programme in May 1979, asked about contact with and opinions of the educational programme, as well as repeating the previous questions about knowledge, attitudes and behaviour.

A second sample of 600 women, selected in the same way, received only the follow-up questionnaire. Similar data were requested, and the purpose of including this group was to assess whether there was any effect of the initial questionnaire on the response to the programme.

Copies of the questionnaires and covering letters are appended.

4.8 GP WORKLOAD

The GPs were asked to complete a form on each woman who consulted them with breast symptoms, or in whom they found breast signs, during the 18 months of the study. The form collected information to allow us to identify the woman so that we could follow her progress, and details of

her symptoms and their duration, any signs found by the GP, the likely diagnosis and the planned management. These forms were collected each week by the Research Health Visitor.

A copy of the form is appended.

4.9 DATA ANALYSIS

The postal questionnaires were coded by the Research Health Visitor, and checked by the author. The GP forms were coded by the author. The data were analysed using SPSS (Nie et al, 1975) on the University of Oxford ICL 2980 computer.

C H A P T E R 5

The extent of the educational programme to promote breast self-examination

INTRODUCTION

This chapter briefly summarises the extent of the health education programme (Section 5.1) and its costs (Section 5.2).

5.1 THE EXTENT OF THE HEALTH EDUCATION PROGRAMME

A total of 85 talks were given to 1761 women during the health education campaign; an average of 21 women attended each talk, with a range of 3 to 55 women (see Table 5.1 for details). Almost two-thirds of the educational sessions were provided in the workplace, one-quarter to women in their leisure groups, and the remainder to schoolgirls, to antenatal patients or to open groups in the Health Centre. Although these last sessions were advertised as open to men and women, no men attended. No data were collected on the women who attended the talks, but the age range is known to have been from 15 to at least 90 years.

Each session included a formal presentation with slides, an open-ended discussion period and the opportunity to practise BSE on the Spenco teaching model. The presentation was modified, often considerably, to suit each audience. The research health visitor developed considerable expertise in anticipating queries and encouraging women to discuss their anxieties, and there were obvious advantages in the education being carried out by one individual only. The discussion period often lasted for as long as one hour, and, in addition, individual women took the opportunity for a one-to-one discussion with the health visitor afterwards. Most of the women appeared enthusiastic about the teaching model.

TABLE 5.1

NUMBERS OF TALKS (PERCENTAGES), NUMBERS OF WOMEN ATTENDING (PERCENTAGES) AND MEAN NUMBER OF WOMEN ATTENDING BY PLACE OF TALK

	Numbers of talks	Numbers of women	Mean number of women at each talk
Work	51 (60)	968 (55)	19
Leisure group	22 (26)	440 (25)	20
Health centre - open meeting	3 (4)	132 (7)	44
Health centre - antenatal class	2 (2)	25 (1)	13
School	7 (8)	196 (11)	28
Total	85 (100)	1761 (100)	21

The educational sessions were given in a variety of settings - in the back room of a shop, on the factory floor, in conference rooms, in classrooms, in living rooms, and once in the form of an after-dinner speech. In some workplaces the women were not allowed to leave work to attend the talk, and so the session was provided during their lunch-break.

No formal record of the discussion periods was kept, but recurrent themes were noted. These included: anxiety about mastectomy and its after-effects, stories of being humiliated and made to feel neurotic by doctors, positive comments about friends and relatives who were alive and well many years after a mastectomy, and interest in BSE, including some women who said that they would tell their daughters about it.

Only 11 women consulted the health visitor in the Health Centre, but some of these attended several times. Most of them wished for advice and support in the care of relatives who were dying of breast cancer.

5.2 THE COSTS OF THE HEALTH EDUCATION PROGRAMME

The costs of the programme, at 1978/9 prices, were as follows:-

	£
Salary of health visitor for 6 months, including superannuation and national insurance (mid-point of scale):	2600.00
Slides (set supplied free):	-
Slide projector:	195.00
Screen:	8.50
Spenco teaching model (x 4):	94.50
Leaflets (excluding development costs):	525.00
Posters (excluding development costs):	222.00
Travelling expenses of health visitor, 337 miles @ 12p a mile:	40.50
Incidental expenses:	5.50
TOTAL:	3691.00

The total costs were £3691, over two-thirds of which was accounted for by the salary and employing expenses of the health visitor. The slide projector and screen were sold at the end of the project for almost cost price,and the teaching models were available for further use had the project continued; thus the real costs of these items were less than is stated. Although most of the talks were provided away from the health centre, the travelling expenses were modest.

C H A P T E R 6

The diagnosis and management of breast disease as reported by the general practitioners

INTRODUCTION

General practitioner (GP) workload was studied to assess any change due to the programme designed to encourage breast self-examination (BSE) described in Chapters 4 and 5. Of particular interest was any increase which might be interpreted as a result of anxiety. Each GP was asked to complete a form on every consultation about breast symptoms. The data also provide a description of the types of breast symptoms and disease which are seen in general practice, and the way in which these are managed. This chapter discusses these epidemiological data (Sections 6.1 to 6.10), with special reference to women with suspected (Section 6.11) or confirmed (Section 6.12) breast cancer, and considers the possible effects of the programme on the workload of GPs (Section 6.13).

6.1 GP PARTICIPATION

Daventry Health Centre provides facilities for 9 GPs, in two practices of 4 and 5 partners. One GP resigned and was replaced during the course of the study, and several locums were employed to cover holiday periods. The original 9 GPs were all invited to attend a planning meeting and several subsequent meetings were held to discuss progress. The newly-appointed GP and the locums also took part in the study.

6.2 NUMBERS OF WOMEN REPORTING SYMPTOMS

Over the 18 months a total of 239 women were reported by the GPs to have consulted with breast symptoms - 82 (34%) during the 6 months before the educational programme, 98 (41%) during the 6 months of the educational programme and 59 (25%)

during the 6 months following the educational programme. Each GP (excluding the locums) recorded data on between 5 and 57 women (mean number 24); the only woman GP in the Health Centre saw the greatest number of women (57, 24% of the total). These differences may be partly accounted for by varying enthusiasm for the completion of questionnaires, but may also represent the extent of lay knowledge of the GPs' interests and sympathies. Altogether 329 visits were recorded, an average of just over 4 per week.

6.3 AGE OF WOMEN REPORTING SYMPTOMS

The women's ages ranged from 13 years to 90 years, with 78% under the age of 45 years, and 96% under the age of 65 years (Table 6.1). One third (81) were aged 25-34 years, and a further one quarter (61) were in the age group 35-44 years.

6.4 SYMPTOMS

Table 6.2 shows that a total of 128 women (54%) were recorded as presenting with a breast lump. Although 55% (71) of these women said that they had attended their GP within 1 month of noting the lump (27% (35) within 1 week), 30% (39) had delayed for 1 month or more before reporting the symptom; in 14% (18) the interval before presentation was not known. Similar figures are seen for women who presented complaining of pain the their breast(s) - a total of 136 women (57%). Again 55% (74) had consulted their GP within 1 month of becoming symptomatic, although 35% (47) had waited for at least one month before presenting; in 11% (15) no data on time interval were available. Other symptoms included nipple discharge (13), an apparent heaviness or swelling of the breasts (8), swollen axillary glands thought to be

TABLE 6.1

NUMBER OF
WOMEN CONSULTING THEIR GP WITH BREAST SYMPTOMS BY AGE GROUP

Age Group	Number of women	Percentage of total	Cumulative percentages
< 15	2	1	1
15-24	42	18	19
25-34	81	34	53
35-44	61	26	78
45-54	30	13	91
55-64	12	5	96
65-74	4	2	98
75+	6	3	100
TOTAL	238	100	100

(Inadequate information available for 1 woman)

TABLE 6.2

NUMBER OF WOMEN (PERCENTAGES) CONSULTING THEIR GP WITH BREAST SYMPTOMS BY DURATION OF SYMPTOMS

	DURATION OF SYMPTOM						
Symptom	Less than 1 week	1 week or more, less than 1 month	1 month or more, less than 3 months	3 months or more	Duration not known	Total women with symptom	Symptom not present
Lump	35 (27)	36 (28)	21 (16)	18 (14)	18 (14)	128 (100)	110
Pain	32 (24)	42 (31)	28 (21)	19 (14)	15 (11)	136 (100)	102
Discharge from nipple	2 (15)	3 (23)	1 (8)	5 (38)	2 (15)	13 (100)	225

(Inadequate information available for 1 woman)

breast lumps (2), bruising after a fall (1), nipple retraction (1), and fluid collection around the nipple (1). Six women were seen for routine review - 3 were known to have had breast cancer, 1 a breast abscess, 1 a fibroadenoma and 1 was breast-feeding. There was no relationship between age and duration of symptoms at presentation.

Table 6.3 shows that the proportions of women with the three most common symptoms were broadly similar across the age-groups, although fewer older women seemed to present with pain.

6.5 GP FINDINGS ON EXAMINATION

A discrete lump was palpable in 91 women (38%) (Table 6.4). In 5% the diameter was estimated by the GP to be less than 1 cm, in 13% 1 cm to less than 2 cms, in 13% 2 cms to less than 5 cms and in 1% 5 cms or more; in 6% the diameter was not recorded. Older women tended to present with relatively larger lumps, but the numbers were too small for there to be any statistically significant trend. Table 6.5 shows the data available on the characteristics of the lumps. In 53 women (60%) the lump was described as hard, and in 40 (45%) tender; in 3 women (3%) the lump was considered to be fixed to the underlying muscle and in 6 women (7%) skin fixation was thought to be present. Generalised nodularity of the breasts was reported in 67 women (28%) - in 39 (17%) this was described as being in one breast only and in 28 (12%) as being in both breasts (Table 6.6). All the women with generalised nodularity were aged under 55 years, all but one being under the age of 45 years; this presumably reflects the actions of oestrogens and progestogens on premenopausal

TABLE 6.3

NUMBER OF WOMEN (PERCENTAGES) IN EACH AGE GROUP CONSULTING THEIR GP WITH BREAST SYMPTOMS

Symptom	AGE GROUP								
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	TOTAL
Lump	1 (50)	23 (55)	45 (56)	36 (59)	14 (47)	5 (42)	2 (50)	2 (33)	128 (54)
Pain	2 (100)	29 (69)	50 (63)	30 (49)	16 (53)	5 (42)	3 (75)	-	135 (57)
Discharge	-	2 (5)	5 (6)	4 (7)	1 (3)	1 (8)	-	-	13 (5)
Total in age group	2	42	80	61	30	12	4	6	237

(Inadequate information available for 2 women)

TABLE 6.4

NUMBER OF WOMEN IN EACH AGE GROUP (PERCENTAGES) BY SIZE OF LUMP PALPATED BY GP

Size of lump	AGE GROUP								
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total
No lump felt	1 (50)	28 (67)	49 (60)	36 (59)	19 (63)	8 (67)	3 (75)	3 (50)	147 (62)
Diameter < 1 cm	-	3 (7)	8 (10)	2 (3)	-	-	-	-	13 (5)
Diameter 1- < 2 cm	1 (50)	9 (21)	4 (5)	14 (23)	2 (7)	1 (8)	-	-	31 (13)
Diameter 2- < 5 cm	-	1 (2)	14 (17)	8 (13)	4 (13)	1 (8)	1 (25)	1 (17)	30 (13)
Diameter 5 cm +	-	- -	-	1 (2)	1 (3)	1 (8)	-	-	3 (1)
Lump felt, diameter not recorded	-	1 (2)	6 (7)	-	4 (13)	1 (8)	-	2 (33)	14 (6)
Total	2 (100)	42 (100)	81 (100)	61 (100)	30 (100)	12 (100)	4 (100)	6 (100)	238 (100)

(Inadequate information available for 1 woman)

TABLE 6.5

NUMBERS OF WOMEN (PERCENTAGES*) IN EACH AGE GROUP BY CHARACTERISTICS OF LUMPS PALPATED BY GP

Characteristics of lump	AGE GROUP								
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total
Total in whom no lump palpated	1 (50)	28 (67)	49 (60)	36 (59)	19 (63)	8 (67)	3 (75)	3 (50)	147 (62)
Number with hard lump	1 (100)	8 (62)	17 (53)	15 (60)	7 (64)	3 (75)	1 (100)	1 (100)	53 (60)
Number with tender lump	1 (100)	8 (57)	16 (50)	9 (36)	4 (36)	1 (25)	1 (100)	-	40 (45)
Number with muscle fixation	-	1 (7)	-	-	1 (9)	-	1 (100)	-	3 (3)
Number with skin fixation	-	-	2 (6)	1 (4)	1 (9)	-	1 (100)	-	6 (7)
Total in whom lump palpated	1 (50)	14 (33)	32 (40)	25 (41)	11 (37)	4 (33)	1 (25)	3 (50)	91 (38)

(Inadequate information available for 1 woman)

* Percentages of the numbers of women for whom the specific items of information were recorded are given for each age group and for the total

TABLE 6.6

NUMBERS OF WOMEN (PERCENTAGES) IN EACH AGE GROUP IN WHOM GENERALISED NODULARITY PALPATED BY GP

Presence of nodularity	AGE GROUP								
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total
No generalised nodularity	1 (100)	25 (60)	56 (69)	38 (62)	29 (97)	12 (100)	4 (100)	4 (100)	169 (72)
Unilateral generalised nodularity	-	13 (31)	15 (19)	10 (16)	1 (3)	-	-	-	39 (17)
Bilateral generalised nodularity	1 (100)	4 (10)	10 (12)	13 (21)	-	-	-	-	28 (12)
Total	2 (100)	42 (100)	81 (100)	61 (100)	30 (100)	12 (100)	4 (100)	4 (100)	236 (100)

(Inadequate information available for 3 women)

breast tissue.

Other findings were much less common. Three women (1%) had discharge from one nipple, 4 women (2%) had nipple retraction and 1 woman (<1%) had nipple displacement. In addition, three women (1%) were considered to have benign conditions of their nipples - 1 papilloma, 1 split nipple and 1 collection of fluid. Five women (2%) had inflammation, with or without induration, of the skin overlying one breast; 2 women (1%) had peau d'orange. Mobile lymph nodes were palpated in the homolateral axilla in 5 women (2%), in the contralateral axilla in 1 woman and in both axillae in 1 woman. Twenty two women (9%) had previously undergone surgery - 14 (6%) for a benign condition, 1 (<1%) plastic surgery, 6 (3%) mastectomy (2 now had metastases) and 1 woman had had bilateral mastectomy (Table 6.7).

The data in Table 6.8 compare the reporting of a lump by the woman with the findings of the GP on palpation. In 103 women (43%) neither the woman nor her GP reported the palpation of a lump; in 84 (35%) both palpated a lump, in 44 (18%) the lump was felt by the woman only and in 7 (3%) by the GP only.

6.6 GP DIAGNOSIS

The GPs were asked to record their provisional diagnosis for each woman; where the woman attended more than once, the provisional diagnosis was taken as that made at her first visit. Table 6.9 shows that 39 women (17%) were considered to have no breast abnormality, and a further 24 (11%) were thought to have only a minor problem, relating to the skin or muscles, often following trauma. The breast symptoms of 17 women (8%) were diagnosed as being due to hormonal

TABLE 6.7

NUMBERS OF WOMEN (PERCENTAGES) IN EACH AGE GROUP WHO HAD A PREVIOUS HISTORY OF BREAST SURGERY

Previous history of breast surgery	AGE GROUP < 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total
No previous breast surgery	2 (100)	42 (100)	78 (96)	51 (84)	26 (87)	10 (83)	4 (100)	2 (40)	215 (91)
Previous surgery for benign disease	-	-	3 (4)	9 (15)	2 (7)	-	-	-	14 (6)
Previous mastectomy, no metastases	-	-	-	1 (2)	-	1 (8)	-	2 (40)	4 (2)
Previous mastectomy, definite metastases	-	-	-	-	1 (3)	1 (8)	-	-	2 (1)
Bilateral mastectomies	-	-	-	-	-	-	-	1 (20)	1 (<1)
Previous plastic surgery	-	-	-	-	1 (3)	-	-	-	1 (<1)
Total	2	42	81	61	30	12	4	5	237

(Inadequate information available for 2 women)

TABLE 6.8

NUMBERS OF WOMEN (PERCENTAGES) IN WHOM THERE WAS AGREEMENT AND DISAGREEMENT BETWEEN THE WOMAN AND HER GP IN THE PALPATION OF A BREAST LUMP

	Lump felt by woman	Lump not felt by woman	Total
Discrete lump felt by GP	84 (35)	7 (3)	91 (38)
Discrete lump not felt by GP	44 (18)	103 (43)	147 (62)
TOTAL	128 (54)	110 (46)	238 (100)

(Inadequate information available for 1 woman)

TABLE 6.9

NUMBERS OF WOMEN (PERCENTAGES) IN EACH AGE GROUP BY PROVISIONAL DIAGNOSIS REACHED BY GP AT FIRST CONSULTATION

Provisional GP diagnosis	AGE GROUP								
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total
Normal	-	6 (15)	9 (12)	10 (18)	9 (32)	3 (30)	1 (33)	1 (17)	39 (17)
Minor problem - trauma, bruising, skin problem, muscular	-	3 (8)	4 (5)	3 (5)	8 (29)	4 (40)	1 (33)	1 (17)	24 (11)
"Hormonal" or "pre-menstrual"	1 (50)	5 (13)	9 (12)	2 (4)	-	-	-	-	17 (8)
Infection	-	-	4 (5)	-	-	-	-	-	4 (2)
Blocked duct	-	2 (5)	1 (1)	-	-	-	-	-	3 (1)
Fibroadenoma	-	4 (10)	2 (3)	2 (4)	1 (4)	-	-	-	9 (4)
Fibrocystic disease, fibroadenosis, mastitis, cyst	1 (50)	20 (50)	48 (62)	35 (63)	5 (18)	-	-	-	109 (49)
Possible breast cancer	-	-	1 (1)	4 (7)	5 (18)	3 (30)	1 (33)	4 (67)	18 (8)
Total	2 (100)	40 (100)	78 (100)	56 (100)	28 (100)	10 (100)	3 (100)	6 (100)	223 (100)

(Inadequate information available for 16 women)

imbalance; 4 women (2%) were considered to have an infective mastitis and 3 (1%) a blocked duct. Almost half the women (109) were diagnosed as having fibrocystic disease (or fibroadenosis, mastitis or a cyst); a further 9 (4%) were thought to have a fibroadenoma and 18 (8%) were considered to be possible cases of breast cancer.

Certain diagnoses - fibrocystic disease, fibroadenoma, hormonal imbalance, infective mastitis or a blocked duct - were made only in women under the age of 55 years, the majority of whom would be either premenopausal or perimenopausal. Half of the women aged 15-24 years, and almost two-thirds of those aged 25-44 years, were thought to have fibrocystic disease. The proportion of the women in whom the diagnosis of possible breast cancer was made increased with age - from 1% of those aged 25-34 years (1 woman out of 78) to 56% of those aged 65 years and over (5 women out of 9). When the possibility of breast cancer had been excluded, women under 55 years were most likely to be diagnosed as having fibrocystic disease, and women aged 55 years and over would usually be considered to have either no abnormality or only a minor problem.

6.7 PLANNED GP MANAGEMENT

The data in Table 6.10 show the management of each woman as planned by the GP after her first consultation. In summary:-

... in almost two-thirds of all cases the management consisted of reassurance, with or without a subsequent review. 66 women (29%) received no treatment and were not asked to attend for review - two-thirds of these (42)

TABLE 6.10

NUMBERS OF WOMEN (PERCENTAGES) WITH EACH PROVISIONAL GP DIAGNOSIS BY GP PLANNED MANAGEMENT

Provisional GP diagnosis	GP PLANNED MANAGEMENT							
	Reassurance only	Treatment with hormone(s)	Treatment with other drugs	No therapy, to attend for review	Referred to hospital	Discussed with consultant, not referred	Already receiving hospital treatment	Total
Normal	29 (73)	1 (3)	2 (5)	8 (20)	-	-	-	40 (100)
Minor problem - trauma, bruising, skin problem, muscular	13 (54)	-	2 (8)	8 (33)	1 (4)	-	-	24 (100)
"Hormonal" or "premenstrual"	5 (29)	-	4 (24)	7 (41)	-	1 (6)	-	17 (100)
Infection	-	-	4 (100)	-	-	-	-	4 (100)
Blocked duct	-	-	1 (33)	-	2 (67)	-	-	3 (100)
Fibroadenoma	-	-	-	4 (44)	5 (56)	-	-	9 (100)
Fibrocystic disease, fibroadenosis, mastitis, cyst	19 (17)	1 (1)	23 (21)	45 (41)	21 (19)	-	-	109 (100)
Possible breast cancer	-	1 (6)	-	-	15 (83)	-	2 (11)	18 (100)
Total	66 (29)	3 (1)	36 (16)	72 (32)	44 (20)	1 (<1)	2 (1)	224 (100)

(Inadequate information available for 15 women)

were considered to have no abnormality or a minor problem only, although over one-quarter (19) received the provisional diagnosis of fibrocystic disease. A further 72 women (32%) were given a follow-up appointment without being prescribed any treatment; nearly two-thirds of this group (45) were thought to have fibrocystic disease.

... Hormones were prescribed for 3 women (1%), antibiotics for 4 women (2%) and diuretics, analgesics or both for 32 women (14%).

... The GPs referred 44 women (20%) to hospital after the first consultation, almost half (19) with the provisional diagnosis of fibrocystic disease, and a further one-third (15) as possible cases of breast cancer. In addition, two women were thought to have recurrent breast cancer, but were already receiving hospital treatment for their primary tumour.

6.8 OUTCOME OF GP MANAGEMENT

Table 6.11 shows the outcome of the GP's management. (The outcome was the end-result of the GP management; if this was still continuing at the end of the study (March 1980), it was defined as the management at that time.) 101 women (45%) were seen once only by intent, either because reassurance was considered to be sufficient or because they were referred to hospital. 52 women (23%) were followed up by the GP; in over half of these cases (27) the condition had subsequently resolved and follow-up was discontinued, 11 women were still being followed-up, 11 had been discharged although the condition persisted and 3 had been discharged but asked to attend again if they were worried. A further 57 women (25%) made, but did not keep, a follow-up appointment; there was no system for noting women who did

TABLE 6.11

NUMBERS OF WOMEN (PERCENTAGES) WITH EACH PROVISIONAL GP DIAGNOSIS BY OUTCOME OF GP MANAGEMENT

Provisional GP diagnosis	OUTCOME OF GP MANAGEMENT							Total
	Seen once only by intent	Didn't attend for intended review	Condition resolved, follow-up stopped	Condition unresolved, follow-up continuing	Condition unresolved, follow-up stopped	Condition unresolved, to see if necessary	Referral to hospital eventually necessary	
Normal	22 (55)	11 (28)	4 (10)	-	-	1 (3)	2 (5)	40 (100)
Minor problem - trauma, bruising, skin problem, muscular	10 (42)	8 (33)	2 (8)	-	2 (8)	-	2 (8)	24 (100)
"Hormonal" or "premenstrual"	6 (35)	3 (18)	4 (24)	2 (12)	2 (12)	-	-	17 (100)
Infection	1 (25)	1 (25)	2 (50)	-	-	-	-	4 (100)
Blocked duct	2 (67)	-	-	-	-	-	1 (33)	3 (100)
Fibroadenoma	5 (56)	2 (22)	1 (11)	-	-	-	1 (11)	9 (100)
Fibrocystic disease, fibroadenosis, mastitis, cyst	39 (36)	31 (28)	14 (13)	8 (7)	7 (6)	2 (2)	8 (7)	109 (100)
Possible or definite breast cancer	16 (89)	1* (6)	-	1 (6)	-	-	-	18 (100)
Total	101 (45)	57 (25)	27 (12)	11 (5)	11 (5)	3 (1)	14 (6)	224 (100)

(Inadequate information available for 15 women)

* Known case of breast cancer, being treated with Nolvadex

not attend for review and these women were not contacted about a new appointment. The majority may have decided not to bother the doctor unnecessarily as their condition had either resolved or they realised that it did not require treatment. 14 women (6%) were referred to hospital at their second or subsequent visit to the GP. About half of these women had been thought at their first appointment to have fibrocystic disease, but in over one-quarter the original diagnosis had been either no abnormality or a minor problem only.

The mean number of GP consultations was 1.4 per woman, with 71% women seeing the GP only once (Table 6.12). All but one of the women with the provisional diagnosis of breast cancer were referred to hospital at their first consultation, and this group had the lowest mean number of visits to the GP. Table 6.13 (columns 2-3) shows similar data for the 58 women referred to hospital, and on whom information was available. Three-quarters were referred at the time of their first attendance; women with the provisional diagnosis of no abnormality or a minor problem only were referred later, apparently often to allay anxiety which continued despite the GP's reassurance.

The time intervals between the woman (i) consulting her GP and attending the hospital out-patient department (columns 4-5) and (ii) attending the hospital out-patient department and receiving definitive treatment (column 7) are also shown. About two-thirds of women waited 2 weeks or more during each period, with some differences across the diagnostic groups, although in many cells the numbers

TABLE 6.12

MEAN NUMBER OF VISITS TO THE GP MADE BY THE WOMEN WITH EACH GP DIAGNOSIS AND THE PERCENTAGE OF WOMEN WITH 1 VISIT ONLY

Provisional GP diagnosis	Mean number of visits to GP	% women with 1 visit only
Normal (n=40)	1.2	83
Minor problem - trauma, bruising, skin problem , muscular (n=24)	1.3	79
"Hormonal" or "premenstrual" (n=17)	2.0	53
Infection (n=4)	2.3	50
Blocked duct (n=3)	1.7	67
Fibroadenoma (n=9)	1.2	78
Fibrocystic disease, fibroadenosis, mastitis, cyst (n=109)	1.4	65
Possible breast cancer (n=18)	1.1	94
Total (n=224)	1.4	71

(Inadequate information available for 15 women)

TABLE 6.13

NUMBER OF VISITS TO GP AND TIME INTERVALS IN SUBSEQUENT PROGRESS FOR WOMEN REFERRED TO HOSPITAL AND WOMEN RECEIVING DEFINITIVE TREATMENT BY PROVISIONAL GP DIAGNOSIS

	All women referred to hospital (n=58)					All women receiving definitive treatment (n=31)	
Provisional GP diagnosis	Number (%) referred to hospital	Mean number of visits to GP before referral	% Women with one visit only	Median time interval between seeing GP and hosp. O.P. appt. (weeks)	% Women where time interval 2 weeks or more	Number (%) receiving definitive treatment	% Women where time interval 2 weeks or more
	(Col. 1)	(Col. 2)	(Col. 3)	(Col. 4)	(Col. 5)	(Col. 6)	(Col. 7)
Normal	2 (5)	2.5	-	14.5	100	1	-
Minor problems - trauma, bruising, skin problems, muscular	3 (13)	1.7	33	3	100	2 (8)	100
"Hormonal" or "premenstrual"	-	-	-	-	-	-	-
Infection	-	-	-	-	-	-	-
Blocked duct	3 (100)	1.3	67	2	67	1 (33)	100
Fibroadenoma	6 (67)	1.2	83	3	67	3 (33)	33
Fibrocystic disease, fibroadenosis, mastitis, cyst	29 (27)	1.3	72	2	76	13 (12)	62
Possible breast cancer	15 (83)	1.0	100	1	40	11 (61)	73
Total	58 (26)	1.3	76	2	67	31 (14)	65

(Inadequate information available on 10 women who were referred to hospital and 5 women who received definitive treatment)

are small. Of the 15 women who were thought to have possible breast cancer, 6 waited 2 weeks or more between consulting their GP and attending the out-patient department, and 8 out of 11 waited at least another 2 weeks for definitive treatment.

6.9 CONSULTANT DIAGNOSIS

Table 6.14 shows the consultant diagnosis for the women who were referred to hospital. Over half of those referred (34) were considered to have fibrocystic disease, 15% breast cancer (10, one of whom had recurrent disease) and 12% (8)were not thought to have any breast disease. The remaining one-fifth were diagnosed as having fibroadenoma (6), a minor problem (3), histiocytoma (1), basal cell carcinoma (1), blocked duct (1) or hormonal imbalance (1). The age-distribution for each consultant diagnosis resembles that seen for the GP diagnoses. Eight women aged 55 years and over were referred to hospital; 5 (63%) were found to have breast cancer (1 recurrent) and a further 1 had a basal cell carcinoma. However, although 57 women aged 15 to 54 years were referred, only 5 (9%) were diagnosed as having breast cancer.

Table 6.15 compares the diagnoses made by the GP, usually after only one clinical examination, and by the hospital consultant who has access to a range of diagnostic facilities. There was complete agreement in 32 (57%) of the women on whom data were available. Six women, thought by the GP to have possible breast cancer, were considered by the consultant to have fibrocystic disease; however, in each case a discrete lump had been palpated by the GP, and the referral was

TABLE 6.14

NUMBERS OF WOMEN (PERCENTAGES) IN EACH AGE GROUP BY CONSULTANT DIAGNOSIS FOR THOSE WOMEN WHO WERE REFERRED TO HOSPITAL

Consultant Diagnosis	AGE GROUP								
	<15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total
Normal	-	1 (8)	1 (7)	4 (19)	2 (20)	-	-	-	8 (12)
Minor problem - trauma, bruising, skin problem, muscular	-	2 (17)	-	-	1 (10)	-	-	-	3 (5)
"Hormonal" or "pre-menstrual"	-	1 (8)	-	-	-	-	-	-	1 (2)
Blocked duct	-	-	1 (7)	-	-	-	-	-	1 (2)
Fibroadenoma	-	2 (17)	3 (21)	1 (5)	-	-	-	-	6 (9)
Fibrocystic disease, fibroadenosis, mastitis, cyst	-	6 (50)	7 (50)	16 (76)	3 (30)	1 (25)	1 (50)	-	34 (52)
Breast cancer	-	-	2 (14)	-	3 (30)	3 (75)	1 (50)	1 (50)	10 (15)
Other cancer	-	-	-	-	1 (10)	-	-	1 (50)	2 (3)
Total	-	12 (100)	14 (100)	21 (100)	10 (100)	4 (100)	2 (100)	2 (100)	65 (100)

(Inadequate information available on 3 women)

TABLE 6.15

NUMBERS OF WOMEN (PERCENTAGES) WITH EACH CONSULTANT DIAGNOSIS BY PROVISIONAL GP DIAGNOSIS FOR THOSE WOMEN REFERRED TO HOSPITAL

Provisional GP diagnosis	CONSULTANT DIAGNOSIS								
	Consultant diagnosis normal	Minor problem-trauma, bruising, skin problem, muscular	"Hormonal" or "pre-menstrual"	Blocked duct	Fibroad-enoma	Fibrocystic disease, fibroadenosis, mastitis, cyst	Breast cancer	Other cancer	Total
GP diagnosis normal	1 (50)	-	-	-	-	-	1 (50)	-	2 (100)
Minor problems - trauma, bruising, skin problem, muscular	1 (33)	1 (33)	-	-	-	-	1 (33)	-	3 (100)
Blocked duct	1 (33)	-	-	1 (33)	-	1 (33)	-	-	3 (100)
Fibroadenoma	-	1 (17)	1 (17)	-	2 (33)	2 (33)	-	-	6 (100)
Fibrocystic disease, fibroadenosis, mastitis, cyst	3 (11)	-	-	-	3 (11)	20 (71)	1 (4)	1 (4)	28 (100)
Possible breast cancer	-	-	-	-	-	6 (43)	7 (50)	1 (7)	14 (100)
Total	6 (11)	2 (4)	1 (2)	1 (2)	5 (9)	29 (52)	10 (18)	2 (4)	56 (100)

(Inadequate information available on 12 women)

therefore to exclude the possibility of cancer. Certain GP diagnoses in women who were referred to hospital appeared to be relatively unreliable. For example, only one-third of the GP diagnoses of either fibroadenoma or blocked duct were corroborated; on the other hand, there was agreement with the GP's diagnosis of fibrocystic disease in over two-thirds of cases.

The GP had provisionally diagnosed 7 out of the 10 cases of breast cancer correctly (including the one recurrence); the provisional diagnoses on the three other patients with breast cancer were fibrocystic disease (1), a possible skin condition (1) and no abnormality(1). This last woman was eventually referred after her third consultation. The one woman who was considered by both GP and consultant to have no abnormality had been referred for reassurance because of anxiety.

6.10 CONSULTANT MANAGEMENT

The results in Table 6.16 summarise the management of the patients who were referred to the hospital consultant. A total of 27 women (42%) did not receive any treatment - 16 were simply reassured, 3 were given a review appointment and 8 had a mammographic examination to exclude malignancy. All these women with the exception of one, who was considered to be too frail for the treatment of her advanced breast cancer, had either no abnormality, a minor problem, hormonal imbalance or fibrocystic disease. Various therapies, and combinations of therapies, were used for breast cancer, the choice being determined by the stage of the disease and the condition of the patient. The majority (5 out of the 7) of the women with breast cancer, who were treated by mastectomy,

TABLE 6.16

NUMBERS OF WOMEN (PERCENTAGES) WITH EACH CONSULTANT DIAGNOSIS BY CONSULTANT MANAGEMENT FOR THOSE WOMEN WHO WERE REFERRED TO HOSPITAL

	CONSULTANT DIAGNOSIS								
Consultant diagnosis	Normal	Minor problem - trauma, bruising, skin problem, muscular	"Hormonal" or "premenstrual"	Blocked duct	Fibro-adenoma	Fibrocystic disease, fibroadenosis, mastitis, cyst	Breast cancer	Other cancer	Total
o treatment, eassurance nly	3 (38)	1 (33)	1 (100)	-	-	10 (29)	1 (10)	-	16 (25)
ontinuing eview	-	-	-	-	-	3 (9)	-	-	3 (5)
yst spirated	-	-	-	-	-	4 (12)	-	-	4 (6)
yst/lump emoved	-	1 (33)	-	-	6 (100)	11 (32)	-	-	18 (28)
imple astectomy	-	-	-	-	-	-	6 (60)	1 (50)	7 (11)
imple astectomy ith adiotherapy	-	-	-	-	-	-	1 (10)	-	1 (2)
adiotherapy nly	-	-	-	-	-	-	-	1 (50)	1 (2)
adiotherapy + hemotherapy	-	-	-	-	-	-	1 (10)	-	1 (2)
amoxifen	-	-	-	-	-	-	1 (10)	-	1 (2)
romocriptine	-	-	-	-	-	2 (6)	-	-	2 (3)
ipple eversion, ryoprobe or icro-ochectomy	1 (13)	1 (33)	-	1 (100)	-	-	-	-	3 (5)
ammography exclude alignancy	4 (50)	-	-	-	-	4 (12)	-	-	8 (12)
otal	8 (100)	3 (100)	1 (100)	1 (100)	6 (100)	34 (100)	10 (100)	2 (100)	65 (100)

(Inadequate information available for 3 women)

underwent the procedure of frozen section biopsy and immediate simple mastectomy. Only one woman, with axillary node involvement, received radiotherapy at the time of the mastectomy.

When the time to treatment was analysed by the consultant diagnosis for each woman, the experiences of the various groups appeared to be similar (table 6.17). The women who were diagnosed by the consultant as having breast cancer had the least delay in achieving their definitive treatment. Despite this, 4 out of 9 were delayed for at least 2 weeks between consulting their GP and attending their out-patient appointment (columns 4-5), and 5 out of 8 did not receive their definitive treatment until 2 weeks or more after their out-patient appointment (column 7).

Post-operative follow-up was provided almost entirely by the hospital. Only 4 (7%) of the women who were referred to hospital were recorded as attending their GP subsequently - 1 woman with breast cancer, 1 with a blocked duct and 2 with fibrocystic disease. Although no data were collected on contact with other Health Centre staff, there were no formal arrangements for community nurses or health visitors to visit these patients.

6.11 WOMEN IN WHOM THE GP MADE THE PROVISIONAL DIAGNOSIS OF BREAST CANCER

The GP made a possible or definite diagnosis of breast cancer in 18 women (Table 6.18); the mean age of these women was 56 years (range 34 years to 90 years). Five women had been diagnosed previously as having breast cancer - 3 who had been treated by mastectomy presented with a recurrence

TABLE 6.17

NUMBER OF VISITS TO GP AND TIME INTERVALS IN SUBSEQUENT PROGRESS FOR WOMEN REFERRED TO HOSPITAL AND WOMEN RECEIVING DEFINITIVE TREATMENT BY CONSULTANT DIAGNOSIS

	All women referred to hospital (n=63)					All women receiving definitive treatment (n=36)	
Consultant diagnosis	Number (%) referred to hospital (Col. 1)	Mean number of visits to GP before referral (Col. 2)	% Women with one visit only (Col. 3)	Median time interval between seeing GP and hosp. O.P. appt. (weeks) (Col. 4)	% Women where time interval 2 weeks or more (Col. 5)	Number (%) receiving definitive treatment (Col. 6)	% Women where time interval 2 weeks or more (Col. 7)
Normal	7 (11)	1.4	75	2	57	1 (3)	100
Minor problems - trauma, bruising, skin problems, muscular	3 (5)	1.7	67	3	67	2 (6)	100
"Hormonal" or "premenstrual"	1 (2)	1.0	100	3	100	-	-
Blocked duct	1 (2)	1.0	100	3	100	1 (3)	100
Fibroadenoma	6 (10)	1.3	67	2.5	67	6 (17)	67
Fibrocystic disease, fibroadenosis, mastitis, cyst	34 (54)	1.4	65	2	65	16 (44)	50
Breast cancer	9 (14)	1.3	78	1	44	8 (22)	63
Other cancer	2 (3)	1.0	100	5.5	100	2 (6)	100
Total	63 (100)	1.4	69	2	63	36 (100)	64

(Inadequate information available for 5 women who were referred to hospital)

LE 6.18

OMEN IN WHOM THE GP MADE THE PROVISIONAL OR DEFINITE DIAGNOSIS OF BREAST CANCER

de ber	Age (years)	Presenting symptoms	Duration of symptoms (weeks)	Findings on GP examination	Time interval between 1st GP visit and O.P. appt. (weeks)	Time interval between O.P. appt. and definitive treatment (weeks)	Eventual diagnosis
7	49	Nipple discharge	Not known	Nipple discharge	1	No Rx	Normal
6	37	Painless lump	< 1	Lump	< 1	< 1	Fibrocystic disease
8	56	Previous mastectomy, symptoms of metastases	Not known	Spinal and skin metastases due to 1° breast cancer	Already attending hospital		Metastatic breast cancer
2	51	Painless lump	26	Lump with palpable axillary node	< 1	3	Breast cancer
3	76	Known breast cancer - on Nolvadex	-	Lump with overlying peau d'orange	Not referred		Breast cancer
)	34	Painless lump	8	Lump	< 1	< 1	Breast cancer
4	60	Painless lump	8	Lump	1	1	Breast cancer
	46	Painful lump	> 12	Lump with palpable axillary nodes	3	4	Fibrocystic disease
	74	Painful lump	8	Fixed lump, nipple retraction, skin ulceration	1	3	Breast cancer
	49	Previous mastectomy, lump in anterior axillary fold	2	Lump in anterior axillary fold	Already attending hospital		Metastatic breast cancer
	36	Painless lump	2	Lump	< 1	4	Fibrocystic disease
	40	Painless lump	2	Lump	< 1	4	Fibrocystic disease
	89	Previous mastectomy, asymptomatic	-	Lump in neck	9	4	Basal cell carcinoma
	40	Painless lump	Not known	Lump	< 1	2	Fibrocystic disease
	59	Painless lump and swelling of breast	8	Lump with palpable axillary nodes	2	2	Breast cancer
	80	Previous bilateral mastectomies - lump in axilla	Not known	Lump in axilla	Already attending hospital		Metastatic breast cancer
	49	Painful lump	2	Tender lump	3	1	Fibrocystic disease
	90	Painless lump	< 1	Lump	7	No Rx	Breast cancer

(cases 078, 177 and 248), 1 had had a mastectomy and at a routine review was found to have a basal cell carcinoma of the neck (case 206) and 1 was currently receiving Nolvadex for inoperable breast cancer (case 098).

The mean age of the 13 women without a history of breast cancer was 51 years (range 34 years to 90 years). Eight (62%) women presented with a painless lump unaccompanied by other symptoms - the "classic" symptom of breast cancer. One (8%) had a painless lump accompanied by swelling of the breast, 3 (23%) had a painful lump and 1 (8%) complained of discharge from the nipple. Although all 13 women were considered by the GP to have a moderately high probability of breast cancer, the response of the GP, as well as of the women themselves, appeared to be influenced by the nature of the symptoms. The 8 women with a painless lump had a median delay of less than 1 week between seeing their GP and attending the hospital out-patient department; they had been symptomatic for a median length of time of 2 weeks before seeing their GP. The 5 women with less characteristic symptoms waited for a median period of 2 weeks between their first GP consultation and out-patient appointment; they had had symptoms for a median length of time of 8 weeks before first consulting their GP. The median delay between the out-patient appointment and definitive treatment was 2 weeks, with no differences between the groups. Delays were not related to the age of the woman.

The provisional diagnosis of new breast cancer was confirmed in 6 (46%) of the 13 women. Of these, two-thirds (4 women) had the classical painless lump, one woman had

swelling of the breast associated with a painless lump, and the sixth woman had a painful lump. Their mean age was 61 years (range 34 years to 90 years). A further 6 (46%) of the 13 women were diagnosed as having fibrocystic disease. The symptoms were a painless lump in 4 women, and a painful lump in the other 2 women and their mean age was 41 years (range 36 years to 49 years). The remaining woman, who complained of nipple discharge, was not considered by the consultant to have any abnormality.

In summary, on the basis of the symptoms and signs, it was possible for the GP to differentiate only approximately between benign and malignant breast disease. The progress of women from first noting the symptom to obtaining definitive treatment was influenced by the nature of the presenting symptom - both the women and their GPs acted more quickly if this was a painless lump. However, one-third of the women who did prove to have breast cancer had atypical symptoms, and only half the women with a painless lump had the diagnosis of breast cancer confirmed.

6.12 WOMEN IN WHOM THE CONSULTANT MADE THE DEFINITIVE DIAGNOSIS OF BREAST CANCER

The definitive diagnosis of breast cancer was made in 13 women (Table 6.19). In 3 women the disease was recurrent (cases 078, 177 and 248) and a fourth woman (case 098) was undergoing treatment with Nolvadex for inoperable breast cancer. Breast cancer was diagnosed by the hospital consultant for the first time in 9 women, with a mean age of 56 years (range 32 years to 90 years). Five women (56%) presented with a painless lump; the other

WOMEN IN WHOM THE CONSULTANT MADE THE DEFINITIVE DIAGNOSIS OF BREAST CANCER

Code number	Age (years)	Presenting symptoms	Duration of symptoms (weeks)	Findings on GP examination	Time interval between 1st GP visit and O.P. appt.	Time interval between O.P.appt. and definitive treatment	GP diagnosis	Eventual diagnosis
030	32	Painless lump	> 12	Lump	< 1	35	Probable cystic fibroadenosis	Breast cancer
078	56	Previous mastectomy, symptoms of metastases	Not known	Spinal and skin metastases due to 1° breast cancer	Already attending hospital - re-referred		Metastatic breast cancer	Metastatic breast cancer
092	51	Painless lump	26	Lump with palpable axillary nodes	< 1	3	Breast cancer	Breast cancer
098	76	Known breast cancer - on Nolvadex	-	Lump with overlying peau d'orange	Not referred		Breast cancer	Breast cancer
149	53	Inflammation of skin over breast	< 1	Erythema of lower breast	5	2	? skin condition	Breast cancer
150	34	Painless lump	8	Lump	< 1	< 1	?Breast cancer	Breast cancer
158	60	Painless lump	8	Lump	1	1	Breast cancer until proved otherwise	Breast cancer
165	74	Painful lump	8	Fixed lump, nipple retraction, skin ulceration	1	3	Breast cancer	Breast cancer
177	49	Previous mastectomy, lump in anterior axillary fold	2	Lump in anterior axillary fold	Already attending hospital		Metastatic breast cancer	Metastatic breast cancer
233	59	Painless lump and swelling of breast	8	Lump with palpable axillary nodes	2	2	Probable breast cancer	Breast cancer
248	80	Previous bilateral mastectomies - lump in axilla	Not known	Lump in axilla	Already attending hospital		Anaplastic carcinoma	Metastatic breast cancer
272	50	Enlarged breast	4	Nil	78	< 1	Normal	Breast cancer
275	90	Painless lump	< 1	Lump	7	No Rx	Probable breast cancer	Breast cancer

symptoms were a painful lump (1), a painless lump accompanied by swelling of the breast (1), inflammation of the skin over one breast (1), and an enlarged breast (1).

The GP had made the provisional diagnosis of breast cancer in two-thirds of the women (6 out of 9). The case histories of the other three women are summarised below:-

Case 030

32 year old woman with a painless lump, noted more than 3 months before she consulted the GP. The provisional diagnosis was "probable cystic fibroadenosis" but she was referred to a hospital outside the Oxford Region for a consultant opinion, and seen in less than 1 week. Two needle biopsies and a mammogram were performed over a period of 6 months, with inconclusive results. She was finally admitted for an open biopsy, which showed an infiltrating duct cancer, and treated by simple mastectomy.

Case 149

53 year old woman who had developed erythema on the lower half of her right breast in the week before consulting her GP. The diagnosis was "? skin condition" and she was reassured; no follow-up appointment was made. Two weeks later, after attending one of the educational sessions, the patient made another appointment to see the GP. She was referred to the dermatologist and thence to the surgeon, where a mammogram indicated a malignant lesion. Frozen section biopsy and simple mastectomy were performed.

Case 272

50 year old woman who had noticed that her left breast was enlarged 4 weeks before consulting the GP. No abnormality was found and she was reassured; no follow-up appointment was made. The enlargement persisted and she returned 12 months later (again she was reassured), and a further 6 months later. At this third visit she was referred to the surgeon and proceeded to frozen section biopsy and simple mastectomy within 1 week.

These 3 women illustrate the difficulties for the GP in discriminating between benign and malignant disease. The first woman was relatively young to have breast cancer, although here it was the hospital not the GP which had a low index of suspicion. The other 2 women presented unusually; in neither case was a lump, painless or otherwise, palpable. If all breast cancer is to be diagnosed as early as possible, then the process of differential diagnosis of breast disease must be considerably developed. A wider range of symptoms must be seen as potential indicators of breast cancer, and a higher rate of referral for hospital investigations and a consultant opinion may be necessary.

6.13 THE EFFECT OF THE HEALTH EDUCATION PROGRAMME

The primary purpose in analysing the GP workload was to detect any effects of the programme to promote BSE. Concern that the educational programme might create unnecessary, and possibly even harmful, anxiety was reinforced in preliminary discussions about the project. It was hypothesised that an increase in anxiety might be manifested by increased numbers of consultations. As well as monitoring

the quantity and quality of consultations, the GPs were asked to record specifically any instances of anxiety which they considered to be either unreasonable, or detrimental to the woman's well-being.

The data on GP workload were divided into three 6 month periods - before, during and after the educational programme - and summarised in Tables 6.20 (by GP diagnosis) and 6.21 (by consultant diagnosis, for those women who were referred to hospital). More women both consulted their GP and were referred to hospital during the 6 months of the educational programme, with relatively fewer after than before. The main increase in GP consultations during the programme was accounted for by women with the diagnoses of either a minor problem or possible breast cancer. After the programme there was a decreased number of diagnoses of either no abnormality, a minor problem or hormonal problems. During the programme increased numbers of women with the eventual diagnosis of a minor problem and breast cancer were also referred to hospital.

Comparison of the GP consultations during the 3 periods reveals several qualitative differences, although none of these achieves statistical significance. The diagnosis of possible breast cancer was made most often during the programme. A definitive diagnosis of new breast cancer was made for 6 women during the programme, compared to 1 before, and 2 afterwards. However, as the data in the previous section show, the majority of women who presented with breast cancer, including those who presented during the programme, had delayed more than 2 weeks between noting a symptom and consulting their GP. There was no evidence

TABLE 6.20

NUMBERS OF WOMEN (PERCENTAGES) WITH EACH PROVISIONAL DIAGNOSIS REACHED BY GP AT FIRST CONSULTATION BEFORE, DURING AND AFTER THE EDUCATION PROGRAMME

Provisional GP Diagnosis	Before Programme (1/4/78-30/9/78)	During Programme (1/10/78-31/3/79)	After Programme (1/4/79-30/9/79)	Total
Normal	17 (43)	18 (45)	5 (13)	40 (100)
Minor problem - trauma, bruising, skin problem, muscular	6 (25)	15 (63)	3 (13)	24 (100)
"Hormonal" or "premenstrual"	7 (41)	7 (41)	3 (18)	17 (100)
Infection	2 (50)	1 (25)	1 (25)	4 (100)
Blocked duct	-	2 (67)	1 (33)	3 (100)
Fibroadenoma	2 (22)	3 (33)	4 (44)	9 (100)
Fibrocystic disease, fibroadenosis, mastitis, cyst	42 (39)	37 (34)	30 (28)	109 (100)
Possible breast cancer	3 (17)	10 (56)	5 (28)	18 (100)
Total	79 (35)	93 (42)	52 (23)	224 (100)

(Inadequate information available for 15 women, 3 first attended before, 5 during and 7 after the programme)

TABLE 6.21

NUMBERS OF WOMEN (PERCENTAGES) WITH EACH CONSULTANT DIAGNOSIS MADE BEFORE, DURING AND AFTER THE EDUCATION PROGRAMME

Consultant Diagnosis	Before Programme (1/4/78-30/9/78)	During Programme (1/10/78-31/3/79)	After Programme (1/4/79-30/9/79)	Total
Normal	3 (38)	4 (50)	1 (13)	8 (100)
Minor problem - trauma, bruising, skin problem, muscular	-	3 (100)	-	3 (100)
"Hormonal" or "pre-menstrual"	-	-	1 (100)	1 (100)
Blocked duct	-	1 (100)	-	1 (100)
Fibroadenoma	3 (50)	1 (17)	2 (33)	6 (100)
Fibrocystic disease, fibroadenosis, mastitis, cyst	7 (21)	14 (41)	13 (38)	34 (100)
Breast cancer	2* (20)	6 (60)	2 (20)	10 (100)
Other cancer	-	1 (50)	1 (50)	2 (100)
Total	15 (23)	30 (46)	20 (31)	65 (100)

(Inadequate information available on 3 women)

* 1 recurrent case of breast cancer

that the programme reduced this delay, although this had been one explicit objective; only one woman stated that she had consulted because of attending a talk - she had re-attended the GP because her symptoms had not resolved (case 149).

The decline in the total number of consultations recorded after the programme was probably due to the diminishing enthusiasm of the GPs for completing the survey forms. The reduction was evident predominantly among women diagnosed as having the relatively less serious conditions, or in whom no abnormality was found. There was no fall in hospital referrals during this period. Thus, it may be concluded that, in terms of diagnosed breast disease, the workload was similar to that before the programme; if allowance is made for less complete data-collection, then the overall workload may also have been comparable.

The numbers of women consulting their GP, or being referred to hospital, with a relatively less significant diagnosis were also considered. As there was some doubt about the complete ascertainment of data during the 6 months after the programme, comparisons were made between the numbers consulting before and during. There were no statistically significant differences between the numbers of women with no abnormality, minor problems or hormonal problems, although there were rather more of the second category seen during the campaign. Women with these diagnoses were more likely to be referred to hospital during the programme (7 compared to 3 before), but again these differences were not statistically significant. Although

fewer women were diagnosed in general practice as having fibrocystic disease during the campaign, the consultant made this diagnosis twice as often in those referred to hospital.

In summary there is some slight evidence of an increased GP consultation rate with minor problems during the programme, but this is not statistically significant. There is also some indication of a change in GP behaviour, with a higher proportion of women being referred to hospital (32% during the programme, 19% before the programme), and with greater numbers diagnosed by the consultant as having minor problems, fibrocystic disease, or breast cancer, although no differences are statistically significant. The increased consultation rate during the programme might be either a result of the education, which encouraged women to see the doctor if they were worried, or a sign of anxiety.

However, there was only one anecdotal report of what was considered by the GP to be unreasonable anxiety. One woman aged 52 years consulted the GP during the 6 months before the campaign complaining of puckering around one nipple. She was reassured, but returned twice during the next week, consulting two different GPs. She was referred for a consultant opinion, although neither GP considered that she had any abnormality, and mammography was reported as normal. She attributed her anxiety to an article which she had read in a Sunday newspaper; this discussed breast cancer and described the techniques of screening and BSE. There were no other reports of unreasonable anxiety among women consulting their GP.

It is difficult to reach firm conclusions about whether

the programme induced anxiety. If it did, then this anxiety was not apparently demonstrated by an increase in consultations with insignificant symptoms or by overtly anxious women. However, anxiety may also be manifested by delay, and the proportions of women waiting longer than 1 week or 1 month before seeing the GP remained constant. The programme did not, though, seem to result,as had been feared, in unduly anxious women.

C H A P T E R 7

The beliefs, attitudes and behaviour of the population regarding breast disease and breast self-examination

INTRODUCTION

Population data on a random sample of women were collected both before and after the educational programme to measure its effectiveness. The evaluation was based on:

... the penetration of the programme - the proportion of women who had heard about the programme, from which source(s) had they heard and whether they had had any direct contact with the programme

... the extent to which the desired changes in knowledge and attitudes about breast disease and breast self-examination (BSE) had been achieved

... the attitudes of the women to the programme.

Postal questionnaires were sent to a random sample of 600 women before and after the programme, at an interval of approximately 12 months. The responses are shown in Table 7.1. A maximum of three mailings were sent, and no further attempt was made to contact the women. The response rate was 84% (505) to the pre-programme questionnaire and 72% (432) to the post-programme questionnaire; 69% (414) of the sample returned both questionnaires completed. Although the sample was drawn from the age-sex registers in the Health Centre, 5% of the questionnaires were returned marked "Gone Away". The true responses might therefore be considered to be 86% (pre-programme), 76% (post-programme) and 73% (both).

7.1 PRE- AND POST-PROGRAMME COMPARISONS

The comparisons between the data in the pre-programme and post-programme questionnaires are based on those 414

TABLE 7.1

NUMBERS OF WOMEN (PERCENTAGES) WHO RESPONDED TO THE POSTAL QUESTIONNAIRES SENT BEFORE AND AFTER THE EDUCATIONAL PROGRAMME

	Questionnaire before educational programme	Questionnaire after educational programme
Replied to 1st mailing	333 (56)	303 (51)
Replied to 2nd mailing	65 (11)	79 (13)
Replied to 3rd mailing	16 (3)	32 (5)
Overall response to both questionnaires	414 (69)	414 (69)
Total response to each questionnaire	505 (84)	432 (72)
Maximum number of questionnaires known to have been received	570* (95)	570 (95)
Total questionnaires sent	600 (100)	570 (95)

* 30 questionnaires were returned marked "Gone Away" and follow-up questionnaires were not therefore sent

women who returned both questionnaires. This was to eliminate any bias which might result from inherent differences between the group of 505 women who returned the pre-programme questionnaire and the group of 432 women who returned the post-programme questionnaire. The reduced response rate might reflect, for example, the greater interest of the latter group in BSE, or a different set of attitudes to breast cancer; such variations might have invalidated any comparisons.

However, limiting the analysis to only 414 pairs of questionnaires might, as a result of excluding 91 pre-programme and 18 post-programme questionnaires, introduce new biasses. This possibility was examined by comparing the complete data sets (505 pre- and 432 post-programme questionnaires) with the 414 pre- and post-programme questionnaires respectively. No statistically significant differences were found, and this potential bias was not therefore considered to be realised.

One further potential source of bias in evaluating the health education programme lay in the possible effects of the questionnaire itself. A post-programme questionnaire was therefore sent to a further random sample of 600 women aged 15-64 years, selected in the same way as the first sample. Similar data were collected from these women, so that comparisons could be made of the effect of the programme on women who had (first sample) or had not (second sample) received a pre-programme questionnaire.

A total of 437 of the 600 women in the second sample replied after receiving a maximum of three mailings. These

women were compared with the 432 women in the first sample, who replied to the post-programme questionnaire. Some differences were found between the two groups. For example, women in the first group were more likely to describe themselves as in excellent or good health (80% v. 74%, χ^2= 4.31, $p<0.05$, 1 d.f.) and less likely to report having visited their GP during the previous 12 months (79% v. 87%,χ^2= 10.31, $p<0.01$, 1 d.f.). Of the first group, 19% described themselves as housewives, compared to 12% of the second group (χ^2= 9.53, $p<0.01$, 1 d.f.). When classified on the basis of their partner's occupation, women in the first group were more likely to be defined as middle class (Social Classes I,II and III non-manual - 35% compared to 31%, N.S.) and considerably less likely to be Social Class IV (18% compared to 28%, χ^2= 8.83, $p <0.01$, 1 d.f.).

However, no further differences were found, and these may merely be chance findings. In particular there were no differences in knowledge of, attitudes to or behaviour about breast disease and BSE; both groups had had similar exposure to, and formed similar views of, the educational programme. It seemed, therefore, that the initial questionnaire had not influenced the women's response to the programme.

7.2 PRE-PROGRAMME DATA

The data obtained from the pre-programme questionnaire reflect the health experiences, knowledge, attitudes and behaviour of a population of women aged 15-64 years, who had not been exposed to any specific educational programmes

about breast diseases or BSE. They provided the basis on which the educational programme was designed, and against which its effectiveness was measured. The data presented refer to only the 414 women who completed both questionnaires, in order that comparisons can be made with the post-programme data (see Section 7.3).

7.2.1 CHARACTERISTICS OF THE WOMEN

The sample was selected by stratification into 5 year age groups and the data in Table 7.2 show that the response rates were maintained across the age-groups. 80% women stated that they were currently married, 8% had been previously married and 12% had never married (Table 7.3).

Table 7.4 shows that 83% women had completed their full-time education at or before the age of 16 years, and a further 9% at the age of 17 or 18 years. Only 6% had continued in higher education; 2% were still in full-time education (all still at school). This relatively low educational status is reflected in the social class of the women, whether defined by their own occupation (Table 7.5) or that of their husband (Table 7.6). Almost two-thirds of the women who were in employment were classified as social class III (45% non-manual, 20% manual and a further 22% were classified as social class IV. When defined on the basis of their partner's occupation, over half were classified as social class III (14% non-manual and 43% manual) and 19% social class IV. 22% women were defined as social class I and II based on their partner's occupation; only 13% on the basis of their own. This social class

TABLE 7.2

PRE-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) IN EACH AGE GROUP

Age Group (years)	Number of women (Percentage)
15-19	35 (8)
20-24	47 (11)
25-29	33 (8)
30-34	43 (10)
35-39	39 (9)
40-44	49 (12)
45-49	34 (8)
50-54	42 (10)
55-59	50 (12)
60-65	42 (10)
Total	414 (100)

TABLE 7.3

PRE-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY MARITAL STATUS

Marital status	Number of women
Never married	51 (12)
Currently married	329 (80)
Previously married	34 (8)
Total	414 (100)

TABLE 7.4

PRE-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY EDUCATIONAL STATUS

Age at completing full time education	Number of women	
16 years or less	342	(83)
17-18 years	37	(9)
19 years or more	23	(6)
Still in full time education	8	(2)
Total	410	(100)

(Inadequate information available on 4 women)

TABLE 7.5

PRE-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY SOCIAL CLASS, DEFINED ON HER OWN OCCUPATION

Social Class, Defined on the Woman's Own Occupation	Number of Women
I	2 (1)
II	40 (12)
III non-manual	150 (45)
III manual	68 (20)
IV	72 (22)
V	1 (<1)
Total classifiable	333 (100)
Women not in paid employment	76

(Inadequate information available on 5 women)

TABLE 7.6

PRE-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY SOCIAL CLASS, DEFINED ON HUSBAND'S OR COHABITEE'S OCCUPATION

Social class, defined on husband's or cohabitee's occupation	Number of women
I	16 (5)
II	58 (17)
III non-manual	48 (14)
III manual	148 (43)
IV	64 (19)
V	7 (2)
Total classifiable	341 (100)
Not currently married or cohabiting	49
Married or cohabiting, but partner not in paid employment	8

(Inadequate information available on 16 women)

distribution was as expected for Daventry. The majority of employed women work in clerical jobs, or in skilled or semi-skilled factory jobs. The men also provide skilled and semi-skilled factory labour, but a higher proportion have professional or managerial jobs. Only one-fifth of the women did not report that they were in paid employment.

7.2.2 PREVIOUS HEALTH

Four-fifths of the women defined their health as excellent or good, 18% as fair and 1% (6 women) as poor (Table 7.7). 13% women reported that they had had a significant adult acute illness, 5% a serious childhood illness, 5% a significant adult chronic illness, only 1% a psychological illness and 1% a serious accident (Table 7.8). About one-third said that they had had some breast problem(s). Difficulties with breast feeding were most common (12%); 10% reported breast pain, 6% a breast abscess, 2% mastitis and 2% premenstrual breast problems. 7% women stated that they had had a breast lump.

7.2.3 KNOWLEDGE AND PRACTICE OF BSE

Table 7.9 shows the knowledge of BSE among the 414 women and the sources of their knowledge before the educational programme. Overall 87% said that they had heard of BSE, with no statistically significant variations across the age-groups. The most common source of information was the media, defined as television, radio, newspapers and magazines; over two-thirds of women reported that they had heard about BSE through the media. A further 10% said they had heard from a friend or relative. A total of only 20% women had heard from a health professional -

TABLE 7.7

PRE-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY SELF-DEFINED HEALTH STATUS

Self-Defined Health Status	Number of Women
Excellent health	64 (16)
Good health	269 (65)
Fair health	75 (18)
Poor health	6 (1)
Total	414 (100)

TABLE 7.8

PRE-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) IN EACH AGE GROUP BY PREVIOUS HEALTH, WITH PARTICULAR REFERENCE TO BREAST PROBLEMS

Previous health	Age Group					
	15-24	25-34	35-44	45-54	55-64	Total
Serious childhood illness	4 (5)	-	2 (2)	5 (7)	9 (10)	20 (5)
Significant adult acute illness	5 (6)	7 (9)	9 (10)	13 (17)	18 (20)	52 (13)
Significant adult chronic illness	1 (1)	-	5 (6)	3 (4)	13 (14)	22 (5)
Psychological illness	-	-	1 (1)	-	2 (2)	3 (1)
Serious accident	-	-	1 (1)	1 (1)	3 (3)	5 (1)
Total breast problems	17 (21)	32 (42)	36 (41)	26 (35)	21 (24)	132 (32)
- difficulties with breast feeding	1 (1)	11 (14)	14 (16)	12 (16)	10 (11)	48 (12)
- breast pain	10 (12)	12 (16)	12 (14)	5 (7)	3 (3)	42 (10)
- breast lump	3 (4)	7 (9)	8 (9)	7 (9)	3 (3)	28 (7)
- breast abscess	1 (1)	2 (3)	6 (7)	8 (11)	7 (8)	24 (6)
- mastitis	1 (1)	3 (4)	3 (3)	2 (3)	1 (1)	10 (2)
- premenstrual breast problems	-	3 (4)	3 (3)	3 (4)	-	9 (2)

(Inadequate information available for 5 women)

TABLE 7.9

PRE-PROGRAMME DATA: NUMBER OF WOMEN (PERCENTAGES) IN EACH AGE GROUP BY KNOWLEDGE OF BSE AND SOURCE OF KNOWLEDGE

	Age Group					
	15-24	25-34	35-44	45-54	55-64	Total
Total women who said that they had heard of BSE	65 (79)	72 (95)	80 (91)	63 (83)	76 (83)	356 (87)
- from GP	2 (2)	4 (5)	8 (9)	9 (12)	6 (7)	29 (7)
- from doctor in cervical cytology clinic	-	2 (3)	8 (9)	8 (11)	9 (10)	27 (7)
- from doctor in family planning clinic	3 (4)	4 (5)	-	-	-	7 (2)
- from nurse or health visitor	4 (5)	6 (8)	3 (3)	2 (3)	3 (3)	18 (4)
- from hospital	-	1 (1)	-	2 (3)	-	3 (1)
- from friend or relative	11 (13)	10 (13)	5 (6)	4 (5)	12 (13)	42 (10)
- from media (television, radio, magazines, newspapers)	51 (62)	50 (66)	66 (76)	42 (55)	53 (60)	262 (64)

(Inadequate information available for 4 women)

the most common sources being the GP (7%), the doctor in the cervical cytology clinic (7%), and the nurse or health visitor (4%). The variations by age probably reflect age-specific variations in exposure to each aspect of health care - for example, younger women are more likely to have heard about BSE from a family planning clinic doctor and older women from a cervical cytology clinic doctor. Ever-married women, middle class women and those who had stayed in education beyond 16 years were more likely to know of BSE, but the differences were not statistically significant.

Although 87% women said that they had heard of BSE, only 15% stated that they had been taught how to practise it (Table 7.10). The main source of teaching was the GP (5%), the cervical cytology clinic doctor (3%) and the nurse or health visitor (3%). Eight women (2%) said that they had been taught by a friend or relative. There were no differences by age, marital status, educational status or social class.

The practice of BSE is reported in Table 7.11. Overall one-third of women said that they never practised BSE, one-quarter that they practised only occasionally, and one-quarter that they practised several times each year. One-sixth of women (54) said that they practised BSE regularly once each month, and a further one-tenth that they practised BSE more frequently than once per month. The proportion of women practising regular monthly BSE was highest in those aged 25-44 years (18%), falling to 6% in those aged 55-64 years. Although only 13% women overall practised monthly BSE, one-third of those who gave the GP as a source of

TABLE 7.10

PRE-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) IN EACH AGE GROUP BY RECEIVED TEACHING OF BSE AND SOURCE OF TEACHING

	Age Group					
	15-24	25-34	35-44	45-54	55-64	Total
Total women who said that they had been taught how to do BSE	4 (5)	17 (22)	12 (14)	15 (20)	12 (13)	60 (15)
- by GP	-	8 (11)	4 (5)	8 (11)	2 (2)	22 (5)
- by doctor in cervical cytology clinic	-	2 (3)	6 (7)	4 (5)	2 (2)	14 (3)
- by doctor in family planning clinic	1 (1)	3 (4)	-	-	-	4 (1)
- by nurse or health visitor	1 (1)	4 (5)	2 (2)	2 (3)	2 (2)	11 (3)
- by hospital	-	1 (1)	-	-	1 (1)	2 (<1)
- by friend or relative	2 (2)	-	-	1 (1)	5 (6)	8 (2)

(Inadequate information available for 4 women)

TABLE 7.11

PRE-PROGRAMME DATA: NUMBER OF WOMEN (PERCENTAGES) IN EACH AGE GROUP BY FREQUENCY OF BSE PRACTICE

Frequency of BSE Practice	Age group					
	15-24	25-34	35-44	45-54	55-64	Total
Never	33 (41)	19 (26)	23 (27)	22 (29)	30 (33)	127 (31)
Occasionally (once each year or less often)	18 (23)	17 (23)	16 (19)	19 (25)	23 (26)	93 (23)
Several times each year	14 (18)	23 (31)	21 (24)	16 (21)	21 (23)	95 (23)
Once each month	9 (11)	13 (18)	16 (19)	11 (15)	5 (6)	54 (13)
More often than once each month	6 (8)	2 (3)	10 (12)	7 (9)	11 (12)	36 (9)
Total	80 (100)	74 (100)	86 (100)	75 (100)	90 (100)	405 (100)

(Inadequate information available for 9 women)

information said that they performed BSE regularly each month (9 out of the 29 women). Again middle class women and those who were or had been married were more likely to practise BSE regularly; but the differences were not statistically significant.

Women who said that they had been taught BSE were also more likely to report practising it on a regular monthly basis (Table 7.12). Only 5% women who had been taught never practised BSE, compared with 36% of those who said they had not been taught. 28% of the taught group, but only 11% of the untaught group, reported monthly BSE (χ^2= 11.89, $p<0.001$, 1 d.f.). Of those who said they never practised BSE, only 2% had been taught; of those who reported the practice of BSE monthly, 31% had been taught. The most effective teacher appeared to be the GP - 8 (36%) of the 22 women who reported teaching by the GP said that they carried out BSE on a regular monthly basis.

Only 4% women reported that their BSE technique had ever been checked by a health professional. However, although the numbers are therefore small, such checking does seem to be positively associated with the practice of BSE (Table 7.13). One-third of the women who had been checked (6 out of the 17) said that they practised BSE monthly, compared to 19% of those who had not been checked. The teaching and checking of BSE was not associated with the individual characteristics of the women.

The practice of BSE was also found to be associated with another preventive health measure - screening for cancer of the cervix (Table 7.14). Only one half of the women who

TABLE 7.12

PRE-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY FREQUENCY OF BSE PRACTICE AND WHETHER BSE TAUGHT

Frequency of BSE practice	Taught BSE	Not taught BSE
Never	3 (5)	124 (36)
Occasionally (once ear year or less often)	10 (17)	83 (24)
Several times each year	21 (35)	74 (21)
Once each month	17 (28)	37 (11)
More often than once each month	9 (15)	27 (8)
Total	60 (100)	345 (100)

(Inadequate information available for 9 women)

TABLE 7.13

PRE-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY FREQUENCY OF BSE PRACTICE AND WHETHER BSE TECHNIQUE CHECKED

Frequency of BSE practice	BSE technique checked by health professional	Practice BSE - technique never checked by health professional	Never practise BSE	Total
Never	1 (6)	-	125 (100)	126 (32)
Occasionally (once each year or less often)	4 (24)	86 (34)	-	90 (23)
Several times each year	3 (18)	90 (35)	-	93 (24)
Once each month	6 (35)	48 (19)	-	54 (14)
More often than once each month	3 (18)	30 (12)	-	33 (8)
Total	17 (100)	254 (100)	125 (100)	396 (100)

(Inadequate information available for 18 women)

TABLE 7.14

PRE-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY FREQUENCY OF BSE PRACTICE AND UPTAKE OF CERVICAL CYTOLOGY SERVICES

Frequency of BSE practice	Cervical smear within last 3 years	Cervical smear over 3 years ago	Never had cervical smear	Total
Never	44 (25)	28 (25)	55 (48)	127 (31)
Occasionally (once each year or less often)	43 (24)	27 (25)	22 (19)	92 (23)
Several times each year	40 (22)	34 (31)	21 (18)	95 (24)
Once each month	33 (18)	13 (12)	8 (7)	54 (13)
More often than once each month	19 (11)	8 (7)	9 (8)	36 (9)
Total	179 (100)	110 (100)	115 (100)	404 (100)

(Inadequate information available for 10 women)

had never had a cervical smear reported that they practised BSE, compared with three-quarters of those who had had a smear. When those women who had had cervical cytology were divided into two groups - those who had had a smear within the last three years and those whose most recent smear had been taken more than 3 years ago - the reported timing was related to the regular practice of BSE. Only 7% women who had never had a cervical smear taken practised monthly BSE, compared with 12% of those whose latest smear was taken more than 3 years ago and 18% of the women who reported more recent cervical cytology (χ^2= 7.17, $p<0.05$, 2 d.f.). This could reflect either the opportunities taken in cervical cytology clinics to discuss and teach BSE, or the fact that the practice of one type of screening is associated with the practice of another. Cervical cytology was reported statistically significantly more frequently in middle class women; young women, many of whom were unmarried, and women who left full-time education at or before 16 years were less likely to have had cervical cytology.

It was postulated that a woman's awareness of BSE might be increased by the experience of breast disease in a relative or close friend (Table 7.15). Women who reported this direct experience of breast cancer were much more likely to practise BSE (χ^2 for trend = 10.85, $p<0.001$, 1 d.f.); women with a history of benign breast disease in a relative or close friend seemed to be more likely to practise BSE, but the association was not statistically significant.

The reported prevalences of breast cancer (36%) and other breast disease (15%) in a relative or close friend

TABLE 7.15

PRE-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY FREQUENCY OF BSE PRACTICE AND WHETHER THERE WAS A RELATIVE OR CLOSE FRIEND WITH BREAST CANCER OR BREAST DISEASE

Frequency of BSE practice	Relative or close friend with breast cancer		Relative or close friend with other breast disease	
	Yes	No	Yes	No
Never	26 (20)	85 (37)	13 (24)	98 (32)
Occasionally (once each year or less often)	29 (23)	48 (21)	10 (19)	67 (22)
Several times each year	36 (28)	52 (23)	14 (26)	74 (25)
Once each month	22 (17)	27 (12)	11 (20)	38 (13)
More often than once each month	15 (12)	16 (7)	6 (11)	25 (8)
Total	128 (100)	228 (100)	54 (100)	302 (100)

(Inadequate information available for 58 women)

contrast with the data presented in Chapter 6, where only about 1 in 20 of the women consulting their GP with breast symptoms had malignant disease. Unlike breast cancer, which usually involves hospital admission and mastectomy and would be difficult to conceal from friends and relatives, much of this benign disease is never discussed.

7.2.4 BELIEFS ABOUT AND ATTITUDES TO BREAST DISEASE

Beliefs about and attitudes to breast cancer were assessed by means of several questions relating to the likely explanation of a lump in the breast, the action which should be taken about a breast lump, the chances of curing breast cancer, the influence of early treatment on cure and possible explanations of why women with breast symptoms delay in consulting their doctor.

... The replies to the question about the cause of a breast lump are shown in Table 7.16. Whilst 28% women thought that the lump was more likely to be something other than cancer, 34% thought it more likely to be and 2% almost certainly cancer. 35% replied that they would not know what to think. The women who practised BSE each month were relatively optimistic; although the numbers are very small, there is an indication that the women who said that they practised BSE more than once each month were relatively pessimistic.

... When asked what action the woman with a lump in her breast should take, 96% women replied that she should see her GP immediately. Three women (1%) thought she should talk it over with friends and relatives and 12 women (3%)

TABLE 7.16

PRE-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY FREQUENCY OF BSE PRACTICE AND REPLIES TO THE QUESTION - "If someone came to you and said she had found a lump in her breast, what would you think about it?"

Frequency of BSE practice	"Almost certainly breast cancer"	"More likely to be cancer than anything else"	"More likely to be something other than cancer"	"Would not know what to think"	Total
Never	5 (4)	36 (29)	31 (25)	51 (41)	123 (100)
Occasionally (once each year or less often)	-	33 (37)	26 (29)	30 (34)	89 (100)
Several times each year	-	36 (40)	27 (30)	28 (31)	91 (100)
Once each month	1 (2)	13 (25)	18 (35)	19 (37)	51 (100)
More often than once each month	2 (6)	15 (45)	7 (21)	9 (27)	33 (100)
Total	8 (2)	133 (34)	109 (28)	137 (35)	387 (100)

(Inadequate information available for 27 women)

did not know what she should do. No women replied that she should "forget about it" or "wait and see if it changed".

... Most women thought that breast cancer is either sometimes cured (59%) or usually cured (33%) (Table 7.17). 1% (6 women) thought it was never cured and 1% (3 women) thought it was always cured; 6% (25 women) did not reply to this question. No association was found between the beliefs about cure and the practice of BSE.

... Most women (96%) thought that the prognosis of a woman with breast cancer was improved by early treatment. 1% (6 women) did not, and 2% (10 women) did not reply.

... An open-ended question asking for possible explanations of delay on the part of the woman with breast symptoms was included. Half the women gave fear of cancer, and one-fifth fear of mutilation as possible explanations (Table 7.18). Fear of hospitals, rejection by partner, death, disease and pain were also suggested. One-fifth of women thought that embarrassment might be an important factor. Other explanations included the possibility that the lump might go away (13%), denial of the importance of the symptoms (12%) or ignorance of their importance (11%). Smaller numbers pointed out that women would not want to be thought neurotic (3%), would not want to bother their doctor (3%) or might have difficulty in seeing the doctor (health centre inaccessible (2%) or woman herself too busy (2%)).

The explanations for delay varied with such factors as age, marital status, educational status and social class. Younger women and unmarried women provided more explanations

TABLE 7.17

PRE-PROGRAMME DATA : NUMBERS OF WOMEN (PERCENTAGES) BY FREQUENCY OF BSE PRACTICE AND REPLIES TO THE QUESTION - "WHAT DO YOU THINK ARE THE CHANCES OF CURING SOMEONE WHO HAS BREAST CANCER?"

Frequency of BSE practice	"Breast cancer is always cured"	"Breast cancer is usually cured"	"Breast cancer is sometimes cured"	"Breast cancer is never cured"	Total
Never	-	35 (29)	85 (70)	2 (2)	122 (100)
Occasionally (once each year or less often	-	34 (38)	55 (62)	-	89 (100)
Several times each year	-	37 (40)	55 (59)	1 (1)	93 (100)
Once each month	2 (4)	18 (35)	32 (62)	-	52 (100)
More often than once each month	1 (3)	11 (33)	18 (55)	3 (9)	33 (100)
Total	3 (1)	135 (35)	245 (63)	6 (2)	389 (100)

(Inadequate information available for 25 women)

TABLE 7.18

PRE-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) RESPONDING TO THE QUESTION - "Lastly, we know that some women who discover something wrong with their breast put off seeking medical help. Could you write below any of the reasons why you think this might happen."

Responses	Number of women
Fear of cancer	207 (50)
mutilation	80 (19)
hospitals	44 (11)
rejection by partner	31 (8)
death	23 (6)
disease	10 (2)
pain	1 (<1)
Fear unspecified	111 (27)
Embarrassment	80 (19)
Lump may go away	52 (13)
Denial of importance of symptoms	48 (12)
Ignorance of importance of symptoms	47 (11)
Don't want to be thought neurotic	11 (3)
Don't want to bother the doctor	11 (3)
Health centre inaccessible	7 (2)
Too busy	7 (2)

than older women, and were especially likely to suggest embarrassment as a reason for delay. Women who had completed their full-time education at or before the age of 16 years were more likely to suggest fear of cancer and death as leading to delay. Women who had continued in full-time education beyond the age of 16 years placed more emphasis on factors such as fear of mutilation and rejection by partner, embarrassment, not wishing to be thought neurotic and denial or ignorance of the importance of the symptoms. Middle class women were almost twice as likely as working class women to specify fear of mutilation or rejection by partner. Working class women were almost twice as likely as middle class women to suggest fear of hospitals and not wishing to bother the doctor.

7.3 POST-PROGRAMME DATA

Again data are presented for the 414 women who replied to both questionnaires.

7.3.1 WOMEN'S EXPERIENCE OF THE EDUCATION PROGRAMME

The postal questionnaire which was sent after the programme included questions about the contact which each woman had had with the programme. Four main sources of information about the programme were mentioned - the local newspaper (by 39%), the post (by 34%), the leaflet (by 27%) and a friend or relative (by 22%). In addition 4% women said that they had heard from their GP and 3% from hospital staff (Table 7.19). A total of 109 women (27%) reported that they had not heard about the programme at all.

Of the sample of 414 women, 90 (22%) replied that they had attended a talk given by the research health visitor (Table 7.20). Over half of these women had been to the

TABLE 7.19

POST-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY SOURCE OF INFORMATION ABOUT PROGRAMME

Heard about education programme	Number of women
In local newspaper	158 (39)
Through poster	137 (34)
Through leaflet	108 (27)
Through friend or relative	90 (22)
Through GP	15 (4)
Through hospital	12 (3)
Total women who heard about education programme	293 (73)
Total women who did not hear about education programme	109 (27)
Total	402 (100)

(Inadequate information available for 12 women)

TABLE 7.20

POST-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY PLACE OF ATTENDING TALK

Attended talk at:	Number of women
Work	48 (12)
Leisure group	24 (6)
Health centre	14 (3)
School	4 (1)
Total women who attended talk	90 (22)
Total women who did not attend talk	312 (78)
Total	402 (100)

(Inadequate information available for 12 women)

talk at work, one-quarter at a leisure group and the remaining one-fifth either at the Health Centre or at school.

The use of the Spenco practice model to reinforce the illustrated presentation was a relatively unusual aspect of the programme and the women were asked specifically for their reactions to this. Out of the 82 women who attended a talk, and on whom data was available, 93% said that they had used the model and found it helpful (Table 7.21). Two women (2%) had used the model but not found it helpful, and 4 women (5%) said that they had not had an opportunity to use it. This positive response is supported by the informal feedback to the research health visitor at the talks.

The replies indicated that the women were most likely to have discussed BSE with either a friend (36%) or their sexual partner (33%). A further 22% discussed BSE with their workmates and 17% with another relative. Only 38% women said they had not discussed BSE with anyone (Table 7.22).

One-quarter of women took the opportunity of writing additional comments on the questionnaire, and these are presented in Table 7.23. There were requests for more health education (7%) and for a screening service for breast cancer (7%). Some women explained that they would have been interested but had not heard about the programme (4%) and others that they would have liked to attend a talk but, for various reasons, were unable to (2%). Generally appreciative remarks were added by 4% and remarks implying some anxiety by 2% (10 women).

The question of expressed anxiety was considered in

TABLE 7.21

POST-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY USE OF PRACTICE MODEL

Use of model	Number of women
Used model and found it helpful	76 (93)
Used model, did not find it helpful	2 (2)
No chance to use model	4 (5)
Total women who attended talk	82 (100)
Total women who did not attend talk	308

(Inadequate information available for 24 women)

TABLE 7.22

POST-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY DISCUSSION OF BSE

Discussed BSE with:	Number of women
Friend	125 (36)
Partner	114 (33)
Workmate	78 (22)
Other relative	59 (17)
Total women who discussed BSE	216 (62)
Total women who did not discuss BSE	133 (38)
Total	349 (100)

(Inadequate information available for 65 women)

TABLE 7.23

POST-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) MAKING ADDITIONAL COMMENTS

Additional comments	Number of women
Would like more "health education"	30 (7)
Would like a screening service for breast cancer	27 (7)
Didn't hear about educational programme	17 (4)
Generally appreciative remarks	17 (4)
Remarks implying some anxiety	10 (2)
Would have liked to attend talk, but unable to	9 (2)

more detail by analysing all the post-programme questionnaires. A total of 28 women added comments which could be construed as indicating some degree of anxiety - 13 women in the first sample, who received questionnaires both before and after the programme (3 were excluded from Table 7.23 as they did not return the pre-programme questionnaire) and 15 in the second sample, who received the post-programme questionnaire only. Several different anxieties were defined:-

... anxiety about BSE itself was expressed by 11 women; the anxiety related mainly to either the difficulties in doing BSE correctly ("as you find so many things like lumps when you press hard, I don't really know what to look for") or the fear that BSE may merely promote unhelpful anxiety ("over self-examination can become hypochondriacal in some subjects").

... anxiety about breast cancer was expressed by 7 women ("I don't read any more or go to talks (about breast cancer) because I'm afraid of my imagination", "some women would rather die than know").

... anxiety about mastectomy was stated by 6 women; this included worries about the relative merits of mastectomy and lumpectomy, the importance of suitable prostheses and the need for post-mastectomy counselling.

... 2 women expressed anxiety about the management of breast cancer by the GP and 2 said that they did not want to discuss BSE or breast cancer at all.

Of these 28 women, 14 expressed anxieties which related specifically to themselves; the other half were concerned

that women in general, rather than themselves, might be worried about various aspects of breast cancer and BSE. Only 7 women defined anxiety about BSE which affected themselves directly. These anxieties were mostly about technique, and occurred despite the fact that three of the seven women had attended one of the education programme talks. One women attributed her anxiety to receiving the questionnaire ("now I find myself examining myself every other 5 minutes"), but none to the education programme.

7.3.2 KNOWLEDGE AND PRACTICE OF BSE

Table 7.24 shows the knowledge of BSE among the 414 women and the sources of their knowledge after the educational programme (compare Table 7.9 for pre-programme data). The proportion of women who said that they had heard of BSE had increased to 98%, with the increase occurring in all age-groups. The media remained the major source of information (63%); 13% women reported that they had heard from a friend or relative. The proportions of women who had heard about BSE from the GP, cervical cytology clinic doctor, family planning clinic doctor or hospital had remained constant. The only increase in professionally-derived knowledge lay in that obtained from a nurse or health visitor, which had risen from 4% to 18%.

The percentage of women who said that they had been taught BSE had also increased, from 15% to 33% (Table 7.25, compare Table 7.10). The increase was seen in all age-groups with the pre-programme age-differential remaining - women aged 25-44 years were most likely to report having been taught BSE. Although there were no changes in the teaching from doctors or the hospital, 19% women said that

TABLE 7.24

POST-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) IN EACH AGE GROUP BY KNOWLEDGE OF BSE AND SOURCE OF KNOWLEDGE

	Age Group					
	15-24	25-34	35-44	45-54	55-65	Total
Total women who said that they had heard of BSE	63 (95)	78 (98)	87 (99)	78 (100)	93 (97)	399 (98)
- from GP	-	9 (11)	6 (7)	7 (9)	5 (5)	27 (7)
- from doctor in cervical cytology clinic	-	1 (1)	6 (7)	5 (6)	7 (7)	19 (5)
- from doctor in family planning clinic	1 (2)	4 (5)	2 (2)	-	1 (1)	8 (2)
- from nurse or health visitor	13 (20)	16 (20)	20 (23)	16 (21)	10 (10)	75 (18)
- from hospital	-	1 (1)	2 (2)	1 (1)	1 (1)	5 (1)
- from friend or relative	9 (14)	5 (6)	9 (10)	8 (10)	22 (22)	53 (13)
- from media (television, radio, magazines, newspapers)	43 (65)	46 (58)	58 (66)	50 (64)	61 (62)	258 (63)

(Inadequate information available for 6 women)

TABLE 7.25

POST-PROGRAMME DATA: NUMBER OF WOMEN (PERCENTAGES) IN EACH AGE GROUP BY RECEIVED TEACHING OF BSE AND SOURCE OF TEACHING

	Age Group					
	15-24	25-34	35-44	45-54	55-65	Total
Total women who said that they had been taught how to do BSE	17 (26)	31 (39)	37 (42)	24 (31)	26 (27)	135 (33)
- by GP	1 (2)	8 (10)	6 (7)	5 (6)	6 (6)	26 (6)
- by doctor in cervical cytology clinic	-	1 (1)	5 (6)	1 (1)	4 (4)	11 (3)
- by doctor in family planning clinic	-	4 (5)	-	-	-	4 (1)
- by nurse or health visitor	13 (20)	15 (19)	21 (24)	16 (21)	12 (12)	77 (19)
- by hospital	-	1 (1)	1 (1)	-	1 (1)	3 (1)
- by friend or relative	2 (3)	-	5 (6)	2 (3)	4 (4)	13 (3)

(Inadequate information available for 6 women)

they had been taught BSE by a nurse or health visitor (including 2 women who did not indicate nurse or health visitor as a source of information about BSE). This increase was highly statistically significant ($\chi^2 = 54.16$, $p<0.001$, 1 d.f.).

The practice of BSE after the education programme is shown in Table 7.26 (compare Table 7.11). The proportion of women who said that they never practised BSE had fallen to one-fifth, with women aged 25-44 years still being the most likely to carry out BSE. Almost one-quarter of women (93) now practised BSE regularly once each month (compare 54 women before the programme, $\chi^2 = 11.88$, $p<0.001$, 1 d.f.). Women aged 35-54 years were most likely to be performing monthly BSE (31%), with the percentage falling to 11% in those aged 55-64 years. The proportion of women practising BSE more often than once a month remained constant, again with the highest percentage (16%) in those aged 55-64 years.

Of the 92 women who said that they practised BSE once each month after the programme and for whom complete data were available, 38% had given the same reply beforehand (Table 7.27). However, 11% had said that they never practised BSE before the programme and a further 12% only occasionally; 13% had practised more than once each month. Women who had attended a talk were more likely to change their behaviour. Of the 39 women who reported practising BSE more than once a month after the programme, 46% had replied similarly before the programme. None of the 39 women said that they had attended a talk. Although practising BSE more than once might be considered a manifestation of

TABLE 7.26

POST-PROGRAMME DATA: NUMBER OF WOMEN (PERCENTAGES) IN EACH AGE GROUP BY FREQUENCY OF BSE PRACTICE

Frequency of BSE practice	Age group					
	15-24	25-34	35-44	45-54	55-65	Total
Never	17 (26)	14 (18)	12 (14)	18 (23)	22 (23)	83 (20)
Occasionally (once each year or less often)	13 (20)	13 (16)	17 (20)	13 (17)	22 (23)	78 (19)
Several times each year	19 (29)	28 (35)	23 (26)	17 (22)	26 (27)	113 (28)
Once each month	13 (20)	19 (24)	27 (31)	24 (31)	10 (11)	93 (23)
More often than once each month	4 (6)	6 (8)	8 (9)	6 (8)	15 (16)	39 (10)
Total	66 (100)	80 (100)	87 (100)	78 (100)	95 (100)	406 (100)

(Inadequate information available for 8 women)

TABLE 7.27

NUMBERS OF WOMEN (PERCENTAGES) PRACTISING BSE BEFORE AND AFTER EDUCATION PROGRAMME, BY WHETHER OR NOT THEY ATTENDED A TALK

BSE practice before programme	BSE practice after programme: Once each month			BSE practice after programme: More often than once each month		
	Did attend talk	Didn't attend talk	Total	Did attend talk	Didn't attend talk	Total
Never	7 (21)	3 (5)	10 (11)	-	5 (13)	5 (13)
Occasionally (once each year or less often)	3 (9)	8 (14)	11 (12)	-	3 (8)	3 (8)
Several times each year	5 (15)	19 (33)	24 (26)	-	8 (21)	8 (21)
Once each month	12 (35)	23 (40)	35 (38)	-	5 (13)	5 (13)
More often than once each month	7 (21)	5 (9)	12 (13)	-	18 (46)	18 (46)
Total	34 (100)	58 (100)	92 (100)	-	39 (100)	39 (100)

(Inadequate information available for 1 woman)

anxiety, none of these women recorded any additional comments which were judged to demonstrate concern about BSE, breast cancer or any aspect of the programme.

7.3.3 BELIEFS ABOUT AND ATTITUDES TO BREAST CANCER

As well as promoting the practice of BSE, the educational programme was also designed to encourage women to report any abnormalities to their GP as soon as possible. It was hoped to achieve this by providing information about the most likely explanations for breast symptoms and the benefits of early treatment for breast cancer.

... Table 7.28 shows the replies to the question about the likely cause of a breast lump (compare Table 7.16). The numbers of women who thought it would almost certainly be breast cancer, or who did not know what to think, remained unchanged (although they were not necessarily the same women). However, 37% of women now thought that the lump was more likely to be something other than cancer (previously 28%), and only 26% now thought it more likely to be cancer than anything else (previously 34%). Thus the beliefs about the relative incidences of breast cancer and benign breast disease appeared to have become significantly more optimistic (37% v. 28%, $\chi^2 = 6.51$, $p<0.05$, 1 d.f.).

... 97% of women thought that a woman with a lump in her breast should see her GP immediately (previously 96%); 3 women replied that she should wait and see if it changed, 1 that she should forget it and 7 (2%) did not know what to think.

... The beliefs about the curability of breast cancer had become slightly, although not significantly, more optimistic

TABLE 7.28

POST-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY FREQUENCY OF BSE PRACTICE AND REPLIES TO THE QUESTION - "If someone came to you and said she had found a lump in her breast, what would you think about it?"

Frequency of BSE practice	"Almost certainly breast cancer"	"More likely to be cancer than anything else"	"More likely to be something other than cancer"	"Would not know what to think"	Total
Never	1 (1)	18 (23)	27 (34)	34 (43)	80 (100)
Occasionally (once each year or less often)	3 (4)	13 (17)	25 (33)	34 (45)	75 (100)
Several times each year	1 (1)	36 (33)	44 (40)	29 (26)	110 (100)
Once each month	2 (2)	22 (24)	39 (43)	28 (31)	91 (100)
More often than once each month	2 (6)	12 (33)	10 (28)	12 (33)	36 (100)
Total	9 (2)	101 (26)	145 (37)	137 (35)	392 (100)

(Inadequate information available for 22 women)

(Table 7.29, compare Table 7.17). 38% women now thought that breast cancer was usually cured (compare 35%), whilst the proportion thinking it was sometimes or never cured had fallen marginally to 62% (compare 65%).

... Most women (97%) still thought that the prognosis for a woman with breast cancer was better if she was diagnosed and treated early.

... The open-ended question on possible explanations of delay was also repeated. Similar answers to those before the programme were received.

Although the reported changes in beliefs and attitudes are in the intended direction, those measured by the questionnaire appear to be relatively small, especially when compared to the alteration in BSE practice. This may indicate the separation of the decision to practise BSE from beliefs and attitudes about breast cancer. However, two questions proved incapable of detecting any change, and the others may have been too insensitive for such a complex area. Thus, the questionnaire may have underestimated,or failed to measure, any alterations which did occur.

TABLE 7.29

POST-PROGRAMME DATA: NUMBERS OF WOMEN (PERCENTAGES) BY FREQUENCY OF BSE PRACTICE AND REPLIES TO THE QUESTION - "What do you think are the chances of curing someone who has breast cancer?"

Frequency of BSE practice	"Breast cancer is always cured"	Breast cancer is usually cured"	"Breast cancer is sometimes cured"	"Breast cancer is never cured"	Total
Never	-	25 (30)	58 (70)	-	83 (100)
Occasionally (once each year or less often)	-	25 (33)	49 (65)	1 (1)	75 (100)
Several times each year	-	52 (47)	59 (53)	-	111 (100)
Once each month	-	37 (40)	55 (60)	-	92 (100)
More often than once each month	1 (3)	13 (34)	23 (61)	1 (3)	38 (100)
Total	1 (<1)	152 (38)	244 (61)	2 (1)	399 (100)

(Inadequate information available for 15 women)

C H A P T E R 8

Discussion and conclusions

INTRODUCTION

The study was designed to evaluate a health education programme about breast self-examination (BSE). Data were collected to assess both the workload of breast disease in general practice, and the effect of the programme on women's knowledge, attitudes and behaviour with respect to breast disease and BSE. This chapter begins with a discussion of the methodology (Section 8.1), then discusses the data obtained from the general practitioners (GPs) (Section 8.2) and from the random sample of women (Section 8.3), and continues by considering some other relevant issues (Section 8.4). The chapter concludes with a discussion of the implications of the results for both health service practice and further research (Section 8.5).

8.1 METHODOLOGY

8.1.1 THE CONDUCT OF THE HEALTH EDUCATION PROGRAMME

This is described in Chapters 4 and 5. Care was taken to ensure that the programme was carried out as effectively and as thoroughly as possible. However, there were difficulties with achieving general publicity, because there was no local radio station and there were problems in displaying the poster. Despite this, almost three-quarters of the women who returned the questionnaire said that they had heard about the programme. However, if this proportion had been increased, the programme might have resulted in greater changes in beliefs, attitudes and behaviour.

The health education session was designed primarily for women within established groups, either at work or in leisure groups, and, over a 6 month period, one health visitor was able to provide all the sessions which were requested. The most efficient way to reach women seemed to be through sessions in the workplace. The flexibility of an unscripted talk, with illustrative slides, enabled appropriate modifications in the presentation to be made for each audience. Almost all the women who had an opportunity to use the practice model at the end of the session said that they found it to be helpful.

Very few women took the opportunity of an individual consultation with the research health visitor. This might indicate either success or failure. If success, the educational session might have covered all the relevant topics, provided comprehensible instruction in BSE, allowed women to discuss any remaining problems and not created unnecessary anxiety or fear. If failure, then the Health Centre might not have been the appropriate place to suggest that women see the health visitor. It may have been considered too remote or too closely associated with the primary care team, and more women might have consulted the health visitor if she had returned to their work or leisure group after an interval. However, we did not find any evidence of significant unmet need, and the former explanation appears to be more likely.

8.1.2 THE COLLECTION OF DATA ON GP WORKLOAD

Although this data collection was discussed and agreed with each of the GPs involved, there were predictable problems in asking them to remember to fill in questionnaires

over an 18 month period. Despite various tactics to maintain their interest and enthusiasm, the decreased number of women whom the GPs reported to have presented with breast symptoms in the 6 months after the programme could be taken as evidence of incomplete recording.

However, there was no concomitant reduction in the number of women referred to hospital, and the frequency of consultations for breast cancer was similar to that found nationally (RCGP/OPCS/DHSS, 1979). The GPs may have become more selective in their reporting, with an increasing tendency to complete a form only on those women with symptoms and signs which were considered to be significant. The data collected during the third 6 month period may not, therefore, accurately reflect total consultations about breast symptoms, although they may provide a relatively complete account of consultations for the more significant symptoms.

8.1.3 THE COLLECTION OF QUESTIONNAIRE DATA

The age-sex register was used as a sampling frame to derive a random age-stratified sample of women registered with the Health Centre. Although the postal questionnaires were sent out within one month of selecting the sample, 5% women had already left the area. This was despite the fact that the Health Centre staff considered the age-sex register to be accurate.

The response rate to the pre-programme questionnaire was high at 84%, although only 72% of the original sample replied to the post-programme questionnaire. This fall may have been attributable, in part, to the fact that

several questions were repeated, and some women may not have considered it worthwhile to reply again. Although only 69% women replied to both questionnaires, the individual characteristics of the women in this group appeared to be similar to those of the women in the larger groups. As there was no evidence of systematic bias influencing the likelihood of responding to the questionnaire, comparisons of pre-programme and post-programme data were made for the smaller group. The pre-programme questionnaire did not appear to enhance or diminish the recipients' responses to the health education programme.

There were problems with two questions about knowledge and attitudes towards breast disease. One question involved defining the course of action which should be taken by a woman who discovers a breast lump, and the other asked about the influence of early treatment on the prognosis of a woman with breast cancer. Almost all women replied by stating conventional medical wisdom - the woman who discovers a breast lump should see her GP straightaway, and the early treatment of breast cancer improves the prognosis.

Thus these questions were not able to detect any changes resulting from the programme. The answers do, however, make an interesting comparison with the data on delay derived from the behaviour of the women who consulted their GP. Over one-third of the women had had their symptoms for longer than one month, and one-sixth had been symptomatic for 3 months or more.

This discrepancy may illustrate a final methodological issue, namely the difficulty in assessing the validity of information about knowledge, attitudes and behaviour as reported to an investigator. The knowledge, attitudes and behaviour which were claimed by individuals completing an apparently well-intentioned questionnaire may owe more to their desire to please by giving the "right" answers, than to reality. This potential problem applies whenever questionnaire data are collected, but may be of particular significance when an intervention (in this case the health education programme) and its evaluation are carried out by the same staff.

8.2 GENERAL PRACTITIONER WORKLOAD

Perhaps the most striking finding from these data is the small proportion of reported breast symptoms which prove to be due to breast cancer. Only 4% women who consulted their GP with breast symptoms were diagnosed as new cases of breast cancer; a further 1% had primary cancers of other sites. From these data, which, as discussed, may underestimate the amount of minor breast disease seen in general practice, it would appear that fewer than half the women who consult their GP with breast symptoms are considered to need any treatment other than reassurance, and possibly a review appointment. Overall one in four women were referred to hospital and one in six required hospital treatment, which was defined to include cyst aspiration.

Although over three-quarters of the consultations were by women aged under 45 years, these included only

one-fifth of the women with newly-diagnosed breast cancer. The majority of consultations, therefore, occurred with women who were unlikely to have breast cancer, more likely to have benign breast disease, and most likely to have no significant abnormality.

The GP's management was, considering this, remarkably efficient. Where the GP suspected breast cancer, all women were referred at their first consultation and the median time interval from GP consultation to hospital out-patient appointment was 1 week. Seven out of the nine women who were diagnosed by the consultant as having new breast cancer were referred at their first GP attendance, and again the median time interval to out-patient appointment was 1 week. Despite the infrequent occurrence of breast cancer, the GPs appeared to maintain a relatively high index of suspicion. The two women who were found to have breast cancer, but were not referred at their first consultation, both presented with symptoms which are not considered to be typical of breast cancer. Other studies have documented the delay which appears to be associated with a less usual presentation (Bywaters, 1977; Adam et al, 1980; MacArthur & Smith, 1981).

The efficiency of the GPs as assessed by "unnecessary referral" was also quite high, even though their provisional diagnosis was not always correct. Only one-quarter of their referrals to hospital were discharged from the clinic without investigation or treatment, and over half were treated with surgery and/or radiotherapy. The extent to which unnecessary referral is acceptable has never been made

explicit. However, the GP consultation could be viewed as a screening test, in which an increased sensitivity (that is the referral of women with breast cancer) can only be achieved at the cost of a decrease in specificity (which will result in more women without breast cancer being referred). If a programme of health education, designed for both lay and professional audiences, is intended to reduce the delay between a woman with breast cancer first noting a symptom and attending the hospital out-patient clinic, it may be necessary to accept that more women with either benign disease or no significant abnormality will also be referred.

Until recently, no comparative data have been available. A small study in Southampton has now been reported, and shows intriguing differences and similarities to this study (Nichols et al, 1980). The major difference lies in the frequency of consultation by women with breast symptoms. In the study in Daventry, a mean of 18.3 consultations were reported each month, 2.0 per GP. In Southampton, the mean was almost twice as high at 3.5 consultations per GP each month. The age distribution of the women, their presenting symptoms and the proportion referred to hospital were nevertheless remarkably similar. The consistency in hospital referral might be interpreted as showing that GPs refer a constant proportion of patients who consult them. Unfortunately, Nichols and her colleagues give no data on outcome. A review of all referrals to hospital by the GP indicates a much lower variation in referral rates than in consultation rates, suggesting that

GPs respond to expressed need rather than any concept of real community need (Loudon, 1977).

However, although the Daventry GPs appeared to provide an efficient referral service for women with breast cancer, there were inadequacies in their own follow-up of patients. One-quarter of the women who consulted the GP made, but did not keep, a review appointment at the Health Centre. Although this may indicate an informed decision, no mechanism had been instituted by the Health Centre to trace these women, in order to determine their reason for not attending. Similar findings have been reported elsewhere (Bywaters, 1977). There also appeared to be very little follow-up provided in general practice for those women who had been referred to hospital; only 7% were recorded as having consulted their GP after discharge from hospital, including only one woman with breast cancer. There were no formal arrangements for follow-up by the community nurses or health visitors, some of whom expressed anxiety about their abilities to provide continuing care for the women who had been treated for breast cancer. These anxieties seemed to relate primarily to their emotional difficulties in coping with breast cancer, particularly as they felt that there was relatively little which they could offer these women. These anecdotal findings are consistent with those from more systematic studies (Baum & Jones, 1979; Maguire et al, 1980).

8.3 QUESTIONNAIRE DATA

8.3.1 PRE-PROGRAMME QUESTIONNAIRE

Replies to this indicated that 87% women had heard of BSE, 18% women had been taught how to do BSE and 13%

women practised BSE regularly once each month. This relatively high level of knowledge of BSE (compared, for example, with 54% in Manchester women (Hobbs et al, 1977)) was reported across the age-groups. The most important source was defined as the media, and this is reflected in the low proportion of women who said that they had been taught BSE. Even fewer women said that they practised BSE each month, with women aged 25-54 years having the highest prevalence of practice; the prevalence is similar to that found in other population-based studies (for example, American Cancer Society, 1974; Hobbs et al, 1977; Richards, 1977; Hill et al, 1980).

There was an element of chance in whether women had heard about BSE from, or had been taught BSE by, a health professional. For example, family planning clinic doctors were an important source for younger women and cervical cytology clinic doctors for older women. Although the availability of health professionals seemed to be to some extent fortuitous, those women who had heard about BSE, been taught BSE or had their technique checked by a health professional were more likely to report practising BSE each month. Other studies have confirmed the important role of health professionals in promoting BSE (for example, Phillips & Brennan, 1976; Mahoney, 1977; Gästrin, 1980; Hill et al, 1980). There was also a positive relationship between monthly BSE and having had cervical cytology performed. This association of different preventive health measures has been reported elsewhere, both with respect to BSE (Haran et al, 1979) and more generally

(for example, Mechanic & Cleary, 1980). Direct experience of breast cancer (in a relative or close friend) also increased the likelihood of BSE practice.

The women indicated knowledge and attitudes about breast disease which appeared to be in agreement with conventional medical wisdom. However, this may not necessarily ensure the least possible delay in presenting after a woman has discovered symptoms, as these reported items were not entirely consistent with the behaviour of those women who consulted the GP (see Section 8.1.3). Fear was seen as the most common explanation of delay, with middle class women placing more importance on fears associated with mastectomy, than those associated with cancer, death or hospitalisation.

The women demonstrated a distorted perception of the relative incidences of benign and malignant breast disease. Twice as many reported that a relative or close friend had suffered from breast cancer as from benign breast disease; in fact, the GP data showed that breast cancer was diagnosed in only 1 in 20 women who consulted their GP with breast symptoms. Breast cancer therefore appears to women to account for a much greater proportion of breast disease than is the case. This may lead the women to erroneous explanations of their own breast symptoms.

8.3.2 POST-PROGRAMME QUESTIONNAIRE

After the programme only 2% women reported that they had not heard of BSE. One-third said that they had been taught how to do BSE and one-quarter reported that they practised BSE once each month.

These increased levels of knowledge and practice appear to be attributable, at least partly, to the health education programme. The greater knowledge and teaching of BSE were both derived almost entirely from "nurse or health visitor", presumably a reflection on the activities of the research health visitor. There was no increase in the contributions of other health professionals, despite the involvement of the GPs in the study and the alleged interest of the doctors in the community health service. Women who attended a talk were more likely to have increased their practice of BSE towards once each month.

Only small changes in the women's knowledge and attitudes about breast disease were demonstrated. This was partly due to the fact that two questions were not sufficiently sensitive to detect any alteration (see Section 8.1.3). However, the changes which were found were as intended - namely that women were less likely to assume that a breast lump was cancer, and slightly more hopeful about the prognosis for a woman with breast cancer.

Previous studies have reported a considerable variation in the post-programme prevalence of BSE practice, ranging from 16% (Richards, 1977) to 78% (Rodrick & Bubb, 1978). However, comparisons are difficult; there are differences in the target populations and in the educational strategies adopted and, in addition, many investigators do not define the precise meaning of BSE practice. The objective in Daventry was to promote the monthly practice of BSE, an objective achieved apparently in 23% of the target population. However, alternative outcome measures could

be defined - for example, BSE practice at least once a month (33% women) or any BSE practice at all (80% women). The relative effectiveness of the education programme in Daventry is, therefore, uncertain. However, it is probably reasonable to conclude that, for a programme which did not offer one-to-one instruction in BSE nor focus on a particularly motivated population, it achieved a satisfactory increase in the prevalence of BSE practice. The proportion of women who reported monthly BSE had increased from 13% to 23%, 3 months after the programme finished.

8.4 GENERAL ISSUES

8.4.1 AGE OF TARGET GROUP

As discussed in Section 4.6.1, the study reported here was unusual in including women from the age of 15 years. The results appear to provide further justification for this decision.

First, the education programme not only provided instruction in BSE, but also stressed the importance of the early diagnosis of breast disease. This not only ensured the best possible outcome if the diagnosis proved to be cancer, but if, as was much more likely, benign disease was found, provided reassurance as soon as possible. As three-quarters of the women who consulted their GP with breast symptoms were under the age of 45 years, it was important not to exclude this age-group from the programme.

Second, both knowledge and monthly practice of BSE before and after the programme were most common in women aged 25 to 44 years, findings which were anticipated from previous studies (Rodrick & Bubb, 1978; Hill et al, 1980).

This may reflect a greater interest in breasts, and thus BSE, in younger women, whose interest declines with age, although this assumption has been questioned by women writers (for example, Boston Women's Health Book Collective, 1978). If the age-differences represent a genuine cohort effect, and the younger women are likely to maintain their interest in BSE, then it is important to encourage its practice from an early age. This question can, however, only be resolved by a longitudinal study.

Third, the importance of health professional involvement in teaching and checking BSE was confirmed. Opportunities for this are relatively more common in younger women attending antenatal, post natal and family planning clinics.

Finally, there was evidence that many women discussed BSE with a friend, workmate or relative. Although no data on the ages of these discussants are available, it seems reasonable to assume that some of the interactions were between younger and older women. Thus, teaching younger women about BSE may have the additional secondary effect of informing older women.

8.4.2 ANXIETY

There was very little evidence of increased anxiety resulting from the health education programme. Women were encouraged to consult their GP about any breast symptom, even the apparently trivial, and this may account for the increased consultation rate for minor problems, which was observed during the programme. Although the GPs had been concerned lest the increased awareness of BSE provoked a concomitant increase in anxiety, they did not find any

evidence of this.

Only 2% women included any expression of anxiety in their questionnaires, and half of these were anxious on behalf of others not themselves. No anxieties were attributed to the education programme itself, although a few women remained anxious about the correct practice of BSE.

A minority of women said that they practised BSE more often than once per month. This could be explained in several ways. First, it could be a function of their wish to please the investigator, by claiming the frequent practice of BSE. Second, it might indicate the extent to which BSE had become routine. Finally, it might be an alternative manifestation of anxiety. The study reported here cannot provide a definitive explanation, although the women who practised BSE more than once a month appeared to be an unusual group. For example, none of the women who replied after the programme that they performed very frequent BSE had attended a talk, although only half of them had said that they practised BSE this often before the programme. They also tended to be older than women who reported monthly BSE. However, none had recorded any additional comments which were considered to imply anxiety, and thus the explanation for their behaviour remains unclear.

8.5 CONCLUSIONS AND IMPLICATIONS

Although direct comparisons with other studies are impossible, the education programme reported here appears to have achieved some of its objectives. The majority

of the target population had had some contact with the programme, and a substantial minority had attended a talk. Modest increases in knowledge and practice of BSE were achieved; women who had attended a talk were particularly likely to increase their practice of BSE. The teaching model was found to be a helpful adjunct to the illustrated talk and discussion. Changes in knowledge and attitudes about breast disease were small, but in the intended direction. The effects of the education programme were apparently achieved without creating unnecessary anxiety.

The data collected by GPs showed a relatively efficient management of breast symptoms, despite the low frequency of significant disease. Unusual symptoms tended to be associated with delay in the women who were found to have breast cancer, and there were also deficiencies in the arrangements for the review and follow-up of women within general practice.

8.5.1 IMPLICATIONS FOR THE MANAGEMENT OF BREAST DISEASE

The data presented here place the diagnosis and management of breast cancer within the context of all the breast symptoms which are seen in general practice. They emphasise the potential difficulties in reducing the delay in hospital referral for women with breast cancer. In this study, the GPs accurately identified most of the possible new cases of breast cancer. The two women who were not identified both presented with symptoms which are considered to be atypical for breast cancer. Thus to ensure that such women are diagnosed promptly, it may

be necessary to accept a much higher index of suspicion on the part of the GPs and thus an increased referral rate. It will also be necessary to educate all GPs that cancer does not always present as a painless lump.

There are further implications for the organisation of general practice. Consideration should be given to a system for ensuring that those women who are given a review appointment either do attend or are known not to require a further consultation. The follow-up of women discharged from hospital also seems to be unsatisfactory. Although it might be argued that women with benign breast disease do not need to return to their GP, those who have been treated for breast cancer are likely to suffer physical and psychological sequelae (see Section 1.3). Such women may benefit from counselling, which can be provided by a suitably-trained nurse (Maguire et al, 1980), although, as yet, this is not usually available.

There is some evidence that a health education programme will increase the number of women consulting with minor abnormalities. This increased workload must be accepted as inevitable if breast cancer is to be diagnosed as early as possible, and the women must be reassured both that all is well and that they were correct to consult their GP.

Appropriate modifications of health service practice should be made and carefully evaluated, from the points of view of the woman, the GP and the NHS.

8.5.1 IMPLICATIONS FOR THE PROMOTION OF BSE

This study reports the evaluation of one particular approach to the promotion of BSE. As a limited, self-contained and relatively inexpensive programme, which did not involve one-to-one instruction, it appears to have achieved some modest changes in the intended directions.

More ambitious programmes could be defined, but meanwhile several problems can be identified:

... the gap between the woman's beliefs about and attitudes to breast disease and BSE, and her behaviour; this may reflect the importance of other beliefs and attitudes which also affect behaviour, and which need to be taken into account in any health education programmes

... the importance of the participation of health professionals in teaching and checking BSE, and yet the difficulties in achieving this

... the relevance of the standard, ritualised method of BSE which is traditionally taught, but which appears to be performed by relatively few women

... the appropriateness of teaching only women, when partners were most often reported to be the person with whom women discussed BSE.

Further research projects which were concerned to increase the practice of BSE might investigate some of these areas. However, the most important problem is the uncertainty about the benefits which accrue from BSE. This can only be investigated by long-term studies which consider the morbidity and mortality from breast cancer in women who do and who do not practise monthly BSE.

Meanwhile, the question of whether priority should be given to the promotion of BSE remains. As discussed in Chapter 3, there are strong political arguments in favour of preventive medicine and health education. However, despite the various explanations for this advocacy, considerable problems remain - for example, conflicting objectives, an inadequate theoretical base for either health behaviour or health education, and difficulties in assessing the effectiveness of health education programmes. There are additional problems which are more specific to BSE - for example, the strong emotional response to any discussion about breasts or breast cancer, and the technical difficulties in teaching BSE and in ensuring that it is practised correctly. The obvious anxieties about breast cancer do, however, demonstrate the importance of health education about breast symptoms and their diagnosis and management.

The results from studies of community programmes to promote BSE indicate that only a moderate increase in practice can be achieved in this way, and that a significant proportion of women will report that they do not practice BSE at all (20% in the Daventry study). Teaching BSE at a one-to-one level, particularly in women whose motivation may be increased by the presence of breast symptoms, appears to be considerably more effective. With the replacement of infectious disease by chronic disease, the emphasis in programmes of preventive medicine has changed, to some extent, from a population to an individual level. There is a growing acceptance that health professionals should use every opportunity to practise health education (see, for

example, RCGP, 1981a).

This may provide the pragmatic solution for BSE. While the benefits of BSE itself remain uncertain, there is a general agreement about the advantages of reducing delay in the treatment of breast disease. This should both produce a probable improvement in outcome, and ensure a reduction in the woman's anxiety once she has noted an abnormality. Education about the importance of early diagnosis and treatment, including the role of the woman in regularly checking her breasts, could be carried out routinely during doctor-patient or nurse-patient consultations. For example, one study showed that most GPs say that they take the opportunity of a consultation during pregnancy, or for contraception or routine examination to examine a woman's breasts (Nichols et al, 1980), and education could be provided at the same time.

Some GPs, community health doctors and other health practitioners already carry out this type of health education. With the increasing interest in preventive medicine, this practice could probably be extended. Appropriate education of the health professionals would also be necessary, including education to promote the changes in the management of symptomatic women (Section 8.5.1). The role of the Health Education Units would include the initiation of these developments, the provision of educational expertise, the monitoring of the relevant literature to up-date the practitioners, and the supply of educational aids as necessary (for example, leaflets and teaching models).

If such a policy were agreed, BSE would become merely one component of a broader educational approach, a more limited role which would appear to be justified by the available evidence. Although no studies have yet reported on the possible long-term benefits, it seems unlikely that programmes designed only to promote BSE will have a major impact on the mortality and morbidity associated with breast cancer. Such programmes appear to be capable of achieving the practice of monthly BSE in only relatively low proportions of women, and, in addition, doubt has been cast on the efficacy with which BSE is performed (Greenwald et al, 1978). Although the reported practice of BSE does appear to be associated with an earlier stage at presentation with breast cancer (Foster et al, 1978; Greenwald et al, 1978), this apparent benefit may be at least partially attributable to other factors. For example, women who practise BSE may be less likely to delay.

Education, designed to encourage the early diagnosis of, and presentation with, symptoms of breast disease, and preferably integrated into routine health care, may offer greater potential in the alleviation of the problem of breast cancer. Some form of self-examination of the breasts should be included in this, but BSE should not be seen as the panacea.

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A P P E N D I X 4

GP QUESTIONNAIRE

GP FORM

Please complete on all women presenting with breast symptoms, and women in whom signs of breast disease are found.

Name: .....

D.o.B.: ..... Age: .....

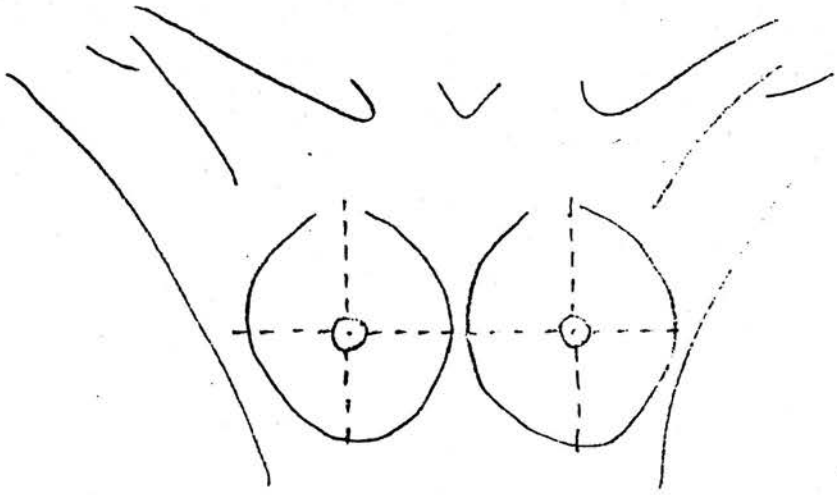
1. Presenting complaint

		Duration			
		<1/52	1/52-1/12	1/12-3/12	>3/12
Lump	Yes/no	.....	.....	.....	.....
Pain	Yes/no	.....	.....	.....	.....
Bleeding from nipple	Yes/no	.....	.....	.....	.....
Discharge from nipple	Yes/no	.....	.....	.....	.....
Other (please specify)	Yes/no	.....	.....	.....	.....
Asymptomatic	Yes/no	.....	.....	.....	.....

2. Sign(s) found by GP

i) Lump Yes/no (please ring as appropriate)

If yes:-



Mark site of lump

Diameters of lump = cms. x cms.

Characteristics:				
	hard/firm	☐	soft	☐
	tender	☐	not tender	☐
	pectoral muscle fixation	☐	not pectoral muscle fixation	☐
	skin fixation	☐	not skin fixation	☐

For abnormal breast only:-

ii) Nipple — Normal/abnormal (please ring as appropriate)

If abnormal:-

discharge	absent	☐	present	☐	+blood ☐
retraction	absent	☐	present	☐	
displacement	absent	☐	present	☐	
Paget's disease	absent	☐	present	☐	

iii) Skin — Normal/abnormal (please ring as appropriate)

If abnormal:-

ulceration	absent	☐	present	☐
dilated veins	absent	☐	present	☐
satellite nodules	absent	☐	present	☐
peau d'orange	absent	☐	present	☐
cancer en cuirass	absent	☐	present	☐

iv) Lymph nodes

	homolateral axilla	supra-clavicular	contra-lateral axilla
not palpable	☐	☐	☐
palpable, mobile	☐	☐	☐
palpable, fixed	☐	☐	☐

v) Any other relevant findings? — Yes/no (please ring as appropriate)

If yes, please specify:-

3. Clinical diagnosis

4. Planned management

5. Date seen

Daventry Health Centre
Daventry
Northamptonshire

Dear

You may have seen, either in the press or on television, that there is continuing concern within the Health Service about breast diseases in general and breast cancer in particular.

Because of this, there are a number of studies going on in various parts of the country aimed at reducing the illness which results from breast disease. However, we know that women vary a lot in their views about breast disease, and that this variation will affect the results of any attempt to improve the care of those with breast trouble.

Therefore, the general practitioners in Daventry Health Centre are working with doctors in Northampton and at Oxford University on a study to measure the views on breast disease of women living in Daventry. We have chosen a random group of women from the general population to help with this study, and we are asking this group, which includes you, to fill in copies of the enclosed questionnaire.

We realise that some of the questions are rather personal and you may feel that you would prefer to omit one or two of them. However, it is important that we receive answers from as many people in our sample as possible, in order for our results to be useful in tackling this important health problem. Any information which you give us will be treated in the strictest confidence. If you have any queries, please contact the Health Centre.

With many thanks.

Yours sincerely,

Gordon Pledger
(Northampton District Community Physician)

Sheila Adam
(Research Officer, Dept. of Social and Community Medicine, University of Oxford)

QUESTIONNAIRE CONFIDENTIAL

Please answer the following questions - where there are several possible answers, please tick the appropriate box.

1. How old are you? .... years

2. What is your marital status?

- single ☐
- married ☐
- divorced ☐
- widowed ☐
- separated ☐

3. How old were you when you completed your full-time education (that is, when you left school/college/university)?

.... years

What is or was your occupation?

Job .....

Industry/business/organisation .....

What is or was your husband's occupation (if you are or were married)?

Job .....

Industry/business/organisation .....

4. How do you rate your health?

- excellent ☐
- good ☐
- fair ☐
- poor ☐

5. Have you ever had any serious illnesses?

- Yes ☐
- No ☐

If yes, which illnesses were they?

.....

6. Have you ever had any operations? Yes ☐ No ☐

If yes, which operations were they?

.....

7. Have you ever had any trouble with your breasts?

No ☐

Yes, trouble with breast feeding ☐

Yes, pain in breast ☐

Yes, lump in breast ☐

Yes, breast abscess ☐

Yes, some other trouble (please give details) ☐

.....

8. During the past 12 months how many times have you been to see your GP?

.... times

9. Some women examine their breasts regularly just to check that all is well. This is called self-examination of the breasts. Have you ever heard of this technique?

Yes ☐

No ☐

If yes, where did you hear about it?

From family doctor ☐

From cervical smear clinic doctor ☐

From family planning clinic doctor ☐

From nurse or health visitor ☐

From newspaper, magazine, TV or radio ☐

From a friend or relative ☐

Other source (please give details) ☐

.....

10. Has anyone ever taught you to examine your breasts?

Yes ☐

No ☐

If yes, who taught you?

Family doctor ☐

Cervical smear clinic doctor ☐

Family planning clinic doctor ☐

Nurse or health visitor ☐

Friend or relative ☐

Other person (please give details) ☐

.....

11. Do you examine your own breasts?

No, not at all ☐

Occasionally (once a year, or less) ☐

Several times a year ☐

Once a month ☐

More frequently than once a month ☐

12. Has anyone ever checked that you examine your breasts correctly?

Yes ☐

No, but I do examine my breasts ☐

Do not examine my breasts ☐

13. Have you ever had a cervical smear taken?

No ☐

Yes, within last 3 years ☐

Yes, more than 3 years ago ☐

If yes, where was the smear taken?

- Cervical cytology clinic ☐
- Family planning clinic ☐
- Antenatal or postnatal clinic ☐
- By family doctor ☐
- By hospital doctor ☐

14. If someone came to you and said she had found a lump in her breast, what would you think about it?

- Almost certainly cancer ☐
- More likely to be cancer than anything else ☐
- More likely to be something other than cancer ☐
- Would not know what to think ☐

15. What do you think she ought to do about it?

- Forget about it ☐
- Wait and see if it changed ☐
- Go and see her family doctor straightway ☐
- Talk it over with her friends and relatives ☐
- Other (please give details) ☐

.....

16. What do you think are the chances of curing someone who has breast cancer?

- Breast cancer is always cured ☐
- Breast cancer is usually cured ☐
- Breast cancer is sometimes cured ☐
- Breast cancer is never cured ☐

17. Do you think early treatment makes any difference to the chance of a cure?

Yes ☐

No ☐

18. Have any of your relatives or close friends had any breast trouble?

Yes, breast cancer ☐

Yes, other breast disease ☐

No ☐

Do not know ☐

19. Lastly, we know that some women who discover something wrong with their breasts put off seeking medical help. Could you write below any of the reasons why you think this might happen.

Thank you very much for your help in answering these questions. Please return this questionnaire in the S.A.E. marked "Confidential".

Daventry Health Centre,
Daventry,
Northants.

June 1979

Dear

You may remember that we wrote to you about a year ago asking for some information about your health. Since then there has been quite a lot of publicity in Daventry about health and about various illnesses, and we are interested to find out how effective this has been. Obviously, if the Health Service spends money on this sort of thing, it is important to make sure that it is money well spent.

With the permission of your family doctor, we are now writing to you again, enclosing a second questionnaire, which we hope you will find fairly straightforward to fill in. Any information which you give us will, of course, be treated in the strictest confidence.

We do apologise for bothering you again, but would be extremely grateful for your help. If you have any queries, please don't hesitate to contact Mrs.Williams at the Health Centre ('phone number Daventry 3333).

Many thanks for your help.

Yours sincerely,

Dr.Sheila Adam (Research Fellow,
University of Oxford)

Mrs.Kate Williams (Research Health Visitor)

CONFIDENTIAL

Please answer the following questions - where there are several possible answers, please tick the appropriate box.

1. How old are you? ....years

2. What is your marital status?

- single ☐
- married ☐
- divorced ☐
- widowed ☐
- separated ☐

3. Do you have any children?

Yes ☐ ____children (please say how many, and please say if they are adopted)

No ☐

4. Have you had any serious illnesses or any operations during the past year?

Yes ☐

No ☐

If yes, please give details.....

.....

.....

5. Have you ever had any trouble with your breasts?

- No ☐
- Yes, trouble with breast feeding ☐
- Yes, pain in breast ☐
- Yes, lump in breast ☐
- Yes, breast abscess ☐
- Yes, some other trouble (please give details) ☐

.....

.....

6. During the past 12 months how many times have you been to see your GP?

.....times

7. Some women examine their breasts regularly just to check that all is well. This is called self-examination of the breasts. Have you ever heard of this technique?

Yes ☐

No ☐

If yes, where did you hear about it?

From family doctor ☐

From cervical smear clinic doctor ☐

From family planning clinic doctor ☐

From nurse or health visitor ☐

From newspaper, magazine, TV or radio ☐

From a friend or relative ☐

Other source (please give details) ☐

.....

8. Has anyone ever taught you to examine your breasts?

Yes ☐

No ☐

If yes, who taught you?

Family doctor ☐

Cervical smear clinic doctor ☐

Family planning clinic doctor ☐

Nurse or health visitor ☐

Friend or relative ☐

Other person (please give details) ☐

.....

9. Do you examine your own breasts?

No, not at all ☐

Occasionally (once a year, or less) ☐

Several times a year ☐

Once a month ☐

More frequently than once a month ☐

10. Has anyone ever watched you examine your breasts, to check that you are doing it properly?

- Yes ☐
- No, but I do examine my breasts ☐
- Do not examine my breasts ☐

11. If someone came to you and said she had found a lump in her breast, what would you think about it?

- Almost certainly cancer ☐
- More likely to be cancer than anything else ☐
- More likely to be something other than cancer ☐
- Would not know what to think ☐

12. What do you think she ought to do about it?

- Forget about it ☐
- Wait and see if it changed ☐
- Go and see her family doctor straightaway ☐
- Talk it over with her friends and relatives ☐
- Other (please give details) ☐

.....

13. What do you think are the chances of curing someone who has breast cancer?

- Breast cancer is always cured ☐
- Breast cancer is usually cured ☐
- Breast cancer is sometimes cured ☐
- Breast cancer is never cured ☐

14. Do you think early treatment makes any difference to the chance of a cure?

- Yes ☐
- No ☐

15. Have any of your relatives or close friends had any breast trouble?

Yes, breast cancer	☐
Yes, other breast disease	☐
No	☐
Do not know	☐

16. We know that some women who discover something wrong with their breasts put off seeking medical help. Could you write below any of the reasons why you think this might happen.

During the past winter there was some publicity in Daventry about breast self-examination. We are interested to see how many women heard about this.

17.	Did you read about breast self-examination in the local newspaper?	Yes	☐
		No	☐
18.	Did you hear about breast self-examination from a friend or relative?	Yes	☐
		No	☐
19.	Did you get a copy of the leaflet about breast self-examination?	Yes	☐
		No	☐
20.	Did you see any of the posters about breast self-examination?	Yes	☐
		No	☐
21.	Did you hear about breast self-examination from your family doctor?	Yes	☐
		No	☐
22.	Did you hear about breast self-examination from a doctor at the hospital?	Yes	☐
		No	☐

23. Did you go to a talk given by Mrs.Williams (a Health Visitor) about breast self-examination?

At work? Yes ☐
No ☐

At a club or group to which you belong? Yes ☐
No ☐

At the Health Centre? Yes ☐
No ☐

Elsewhere?(Please specify) Yes ☐
No ☐

24. If you went to a talk by Mrs.Williams, did you have a chance to examine the practice model?

Yes, found it helpful ☐

Yes, didn't find it helpful ☐

No ☐

Didn't attend ☐

25. Did you discuss breast self-examination with

your friends? Yes ☐
No ☐

your husband? Yes ☐
No ☐

other relatives? Yes ☐
No ☐

your workmates? Yes ☐
No ☐

26. If you did hear about breast self-examination, did you find what you heard

very unhelpful	☐
unhelpful	☐
helpful	☐
very helpful	☐
didn't hear about it	☐

27. Do you have any other comments which we might find useful?

Thank you very much for your help in answering these questions.

Please return this questionnaire to Dr.Adam in the envelope marked "Confidential".

POST-PROGRAMME QUESTIONNAIRE TO SECOND SAMPLE

Daventry Health Centre,
Daventry,
Northants.

June 1979

Dear

During the past year there has been quite a lot of publicity in Daventry about health and about various illnesses, and we are interested to find out how effective this has been. Obviously, if the Health Service spends money on this sort of thing, it is important to make sure that it is money well spent.

With the permission of your family doctor, we are writing to you enclosing a questionnaire, which we hope you will find fairly straightforward to fill in. Any information which you give to us will, of course, be treated in the strictest confidence.

We do apologise for bothering you, but would be extremely grateful for you help. If you have any queries, please don't hesitate to contact Mrs. Williams at the Health Centre ('phone number Daventry 3333).

Many thanks for your help,

Yours sincerely,

Dr. Sheila Adam
(Research Fellow, University of Oxford)

Mrs. Kate Williams
(Research Health Visitor)

CONFIDENTIAL

Please answer the following questions - where there are several possible answers, please tick the appropriate box.

1. How old are you? .....years

2. What is your marital status?

- single ☐
- married ☐
- divorced ☐
- widowed ☐
- separated ☐

3. Do you have any children?

Yes ☐ ____children (please say how many, and please say if they are adopted)

No ☐

4. How old were you when you completed your full-time education (that is, when you left school/college/university)?

.....years

What is or was your occupation?

Job.....

Industry/business/organisation.....

What is or was your husband's occupation (if you are or were married)?

Job.....

Industry/business/organisation.....

5. How do you rate your health?

- excellent ☐
- good ☐
- fair ☐
- poor ☐

6. Have you ever had any serious illnesses? Yes ☐ No ☐

If yes, which illnesses were they?

.....

7. Have you ever had any operations? Yes ☐

No ☐

If yes, which operations were they?

.....

8. Have you ever had any trouble with your breasts?

No ☐

Yes, trouble with breast feeding ☐

Yes, pain in breast ☐

Yes, lump in breast ☐

Yes, breast abscess ☐

Yes, some other trouble (please give details) ☐

.....

9. During the past 12 months how many times have you been to see your GP?

.....times

10. Some women examine their breasts regularly just to check that all is well. This is called self-examination of the breasts. Have you ever heard of this technique?

Yes ☐

No ☐

If yes, where did you hear about it?

From family doctor ☐

From cervical smear clinic doctor ☐

From family planning clinic doctor ☐

From nurse or health visitor ☐

From newspaper, magazine, TV or radio ☐

From a friend or relative ☐

Other source (please give details) ☐

.....

11. Has anyone ever taught you to examine your breasts?

Yes ☐

No ☐

If yes, who taught you?

Family doctor ☐

Cervical smear clinic doctor ☐

Family planning clinic doctor ☐

Nurse or health visitor ☐

Friend or relative ☐

Other person (please give details) ☐

.....

12. Do you examine your own breasts?

No, not at all ☐

Occasionally (once a year, or less) ☐

Several times a year ☐

Once a month ☐

More frequently than once a month ☐

13. Has anyone ever watched you examine your breasts, to check that you are doing it properly?

Yes ☐

No, but I do examine my breasts ☐

Do not examine my breasts ☐

14. Have you ever had a cervical smear taken?

No ☐

Yes, within last 3 years ☐

Yes, more than 3 years ago ☐

If yes, where was the smear taken?

- Cervical cytology clinic ☐
- Family planning clinic ☐
- Antenatal or postnatal clinic ☐
- By family doctor ☐
- By hospital doctor ☐

15. If someone came to you and said she had found a lump in her breast, what would you think about it?

- Almost certainly cancer ☐
- More likely to be cancer than anything else ☐
- More likely to be something other than cancer ☐
- Would not know what to think ☐

16. What do you think she ought to do about it?

- Forget about it ☐
- Wait and see if it changed ☐
- Go and see her family doctor straightaway ☐
- Talk it over with her friends and relatives ☐
- Other (please give details) ☐

.....

17. What do you think are the chances of curing someone who has breast cancer?

- Breast cancer is always cured ☐
- Breast cancer is usually cured ☐
- Breast cancer is sometimes cured ☐
- Breast cancer is never cured ☐

18. Do you think early treatment makes any difference to the chance of a cure?

Yes ☐

No ☐

19. Have any of your relatives or close friends had any breast trouble?

Yes, breast cancer ☐

Yes, other breast disease ☐

No ☐

Do not know ☐

20. We know that some women who discover something wrong with their breasts put off seeking medical help. Could you write below any of the reasons why you think this might happen.

During the past winter there was some publicity in Daventry about breast self-examination. We are interested to see how many women heard about this.

21. Did you read about breast self-examination in the local newspaper? Yes ☐ No ☐

22. Did you hear about breast self-examination from a friend or relative? Yes ☐ No ☐

23. Did you get a copy of the leaflet about breast self-examination? Yes ☐ No ☐

24. Did you see any of the posters about breast self-examination? Yes ☐ No ☐

25. Did you hear about breast self-examination from your family doctor? Yes ☐ No ☐

26. Did you hear about breast self-examination from a doctor at the hospital? Yes ☐ No ☐

27. Did you go to a talk given by Mrs.Williams (a Health Visitor) about breast self examination?

At work Yes ☐ No ☐

At a club or group to which you belong? Yes ☐ No ☐

At the Health Centre? Yes ☐ No ☐

Elsewhere? (please specify) Yes ☐ No ☐

28. If you sent to a talk by Mrs.Williams, did you have a chance to examine the practice model?

Yes, found it helpful ☐

Yes, didn't find it helpful ☐

No ☐

Didn't attend ☐

29. Did you discuss breast self-examination with

your friends? Yes ☐ No ☐

your husband? Yes ☐ No ☐

other relatives? Yes ☐ No ☐

your workmates? Yes ☐ No ☐

30. If you did hear about breast self-examination, did you find what you heard

very unhelpful	☐
unhelpful	☐
helpful	☐
very helpful	☐
didn't hear about it	☐

31. Do you have any other comments which we might find useful?

Thank you very much for your help in answering these questions.

Please return this questionnaire to Dr.Adam in the envelope marked "Confidential".