PREFERENCES FOR INFORMATION AND DECISION MAKING IN WOMEN WITH BREAST CANCER: A FOLLOW UP STUDY

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor in Philosophy in the Faculty of Medicine.

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DECLARATION

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification in this or any other university or institute of learning.

Kimba Bower.

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ABSTRACT

Although health care professionals may see their role as encouraging consumer involvement in care and treatment, it is not known whether the concepts surrounding involvement in care are clearly understood or even agreeable to the consumer. Understanding the consumers perspective is of paramount importance if we are to improve quality of care.

This study incorporated a longitudinal design to examine the concepts of decision making and information need from the perspective of women with breast cancer. Interviews were carried out with a consecutive sample of 150 women, newly diagnosed with breast cancer, with 105 of these women being interviewed on a second occassion, a mean of 21 months from diagnosis. A sample of 200 women with benign breast disease were interviewed as a comparison group. The study aimed to determine what role these women wanted to play in treatment decision making using a card sort technique developed in Canada (Degner and Sloan 1992), enabling a preference order to be established that could be analysed using a unidimensional scaling model termed unfolding theory (Coombs, 1964).

To establish priority information needs for the study samples a Thurstone Scaling approach was used (Thurstone, 1974) allowing nine items of information to be placed in order of perceived importance. An investigation was also made of the sources of information utilised at two time points.

The findings from this study showed that a majority of women, newly diagnosed with breast cancer, preferred to play a passive role in treatment decision making and this passive preference was sustained at a mean of 21 months from diagnosis.

The priority information needs for women newly diagnosed with breast cancer were survival issues (cure, spread of disease, treatment). Further from diagnosis a similar pattern of information needs emerged although information about the risk to the family of getting breast cancer had become more of a priority issue.

At the time of diagnosis women obtained their information from the breast specialist service with a majority of women perceiving that they had received no information from their General Practitioner (GP), hospital nurses or the voluntary sector. At the follow up stage the sources of information that were considered the most useful were media sources. At this stage a minority of women were receiving useful information from professional sources such as the breast care nurse, the GP, or hospital nurses.

The findings from this study suggest that it is important to establish individual decision making preferences rather than advocating participation or non-participation for all. It is also important to establish the information needs of women with breast cancer and to meet the differing needs for information at different points in time. The women in this study had information needs further from diagnosis but had few professional sources of information. A deficit in information giving appeared to occur once women had been discharged from the hospital environment.

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INTRODUCTION

Breast cancer is a common disease that affects one in twelve women in the UK (Dixon and Sainsbury, 1993). Rapid advances in early detection, diagnosis and treatment have taken place in recent years in parallel with changes in the status of service users from that of passive recipient of health care to equal partner. These changes have meant that many women are faced with difficult treatment choices. Providing accurate information in order to enable the decision making process has increasingly become part of the health care professional's remit.

Meeting the physical, psychological and social needs of individual patients is a primary concern for the nursing profession. However, nurses and other health care professionals may be in danger of making assumptions about the needs of patients without prior assessment of what patient's perceive their needs to be.

An interest in the psychological aspects of health care and a specific interest in the needs of women with breast cancer developed from the researcher's academic and clinical background as a psychology graduate and a registered general nurse. When the researcher commenced nurse training there was an increasing interest in the application of psychological theories and processes to the provision of nursing care. When this interest was formalised it had a major impact on practice. The nursing process introduced a holistic approach to nursing, a change of focus from the physically orientated approach of the biomedical model.

While this approach seemed admirable in terms of improving the quality of patient care it was not clear if nurses had the necessary skills to assess the psychological needs of their patients, if they knew how best to respond to these needs, or if they had the time available to respond to these needs. This became particularly apparent to the researcher while working as a staff nurse on a number of acute general surgical wards. In particular it was not clear which health care professional had responsibility for imparting certain types of information. Information about diagnosis and prognosis appeared to be the domain of the doctor but in other areas the situation seemed less clear.

The researcher spent the most part of her clinical experience on female surgical wards where women with breast cancer were admitted for treatment on a regular basis. Providing information for women with breast cancer appeared to present particular problems for nurses. In their desire to avoid emotionally sensitive areas, nurses were observed to focus on the physical aspects of care and avoid discussion of psychological needs. In this respect information was often not given unless it was asked for.

The breast specialist nurse, however, appeared to have a particularly important role in providing information for women with breast cancer. While employed as a breast care nurse the researcher observed that, in many instances, ward nurses would avoid discussion of sensitive areas, deferring to the breast care nurse. However, the researcher was not given any specific training in communication skills nor was she given any specific teaching on the psychological aspects of breast cancer. The post incorporated both breast and stoma care and the researcher, by necessity of limited time and resources, had to focus her attentions on the women with breast cancer at the time of their hospital admission. Although home visits were feasible they were only offered to the stoma patients who presented with more physical and practical problems that would affect future rehabilitation and well being. The women with breast cancer had to be given all the information that was thought necessary during admission, and with the length of hospital stay decreasing rapidly, this was often difficult. The researcher was concerned that these women had many unanswered questions or questions may have arisen at a later date with little access to information sources.

As breast cancer is affecting increasing numbers of women these experiences emphasised for the researcher the relevance of this area to nursing and the importance of finding out individual preferences and needs if nurses are to provide the individualised nursing care espoused by the nursing process and the many models of nursing in use by the nursing profession today.

This study investigated the degree of involvement that women with breast cancer felt they would want to have in the treatment decision making process. Decision making and information need may be inextricably bound together, in that any decision made about health care may be dependent on the amount and type of information received. It was, therefore, of interest to explore the service users perspective on these areas and to examine the type of information considered to be important to women with breast cancer as well as to explore the sources of information utilised by these women.

CHAPTER 1

LITERATURE REVIEW

SELECTION OF LITERATURE

There is a vast literature concerned with the experiences and feelings of women with breast cancer arising from disciplines such as nursing, medicine, psychology and sociology. The researcher aimed to select literature that was relevant to the issues involved in the study and that was also methodologically sound, in terms of validity and reliability, as well as being up to date.

There have been many changes in the practice of nursing in recent years and many policy changes within the National Health Service (NHS) that impact on the concepts under investigation. For these reasons literature published during the late 1980's and 1990's that is able to reflect the changes in current practice has been seen to be most relevant, although older studies have been included where they have provided seminal work particularly with regard to methodological issues and measurement tools.

While studies from countries other than the United Kingdom (UK) have been cited, the researcher has attempted to review studies that were relevant to the current health care system in the UK. For this reason studies carried out in the UK are seen as most pertinent and studies carried out in Canada and parts of Europe are also considered to be relevant. While it is acknowledged that the health care system of the United States of America (USA) is not directly comparable to that in operation in the UK there is a huge body of literature emanating from the USA relevant to women with breast cancer and it would be an omission not to include some of these studies.

BREAST CANCER: THE EXTENT OF THE PROBLEM

One in twelve women in the UK will develop breast cancer at some time during their lives, with approximately 25,000 new cases being diagnosed each year (Kings Fund Forum, 1986). Breast cancer is the most common malignant tumour in women in the western world and incidence has slowly increased over the last thirty years. Incidence is known to increase with age and, given the demography of the UK, the prevalence of breast cancer is likely to increase. In 1991 13,000 deaths occurred in England as a result of breast cancer with 89% of these in women aged fifty years or older (Department of Health, 1993).

The cause of breast cancer is unknown and there is no certain way of predicting who will develop the disease. Certain risk factors have been indicated such as early menarche, late menopause, late child bearing, benign breast disease, genetic predisposition and oral contraception but evidence remains inconclusive (Department of Health, 1993).

These are depressing statistics and a cause for concern for women and their families, as well as health care professionals who are increasingly likely to come into contact with women with breast cancer at some stage of the disease trajectory.

A vast amount of media attention has been given to breast cancer in recent years for various reasons. Following the recommendations of the Forrest Report (Forrest, 1986) national breast screening came into operation in the UK with every woman between 50 and 64 years of age being invited to attend for mammography. Initial opinion was that screening would detect breast cancer at an earlier stage and treatment, as a result, would be more conservative. This would, therefore, benefit women and hopefully prolong life if early detection impacted on mortality rates. However, no reliable evidence has yet emerged to demonstrate the effectiveness of breast screening in terms of reducing mortality rates (Roberts et al 1990, Taylor & Little 1992). This has major implications for policy makers investing substantial amounts of money into the screening programme and for women who may well gain no benefit in terms of prolonging life, but who may be given increased anxiety for a longer period of time than if they had waited for the screen detected lesion to appear as a symptom.

Media attention has also focused on the identification of a gene for breast cancer. This work has brought to the public eye the importance of genetic factors in the transmission of breast cancer with increasing numbers of people being aware that breast cancer can have a hereditary component. The cloning of the BRCA1 gene was reported in Science in 1994 (Miki et al 1994). Family risk clinics have already been established in some parts of the UK for the assessment of women who believe they are at risk of developing or transmitting breast cancer and it is likely that attendance at these clinics will increase as more women become aware of the possible impact of hereditary factors in the development of breast cancer. At present there is no test for the BRCA1 gene available and assessment of high risk is based on clinical factors;

for example, having a first degree relative with breast cancer who was pre-menopausal at the time of diagnosis. Increasing public awareness of the cloning of the BRCA1 gene may not necessarily help women who believe they are at high risk of developing breast cancer in terms of reducing anxiety as the only options normally available are regular examinations with the onus often being on the women to carry out regular breast self examination and report any abnormalities.

Problems have also been reported with silicone breast implants, although these problems seem to have arisen primarily in the USA. The concerns reported about the different disorders caused by the leakage of silicone implants have created anxiety in the population of women in the UK who have received a silicone breast implant as part of their breast cancer treatment. However, there is no medical evidence that has yet emerged to substantiate claims made by American women and their lawyers.

The examples above serve to demonstrate that increased media attention to changes in the detection and treatment of breast cancer may not necessarily provide clear answers for health care professionals or women with breast cancer. There are no certain answers for women to the problems cited. Evidence on breast screening and silicone implants is inconclusive while genetic risk of developing breast cancer is a complex area. If health care professionals do not have clear information on these areas then women may well receive conflicting and confusing information.

CHANGES IN PRACTICE

A number of changes over the years have encouraged greater patient control and participation in medical decisions. The consumer movement has led the Government to introduce policies that demand more rights for individuals in their dealings with the health care service (Department of Health, 1991). The general public are also more knowledgable about health matters, partly due to the increased attention given to health topics by the media. Many practices now make case notes available to individuals. All these changes have gone some way to demystifying health care.

With the introduction of such government documents as the Patient's Charter (Department of Health, 1991) service users were increasingly encouraged to play an active part in their care and treatment. These changes in government policy parallelled changes within the nursing and medical professions in moving towards a more collaborative partnership between health care professionals and consumers of health care.

Traditionally nursing based its practice on the biomedical model, with an overriding concern for cure and a focus on disease (Pearson & Vaughan, 1989). Within the framework of the biomedical model there was no conflict over who had responsibility for the patient. The doctor was seen as the decision maker with the nurse and the patient playing subservient roles.

For the nursing profession, the introduction of the nursing process involved a move away from the previous task allocation model of care towards a more holistic individualised approach to care. Encompassed within this was a more interactive partnership between the nurse and patient. The holistic approach incorporated a consideration of the whole person with physical, psychological and social needs and patient participation was seen as something of value (Wright, 1986).

The nursing profession in recent years appears to have embraced the participatory model wholeheartedly as evidenced from the many models of nursing that focus attention on the whole person and involve a partnership in assessing health needs and planning care (for example: King 1971, Neuman 1982, Orem 1980, Roper, Logan and Tierney 1985, Roy 1976). The Activities of Daily Living Model described by Roper, Logan and Tierney showed how the four stages of the nursing process (assessing, planning, implementing and evaluating) could be carried out in an individualised manner stating that "throughout all four phases of the process the patient should wherever possible be an active participant" (Roper, Logan and Tierney, 1985, p71).

Wright (1986) described how nurses could build their own models of nursing that would be relevant to their areas of clinical practice and that would involve the patient as 'partner'. Patient participation has also been described in the nursing literature as having certain benefits in terms of achieving 'positive health' (McCarthy, 1985), increasing patient compliance (Macleod Clark & Latter, 1992) and increasing patient satisfaction (Manthey, 1980). However, it is a simple matter to articulate the potential benefits of participation as perceived from a health care professionals point of view. It is a more complex process to investigate the benefits as perceived from the service users perspective. Increasing patient compliance may be perceived as beneficial to health care professionals but there is an argument to suggest that valuing the input of the service user in a sharing partnership is not compatible with the concept of compliance.

The medical profession has also attempted to introduce a participatory role for the patient and has addressed criticisms of the traditional paternalistic attitudes of doctors. The imbalance of power between doctors and patients was maintained for a long time and for a number of reasons (Brody, 1980). Brody (1980) suggested that doctors had an esoteric body of knowledge that produced an information gap that was difficult to close. He further suggested that doctors often made assumptions that they knew their patients needs without having to ask, that doctors were reluctant to relinquish their power and control over patients, and that doctors saw a loss of power as a threat to their professional status.

It has been argued that the model of mutual participation is largely unknown to medicine (Meredith, 1993) and despite changes in government policy it is not clear if medicine has found it easy to accept the concept of patient participation. Meredith (1993), a surgeon in the UK, examined the concept of patient participation in decision making using a non-participant observation approach that involved carrying out in depth questioning and observation of surgeons and patients over a ten week period. From this initial data collection 100 standard questions were devised to explore the patients' feelings about participation and quality of care. These questions formed the basis of open interviews held with 30 post-operative patients. The most cited limitation on patient participation, as far as the patient was concerned, was the need to absorb the meaning of a diagnosis and react to it in the few minutes that were available for consultation. The 14 surgeons in this study who were interviewed in depth were not enthusiastic about setting aside more time to discuss treatment options, expressing beliefs that patients did not have the knowledge to assess alternatives, that many did not show an interest in making decisions, and that some seemed too emotionally distraught to be involved. Although sample sizes were small in the Meredith study, it has relevance as it involved in-depth questioning of both service users and health care professionals in the UK health care system and provided useful insights into the way in which health care professionals can make assumptions about individuals in their care without actually seeking to examine the preferences of individuals.

Participation Defined

Although it seems clear to government and health care professionals that participation should be encouraged there have been different approaches in defining what participation means (Brierley, 1990). In a review of the literature on patient participation Brierley (1990) noted that some individuals have assumed the terms patient participation and self care are interchangeable while others have focused on the participating patient as an active patient. A model of collaboration and partnership between users and providers of health care may be a more appropriate basis on which to consider the concept of patient participation.

Providing a definition of patient participation may then be somewhat problematic. However, a definition provided by Brownlea (1987), and favoured by Brierley (1990) in her review of patient participation literature, may be the most appropriate:

> *"Participation means getting involved or being allowed to become involved in a decision making process or the delivery of a service or the evaluation of a service, or even simply to become one of a number of people who are consulted on an issue or a matter."*
>
> *(Brownlea, 1987, p 605)*

The appeal of this definition lies in its acknowledgement that participation is a matter of collaboration while not failing to appreciate that health professionals can influence the degree of collaboration 'allowed'. The definition also enables individuals to be involved in, and given information about, their care and treatment without necessarily having to make health care decisions.

Enabling Participation

Allied to the concept of patient participation are the concepts of empowerment and advocacy. Empowerment can be defined as an enabling process and providing information can be seen as a way of empowering individuals and enabling them to take responsibility for care and treatment decisions.

However, many practical difficulties exist for nurses who want to empower individuals. Although empowerment goes some way to try and reduce the status gap between users and providers of health care, service users are often disadvantaged by their lay status and their illness. Also, many individuals may not wish to be empowered. This is an important point as there is a danger that nurses and other health professionals may take on the current popular concepts of empowerment and patient participation, without stopping to consider the preferences of service users.

In seeking to empower patients the nurse is being encouraged to act as patient advocate which may be seen to conflict with the concept of patient participation. Copp (1986) described advocacy as speaking for 'vulnerable persons'. However, regarding people as vulnerable may not encourage nurses to promote an active participatory role in care and treatment decisions. Indeed, regarding people as vulnerable may lead nurses to usurp the rights of individuals to speak for themselves (Brierley, 1990). Brierley (1990) suggested that nurses could more appropriately act as patient advocates if they added their voice to that of the patient rather than speaking for the patient and this emphasises the more collaborative partnership between health care professionals and service users that may be the most appropriate model for understanding patient participation.

Participation, empowerment and advocacy have all aimed to redress the imbalance of power between health care professionals and service users. However, service users may have come to expect this imbalance of power, particularly older people who have traditionally become accustomed to the role of passive recipient of health care. This may become a self fulfilling prophecy if health care professionals assume that a decision not to participate means that the individual does not require information. If information is not given then an individual may find it difficult to make a decision. A desire not to make decisions may then be confused with a desire for no information.

Participation in care and treatment decisions may be dependent on being given information about options and health care professionals have the power, consciously or unconsciously, to weight one option as being more preferable than another. They also have the power to be selective in giving information to service users. If different health care professionals have different biases and preferences then service users may receive conflicting information.

There is evidence to support that, prior to the shift from paternalism to partnership, very little information was provided on certain aspects of care. With a life threatening condition such as cancer it was traditional not to divulge information about the cancer diagnosis (Novack et al 1979). If individuals are not aware of their condition then it is difficult to see how they could participate in care and treatment decisions. Novack et al (1979), in a study that involved 264 medical staff in the USA, found that attitudes had changed as regards telling cancer patients their diagnosis; 97% of the study sample now preferred to tell cancer patient's their diagnosis whereas a similar study, carried out in 1961, had found that 90% of 219 medical staff advocated not telling cancer patients their diagnosis (Oken, 1961). These studies are interesting in highlighting the way that attitudes have changed and attempts at redressing the balance of power in health care are being made. This may be particularly pertinent in health care systems, such as that in operation in the USA, where informed consent is a legal requirement and much more formalised than in the UK.

Although honesty and open communication about a cancer diagnosis may go some way towards promoting participation, empowerment and autonomy for patients, health care professionals can remain in a position of power in relation to the patient. Making rational choices and acting on these choices is only possible if a choice has been presented in the first instance. Health care professionals have the power to withhold information and to present all options, selected options or no options at all. Patients may only be able to act on choices if 'allowed' to do so by health care professionals. Also, not all individuals may make rational choices. Encouraging patients to participate in health care decisions may mean health care professionals have to accept that patients may not always make the logical choices they would expect them to make.

Imbalance in Health Care

Evidence suggests the existence of an information gap between the health care professional and the service user (Audit Commission, 1993). If health care professionals choose not to divulge information about the existence of particular services then, in practice, an imbalance in health care will result that impacts on the quality of patient care and effects the creation of collaborative partnerships. For example, receiving the highest quality treatment for breast cancer has been likened to a lottery depending on which part of the country a person happens to reside (Chadda, 1995). A high quality service for women with breast cancer would include access to specialist services and personnel. However, not all health authorities employ a breast specialist consultant or a breast specialist nurse.

For many women with breast cancer the clinical reality involves a short stay in hospital where, by necessity of limited time, care is focused around the time of diagnosis and treatment. In this short space of time nurses are expected to adequately assess these women's physical, psychological and social needs and, using a participatory model, produce a plan of care that can be implemented. If nurses are well informed on the proposed plan of treatment and have effective communication skills then a free flow of information between the nurse and the woman with breast cancer would enable a plan of care to be devised that would reflect the true needs of the woman. If nurses do not have the necessary information to impart or do not feel clear as to their role as information givers then this collaborative partnership may be superficial.

In summary, changes in nursing and medical practice, in parallel with government policies, have advocated a participatory model of care as best practice, with the expectation that involving service users in the decision making process will be received positively and will benefit the individuals concerned.

CHOICE OF TREATMENT

Underlying a model of participation and involvement in the decision making process is the issue of choice. To make decisions about treatment, information is necessary and choices or alternatives need to be presented so that informed decision making can take place. In many cases service users are being presented with a number of options and asked to state a preference about their care and treatment. In this case it may be important to examine the type of choices available to these women and the impact of being offered a choice on outcome, in terms of psychological adjustment to a cancer diagnosis.

Changes in the Surgical Treatment of Breast Cancer

One of the pro-screening arguments was that early detection of breast cancer would allow for more conservative surgery to be carried out which would be received positively by women diagnosed at an early stage. Before it was fully appreciated that breast cancer was a systemic disease the surgeon's choice of treatment was mastectomy (Gazet et al 1985). In 1985 Fisher and his colleagues published work that stated there was no difference, in terms of long term survival, between women treated with mastectomy and women treated with more conservative surgery (for example, lumpectomy) followed by radiotherapy (Fisher et al 1985).

Following the publication of these findings notable differences were observed in the surgical management of breast cancer in England (Morris, Royle and Taylor, 1989).

One study reported that 64.4% of surgeons now preferred to carry out conservative surgery compared to 18% of surgeons who had preferred to carry out conservative surgery prior to the publication of Fisher's work (Gazet et al 1985).

This meant that for many women there was now a choice of treatment and presenting a choice of treatment was advocated as best practice. Indeed at the Kings Fund Forum held in London in 1986 a consensus conference, involving health care professionals as well as patients, advocated that treatment options should be discussed and women should be able to make choices if they wished to do so (Kings Fund Forum, 1986).

Assumptions Surrounding Choice

The advent of treatment options for women with breast cancer led to a whole myriad of studies that looked at the implications, mainly in terms of psychological outcome, in choosing one treatment over another. As no cause for breast cancer could be determined and the efficacy of breast screening was yet to be proven, attention on psychological issues, such as the emotional impact of cancer, continued to be seen as important in improving the quality of life for women with breast cancer.

It was envisaged that the availability of less mutilating surgery would lead to better psychological adjustment and a decrease in psychological morbidity and there is some evidence to suggest that this may be the case (Kemeny et al 1988). However, many other studies indicated that there were no differences, in terms of psychological adjustment, between women treated by mastectomy and women treated with more conservative surgery (Fallowfield et al 1986, Fallowfield et al 1990, Ganz et al 1992, Levy et al 1992, Maunsell et al 1989, Meyer and Aspegren 1989). Indeed, when presented with a choice of treatment, some studies indicated that women do not automatically choose to retain their breast (Tate et al 1993, Wilson et al 1988).

The studies cited above indicate how health care professionals can often assume that they know what options individuals would choose without seeking to investigate individual preferences. A difference in perception is apparent here as health care professionals assume that women will opt for more conservative surgery and this will benefit the women in terms of psychological morbidity, assumptions not borne out by the reality of the situation. More complex issues appear to be involved than a simple logical and rational choice. A whole host of physical, psychological and social factors may impact on the woman in influencing her choice; for example, attitudes concerning breast cancer, knowledge of breast cancer, attitudes and feelings of partner and family members, age at diagnosis, concerns about side effects of adjuvant therapy and proximity to treatment centre.

There is still much debate within the medical profession about the most effective combination of treatments for particular age groups of women and tumour types. The Early Breast Cancer Trialists Collaborative Group (1992a, 1992b) concluded that a reduction in deaths from breast cancer could be achieved by the use of tamoxifen, chemotherapy and ovarian ablation in women under 50 years. This effect could be maintained for up to ten years. It has been suggested that many more patients are needed to take part in clinical trials (Gelber, Coates and Goldhirsch, 1992). Although

Gelber et al (1992) state that care will not be compromised it is a cause for concern that the only choice that may be available in this scenario would be to enter a trial or not.

If more women are needed to enter trials then clear and accurate information about trials will need to given to women so that they can make an informed choice to participate or not. The concern here is that women may be coerced into taking part in trials and feel guilt if they do not show willing to help other women with breast cancer.

Impact of Choice on Outcome

Although the area of treatment choice for women with breast cancer may be somewhat complicated it is generally considered that a choice of surgery between mastectomy and lumpectomy followed by radiotherapy is the most common choice scenario and studies have been carried out to examine the impact of being presented with such a choice (Ashcroft, Leinster and Slade 1985, Fallowfield et al 1994, Leinster et al 1989, Morris and Royle 1988).

One of the few studies carried out in the UK on the impact of patient choice on psychological outcome assessed 49 women who had undergone treatment for breast cancer and had been presented with a choice of surgery (Ashcroft, Leinster and Slade 1985). Ashcroft, Leinster and Slade (1985) used tests of anxiety, depression, marital adjustment, self esteem, body satisfaction, sociability and life change. Women who chose lumpectomy talked about their concern over bodily appearance and the need to retain the breast while women who chose mastectomy talked about the affected breast being 'foreign' and preferred to be rid of it. The important element here appeared to be that of choice with the reporting of little psychological morbidity within the study sample irrespective of choices made.

There is also evidence to suggest that the benefits of choice for women with breast cancer, in terms of preventing psychological morbidity, may extend to the women's husbands. In a small study carried out in the UK, Morris and Royle (1988) examined the impact of choice on 30 women with breast cancer, and their husbands, in terms of anxiety and depression pre- and post-operatively. Significantly more women who had not been offered a choice of surgery had clinical levels of anxiety and depression up to two months post operatively than women who had been offered a choice, and this finding was similar for the husbands of these women.

Sample sizes were small in both the Ashcroft et al (1985) and Morris and Royle (1988) studies. However, a study carried out by Fallowfield et al (1994) produced similar findings when 269 British women with breast cancer were assessed using semi-structured psychiatric interviews and standardised questionnaires. The women were assessed prior to treatment, two weeks after treatment and at three, 12, 24 and 36 months after treatment. Of the 269 women involved in the study 118 were offered a choice of treatment. The benefits, in terms of lower levels of anxiety and depression, in being offered a choice of surgery were apparent up to three years post-operatively (Fallowfield et al 1994). Although there is little evidence to support that choice actually prevents psychological morbidity it may be that effective communication of treatment options in an information exchange can have certain benefits for the service user.

Psychological impact of breast cancer

The stress and anxiety surrounding a diagnosis of cancer may make it difficult for individuals to absorb information and make decisions about their treatment. It has been suggested that many patients do not mention psychological morbidity because they do not think it is appropriate or acceptable to mention it to a health care professional (Maguire, 1994). However, some individuals may need psychological support before they feel able to become involved in the decision making process and it may be important for health care professionals to have some degree of awareness of the psychological impact of the diagnosis to the individual.

There is evidence to suggest that pre-existing psychological problems may influence the degree of psychological morbidity experienced by women who are diagnosed with breast cancer. Maunsell et al (1992) assessed 205 women newly diagnosed with breast cancer at 3 and 18 months after surgery. Maunsell et al found that the number of stressful life events before diagnosis and a history of depression appeared to be useful indicators of which women would require more intensive psychological support. High levels of psychological distress were apparent in 63.1% of women with a history of depression compared to 14.3% of the women with no such history and this association remained at 18 months from diagnosis. It is a cause for concern that these women had such high levels of psychological distress up to 18 months from surgery and that these problems had not been identified by a health care professional.

Although the Maunsell et al (1992) study indicates that it may be possible to predict those individuals who will need more psychological support than others based on pre-existing conditions, other studies indicate that assumptions should not be made about who will need psychological support and who will not. Fallowfield et al (1986) assessed psychological morbidity in 101 women treated for early breast cancer. The incidence of anxiety states and depressive illness was found to be high (33% in women who had undergone mastectomy and 38% in women who had undergone conservative surgery) irrespective of the extent of surgical treatment. Based on these findings Fallowfield et al suggested that all women with breast cancer should receive counselling and have their psychological needs assessed and not just women being treated by mastectomy.

Psychological problems in women with breast cancer have not been confined to the diagnostic phase. Hopwood et al (1991) reported on a study of 214 women with advanced cancer of the breast. The women were asked to complete questionnaires (Hospital Anxiety and Depression Scale, HADS, and the Rotterdam Symptom Checklist, RSCL) in order to determine the prevalence of psychiatric morbidity. Of the women who completed the HADS, a total of 27% were defined as 'cases' in that they had scores indicative of affective disorder. Of the women who completed the RSCL 22% were defined as 'cases'. Overall 33% of the patients were believed to have an affective disorder when the scores of the two questionnaires were combined.

If psychological problems are prevalent in women with breast cancer then the psychological impact of the breast cancer experience may impact on the way in which information is received and may influence both the desire and the ability to make decisions.

Information Processing

If there are benefits for individuals who are presented with a choice of treatment then the role of information in enabling the decision making process may be critical for making that choice. However, times of stress, such as initial diagnosis, may make participation difficult. For example, a descriptive study carried out in the USA of women who had undergone mastectomy for breast cancer examined which period of time was the most distressing: the diagnostic phase, the treatment phase or the adaptation phase at home (Northouse, 1989). Of the 50 women and their husbands interviewed in the Northouse (1989) study, 83% of the women and 50% of the husbands stated that the time of diagnosis was the most stressful period. This is an important consideration as, for many women with breast cancer, the time of diagnosis is when they are most likely to be involved in the decision making process.

The diagnosis of breast cancer has been described as a time of crisis (Parry 1990) and under these circumstances there may be problems with the way in which information is processed by individuals. Giving information is of no benefit if that information is not understood or if the individual cannot retain and recall the information at a later date.

It has been suggested that individuals respond to crises with anxiety and an inability to think clearly (Parry, 1990). This is an important point as women with breast cancer are often expected to think clearly and logically when they have been told they have breast cancer and to weigh the advantages and disadvantages of different treatment options. For many women this will be a time of extreme anxiety where they may have to confront their own mortality for the first time.

If individuals have problems in retaining and recalling information at this stressful time then there is an argument for not overloading individuals with information that they cannot assimilate. However, the need to make treatment decisions is often most prominent at the time of diagnosis and information is needed to make an informed choice. Therefore, getting information is important and, as Parry (1990) states:

> *"information gathering reduces uncertainty and gives a sense of control as well as preparing the way for further action"*
>
> *(Parry 1990, p55)*

Individuals need to direct attention if they are to deal with incoming information and intense mental exertion can lead to a decreased capacity to concentrate and direct attention, termed 'attentional fatigue' (Cimprich 1992). Cimprich (1992) examined the concept of attentional fatigue in women who were a mean of three days from surgery for breast cancer using measures that included, for example, asking individuals to recite the alphabet backwards from a specified letter. In this study the women displayed a decreased capacity to direct attention regardless of the type of surgery they had received and the findings suggested that attentional fatigue may start to develop prior to treatment when a great deal of mental exertion was needed. Cimprich stated that one important consequence of the loss of attention was the difficulty in acquiring and using information.

If important information is lost at the time that treatment choices are presented then the ability and desire to make decisions may be influenced. In this respect it seems important to investigate if individuals feel comfortable making choices at times of stress and crisis.

PREFERENCES FOR PARTICIPATION IN DECISION MAKING

In reviewing the literature on preferences for participation in decision making many conflicting findings emerged. The studies reviewed in this section of the literature review are summarised in Table 1 and indicate no clear consensus on the role that service users would prefer in the decision making process.

Table 1. Preferences for Participation in Decision Making: Summary of Studies Reviewed

Authors	Year	Sample	Country	Measure/design	Preferred role
Blanchard et al	1988	n=439 cancer patients	USA	2 DM roles (participation vs non-participation)	Active
Cassileth et al	1980	n=256 cancer patients	USA	2 DM roles (participation vs non-participation)	Active
Catalan	1994	n=60 men HIV n=80 staff	UK	Autonomy Preference Index (API) 6 DM roles	Active
Degner & Sloan	1992	n=436 cancer patients n=482 general public	Canada	Control Preferences Index (CPI) 5 DM roles	Passive Share
Ellis & Leventhal	1993	n=50 children with cancer	USA	Survey. Multiple choice and open ended questions	Passive
Ende et al	1989	n=313 medical patients	USA	Autonomy Preference Index (API) 6 DM roles	Passive
Pickering & Broadley	1995	n=82 women with breast cancer	UK	Qualitative interviews	Share or Passive
Sutherland et al	1989	n=52 cancer patients	Canada	5 DM roles	Passive

DM= Decision making

Preference for an Active Role

There is evidence to suggest that many service users may prefer an active role in the decision making process. Cassileth et al (1980) examined the treatment decision making preferences of 256 cancer patients in the USA. They found that the majority of their study sample preferred active participation and that younger, more highly educated individuals were more likely to prefer active participation than older, less well educated individuals.

However, Cassileth et al (1980) only presented their study participants with two decision making roles: 'I prefer to leave decisions about my medical care and treatment up to my doctor', and 'I prefer to participate in decisions about my medical care and treatment'. The definition of participation inherent in this measure is not clearly defined. Preferring to participate in decisions does not necessarily equate with wanting to make decisions. It may be that an individual wants to be well informed and to be involved in the decision making process but does not want the responsibility of actually making a decision. Alternatively, participating for some individuals may encompass the desire to make decisions. Two decision making roles may not be sufficient to capture the preferences that individuals have for involvement in decision making.

Despite the limitations of the Cassileth et al (1980) measure it was used in a more recent study of the treatment decision making preferences of 439 adult cancer patients (Blanchard et al 1988). Blanchard et al (1988) found that 69% of the study sample preferred to participate in decision making. As with the Cassileth et al (1980) study, demographic variables were found to have an impact on decision making preferences. Age was a significant factor with younger people preferring to play a more active role in decision making. The people less likely to want an active role in the Blanchard et al study were male, married and had a low health status (for example, poor mobility). They also found that people with lung cancer were more likely to prefer that the doctor make decisions for them, a passive role, than people who had a diagnosis of breast cancer, prostate cancer, colon cancer or lymphoma.

However, Blanchard et al (1988) do not say what choices were available for people with lung cancer. It may be that the options were quite clear for women with breast cancer with no difference in outcome, whereas outcome may be very different for different types of treatment for lung cancer. Lung cancer generally has a poor prognosis and decisions may be complicated if more immediate attention has to be given to morbidity and mortality issues.

Both the Cassileth et al (1980) and the Blanchard et al (1988) studies were carried out in the USA where service users have been aware of their rights in health care for some time. Service users in the USA are familiar with seeking out their own specialist health professional rather than following the pattern of GP referral evident in the UK health care system. It may be that this difference in health care systems encourages more people to want to play an active role in decision making in the USA.

However, a study carried out in the UK demonstrated that British service users may also prefer active involvement in decision making. Catalan et al (1994) examined the decision making preferences of 60 men with HIV infection and 82 members of staff who had contact with these men using a measure of decision making preference developed by Ende et al (1989) and termed the Autonomy Preference Index (API). Although this measure presented six possible roles in decision making, four of these roles were passive (where the doctor would be the primary decision maker) and two were active (where the service user had some degree of involvement in the decision making process).

Catalan et al (1994) found that the majority of the men with HIV infection preferred active involvement although the staff had higher preferences for patient involvement than did the patients themselves. It is interesting to note that the Catalan et al study found that doctors had lower preferences for active participation than did nurses, and that symptomatic patients had lower preferences for active participation than did asymptomatic patients.

The findings from the Catalan et al (1994) study could reflect a preference for decision making dependent on type of disease and severity of condition. Arguably the decision making preferences of a sample of men with HIV infection may be different to the preferences of women with breast cancer.

Preference for a Passive Role

Although the studies reviewed so far indicate that individuals may be willing to participate in decisions concerning their care and treatment there is evidence to suggest that for many individuals the preference is for a passive role with the doctor taking on the role of primary decision maker.

For example, a large study carried out in Canada, using a measure that involved five decision making preferences ranging from an active, through sharing to a passive role, found that 59% of 436 newly diagnosed cancer patients preferred a passive role in decision making (Degner and Sloan, 1992). A comparison was made in this study to 482 members of the general public, 64% of whom believed they would want to play an active role in decision making if they were ever diagnosed with cancer. This led Degner and Sloan (1992) to suggest that the impact of the diagnosis of cancer may be influencing decision making preferences.

Another Canadian study, using a similar measure of decision making preference to that used by Degner and Sloan (1992), also indicated that a passive role in decision making may be the preferred role for the majority of individuals (Sutherland et al 1989). Sutherland et al (1989) described the decision making preferences of 52 cancer patients. Although many of these individual actively sought information, 63% preferred the doctor to be the primary decision maker.

A qualitative study carried out in the UK examined the decision making preferences of women with breast cancer, involving interviews with 82 women who were between six and eighteen months from a diagnosis of breast cancer (Pickering and Broadley 1995). They looked at how the decisions regarding treatment had taken place and concluded that women in the study felt that an active role in decision making was inappropriate and preferred a sharing or passive role, although Pickering and Broadley (1995) do not provide data on how many women had these preferences.

Studies in the USA with different patient groups have also indicated that many individuals may not want to play an active role in decision making and that demographic and treatment variables may impact on preference (Ende et al 1989, Ellis and Leventhal 1993). Ende et al (1989) examined the decision making preferences of 313 medical patients, using the API index, and found that the majority preferred a passive role in decision making; on a scale where 0 indicated a very low and 100 indicated a very high preference for decision making, the mean score for the study sample was 33.2. Younger individuals were more likely to prefer active involvement in decision making and people with a better health status were more likely to prefer an active role in decision making, although socio-demographic variables only accounted for 15% of the variability of patients' decision making preferences.

The impact of age on decision making preferences has not been clearly established and while evidence presented so far indicates that younger people may prefer a more active role in decision making than older people, this has not been found to extend to children's preferences for involvement in decision making. A study carried out in the USA examined the decision making preferences of 50 children with cancer (aged between 8 and 17 years of age and mainly leukaemia sufferers) and their parents using a written survey containing many multiple choice questions and a few open ended short questions (Ellis and Leventhal, 1993). Ellis and Leventhal (1993) found that 89% of the children and 69% of the parents wanted the doctor to make the decisions. Although most of the children did not want to make decisions about initial treatment, 44% said they would want to make their own decision about palliative therapy indicating that decision making preference may change according to severity of illness.

The literature reveals conflicting findings as to what level of involvement service users desire in the decision making process. Evidence is inconclusive on whether active involvement in decision making is a role that many individuals in the UK feel comfortable adopting. The influence of socio-demographic variables such as age, level of education, gender, marital status and severity of disease may have some impact in predicting decision making preferences but the evidence to date is not convincing.

Aiding the Decision Making Process

Despite conflicting evidence on decision making preferences studies have reported on attempts to aid the decision making process, presumably working from the premise that choice is beneficial to individuals. For example, Valanis and Rumpler (1985), reported on a nursing study carried out in the USA, suggesting that nurses were in an excellent position to provide women with information on treatment options for breast cancer and to help them make decisions. They emphasised the importance of considering women's own values and beliefs and allowing time to consider alternative treatments. They believed that this process should start before a problem has arisen and that nurses should make the most of opportunities to talk to all women about breast cancer and to aid in deciding which treatment options would be most appropriate. This would save women having to make decisions at the stressful time of diagnosis as they would already know what their treatment preference was.

However, it could be suggested that Valanis and Rumpler (1985) are creating anxiety for healthy women who may go on to worry that they will develop breast cancer. This is not to say that having information that may aid in the early detection of breast cancer is not valuable but Valanis and Rumpler are suggesting that nurses take time to discuss treatment options with well women. When there are so many women with breast cancer in the western world who need professional support and information it may not be appropriate, and there may not be the resources in terms of manpower and finances, to offer such an ethically questionable service.

Other studies carried out in different countries have suggested a more structured approach in aiding the decision making process. Neufeld, Degner and Dick (1993) reported on a Canadian nursing intervention study that aimed to provide decisional support for women with breast and gynaecological cancer. The intervention was aimed at women who wanted to participate in decision making and was incorporated into a busy oncology clinic where a nurse would interact with the women before and after their consultations and would be present during their consultation.

The approach espoused by Neufeld, Degner and Dick (1993) has its advantages in that it allows for individuals who want a lot of information but who do not want to be the primary decision maker. It also ensures that an individual approach is taken in establishing decision making preferences and does not place a burden of enforcing choice on an individual who does not want to be involved in making decisions. It also allows for continuity in that the woman sees the same nurse before, during and after the consultation. The disadvantages are that this may be a time consuming exercise in a busy clinic and it is not certain if the resources would be available for a clinic nurse to spend so much time with one patient. However, this is a role that a specialist nurse may be able to fill. The breast care nurse, for example, is often present before, during and after a consultation and the resources may be available for her to establish decision making preferences and encourage the articulation of questions.

A different approach was taken in a study carried out in the UK where a type of decision analysis was used to assist 43 women with breast cancer make decisions about their treatment (Owens et al 1987). The type of analysis used by Owens et al (1987) helped identify which of the presented options was expected to be of the greatest value to the woman, the decision making process being aided by a clinical psychologist. From this information a decision tree was constructed from which the expected utility of each option could be calculated. The treatment with the highest subjective utility would represent the rational choice.

The advantage of the Owens et al (1987) aid to decision making was that the decision could be broken down into component parts and each option carefully weighted against alternatives, so giving the patients a framework in which to work. However, it does seem a somewhat complex procedure to expect women who have just been diagnosed with breast cancer to carry out and would assume that these women were capable of rational and logical thought at a time of crisis. Clearly not all individuals will want the rational choice in any case and many people may find it difficult to articulate their feelings and transfer them into scores at this stressful time.

A more complex form of decision analysis necessitating the use of a computer software package was suggested by Dolan and Bordley (1993), two doctors in the USA. They proposed a method based on the Analytic Hierarchy Process (AHP) for involving patients in complex decisions. The basic elements of the decision first had to be defined: the goal, the alternatives, and how all the alternatives met the goals. These elements were then arranged in a decision model showing a hierarchical order to the elements with the goal at the top, the criteria for establishing how the alternatives meet the goal in the middle, and the alternatives at the bottom. In practice this would be complex to carry out and may add to the confusion over treatment options rather than clarify the issues. Many comparisons would need to be made if there were numerous treatment options and the authors acknowledge that the AHP would be difficult to carry out without the aid of a computer and the appropriate computer software. It is unlikely that these resources would be widely available in clinical practice or that the time would be available for explaining and carrying out this form of decisional support.

The strategies proposed to aid the decision making process seem to have an underlying assumption that people would be able to clearly articulate their feelings about treatment options in a logical manner and would indeed prefer the most rational option. This may not always be the case. There also appears to be the underlying assumption that aiding the decision making process must have positive benefit for the individual and that individuals should be encouraged to make decisions even though they may not feel comfortable with the role of decision maker.

Working from these assumptions it is not clear from the evidence who is the best person to assist an individual in making decisions. The clinical reality is often that the consultant presents the options and the nurse (clinical nurse specialist, ward nurse or clinic nurse) is left to re-iterate the options and provide information to enable the decision making process. Introducing other disciplines into this arena has certain advantages and disadvantages. A multidisciplinary approach may enable the specialist skills of each discipline to be employed to the patients benefit, although this approach may be seen by the patient as confusing.

In summary, it seems that few studies have presented a simple means of providing decisional support to those who want it. At a time of stress and crisis, such as a diagnosis of breast cancer, putting pressure on people to carry out complex decision procedures may not be appropriate.

PREFERENCES FOR INFORMATION

Weighing the costs and benefits of different treatment options will require information. Enabling individuals to make these sort of choices will necessitate the health care professional having information available to aid the decision making process. In this respect it would appear important to examine how information is provided for service users as well as how much and what type of information is perceived to be necessary.

Problems with Providing Information

If information plays an important part in enabling the decision making process then it is disappointing to read of the problems that health professionals have in their interactions with service users, as described in the document "What Seems to be the Matter: Communication between Hospitals and Patients" (Audit Commission, 1993). The Audit Commission describe how patients are not getting the information they need, with many individuals denied access to information or being provided with poor quality information. This document states that:

> *"Communication lies at the heart of health care delivery. To be effective it must be a two-way process: the service must give patients the information they want and need, and it must listen and respond to them."*
>
> *(Audit Commission, 1993, p3)*

The Audit Commission (1993) reported that service users needed more information on clinical matters and listed several problems in the communication process. Service users were aware of the pressures on health care professionals time and felt that they should not take up too much of that time with their own questions and problems. Often individuals were given information at inappropriate times when they could not absorb the information given. In many cases doctors did not introduce themselves and conducted consultations with people who were undressed and many individuals did not have another person with them when they were told bad news. Also conflicting information was given by different health care professionals, and the report gave the example of a consultant surgeon saying to a woman that her breast lump was 'nothing to worry about' while the radiotherapist talked about the 'risk of recurrence'. Individuals were not always routinely given the name and number of a person to contact if they had any questions between appointments and they were not clear as to who they should contact if they had any questions.

The Audit Commission (1993) report also stated that individuals were not receiving the information they needed and the quality of much of the information given was poor. In addition the report commented on poor communication between health professionals with a lack of liaison between different services.

Nurses have always considered that providing information is an essential part of their role and yet the Audit Commission findings imply that nurses, as well as other health care professionals, are not providing the information that individuals need. The reasons for these omissions are not clear. It could be, for example, that nurses do not have the information to impart.

These findings do not seem confined to the UK. Suominen (1993) interviewed 176 nurses in Finland, the majority of whom considered that they gave women with breast cancer insufficient information; only 5% of these nurses felt that the women knew enough about their care and treatment. The nurses in the Suominen study were not clear about their own role in providing information and felt that the dissemination of information was the doctor's responsibility. If nurses feel that the giving of information is the doctor's responsibility then they may make certain assumptions about what information individuals need.

Nurses in the Finnish study (Suominen, 1993) felt that, following hospitalisation, women with breast cancer should be given information only if they showed signs of wanting it. It may not be easy to identify individuals who show signs of wanting information in a busy oncology out patient clinic. It is also unclear as to how much time would be available for nurses to provide information in this environment. It may be that nurses do not have the resources to spend time with individuals and that as a result of this they are more likely to adopt the approach of 'wait until asked' rather than assessing information needs.

American health care professionals have also been shown to have difficulties in their interactions with service users in terms of providing information. A qualitative study, carried out in the USA, examined 158 communications between health care professionals and individuals with cancer (Thorne, 1988). Communications were divided into those considered to be helpful and unhelpful. A helpful communication was defined as one which was perceived as constructive, encouraging and supportive. An unhelpful communication was perceived as frustrating, impeding and demoralising. Most of the information (65.1%) and advice (90.5%) given by doctors and nurses was considered to be unhelpful. The majority of these unhelpful communications were perceived as being 'intentionally unhelpful' and included, for example, withholding information. In only a minority of instances (37.3%) did individuals perceive that health professionals expressed concern for them. Indeed most unhelpful instances were associated with a communication style that indicated a definite lack of concern. An example was given of one woman being called a 'crazy hypochondriac' by her doctor when she asked for a thorough examination.

In the Thorne (1988) study, although the ratio of helpful to unhelpful communications was similar for doctors and nurses, doctors were most often perceived as giving information while nurses were most often perceived as giving advice. It should be recalled that 90.5% of advice given was considered to be unhelpful, indicating that service users may not perceive nurses to be important sources of information. This may emphasise the importance of the quality of the information provided and the importance of providing the right type of information.

Sources of Information

If service users are not utilising professional sources of information or if they are utilising a variety of different sources then they may be getting conflicting information or inaccurate information. In this context information could be disabling rather than enabling and may hinder the decision making process.

There is some evidence to suggest that health care professionals, particularly nurses, may not be perceived as appropriate sources of information, although many studies in this area do not have large enough sample sizes on which to base any firm conclusions. However, some of these studies have been included in the literature review to make explicit the evidence that is available in this area.

A small study carried out in the USA examined the sources of information considered to be important to 22 women who had undergone surgery for breast cancer (Ward et al 1989) The women in the Ward et al (1989) study rated people sources of information as more important than written or visual materials and doctors rated more highly than nurses as sources of information. The information sources in order of importance were: physician, family and friends, a clinic handout, nurses, scientific journals, media sources, and a clinical videotape.

These findings have not been confined to the initial period of diagnosis and surgery. Hopkins (1986) asked 38 women receiving chemotherapy for breast cancer in the USA to indicate their sources of verbal information about chemotherapy. In descending order they listed the oncologist, television programmes, nurses, voluntary organisations, family and friends. That media sources of information were seen as more relevant than nursing sources of information is a cause for concern when consideration is given to the doom and gloom scenarios portrayed by some media programmes. Although some television programmes can be said to be beneficial in providing accurate information, the popular case study approach of individual sufferers may not provide the individualised information needed by most women with breast cancer.

However, there is evidence to suggest that non-professional sources of information may play an important role in the provision of information. The importance of support groups as a source of information was highlighted in a study carried out in the USA (Stevenson and Coles, 1993). Stevenson and Coles (1993) reported on the reasons why 106 women attended a breast cancer support group. The most important reasons given were receiving emotional support, information exchange, giving support, listening to speakers, and the social opportunities provided. The hope of receiving and giving emotional support and of obtaining increased information were rated as important factors and the types of meeting that the women rated as most enjoyable were those at which a speaker had been invited. It should be noted that 25% of the attenders at the support group were more than five years from diagnosis, 89% had not had a recurrence of their breast cancer, and 97% were not undergoing any treatment. Therefore, even though a large number of these women could essentially be considered 'cured', getting information was still important to them. Preferring a speakers attendance at meetings indicates a need for information as presumably the speaker would be someone knowledgable about certain aspects of breast cancer.

The women in the Stevenson and Coles (1993) study were asked about the type of information they received from the support group and they stated that the information concerned treatments and general information about breast cancer. If 97% of the women attending the support group were no longer undergoing treatment it is difficult to understand why these women still wanted information about treatments. It may be that they had found a source of information to answer questions that had gone unanswered when they were receiving treatment.

The format in which information is presented may also have an impact on the way in which information is perceived to be useful. Hogbin and Fallowfield (1989) reported on 46 individuals with cancer in the UK (including 35 women with breast cancer) receiving benefit from being given an audiotape recording of their bad news consultation. The tapes explained the results of investigations and described the treatment options available and the diagnosis of cancer was made explicit. All of the patients who listened to the tape (39 out of 46 individuals) agreed that the tape was helpful and 38 of these 39 individuals had played the tape to a family member or friend. The surgeon in this study agreed that he spent longer on the consultation when he was aware that it was being recorded which may imply that the individuals in this study were receiving information that would ordinarily have been omitted or made more concise.

It appears that women with breast cancer utilise a variety of sources for obtaining information about breast cancer including professional sources, audiovisual sources, media sources, family, friends, and support groups. It is not clear how important health care professionals are as a source of information and nurses do not always appear to be considered important sources of information.

Difficulties in Communicating with People with Cancer

There may be a number of explanations as to why health care professionals are not always considered useful sources of information. They may not be equipped with the necessary skills to impart information, they may not have the necessary knowledge base from which to provide information or they may not feel comfortable in their communications and interactions with certain patient groups. While it is appreciated that providing information is only a part of the communication process, and that effective communication involves far more than simply providing information, it may be useful to examine the literature that suggests health care professionals have difficulties in communicating with individuals with cancer.

A study carried out in the UK examined the communications of 54 nurses (35% of these had attended a communications skills course) and identified four different communication styles (Wilkinson, 1991). 'Facilitators' (n=10) used facilitating behaviours to carry out an in depth assessment of individuals problems. 'Ignorers' (n=12) tended to ignore cues presented by the patient and changed the subject swiftly to avoid emotionally loaded areas such as a discussion of diagnosis and prognosis.

While 'informers' (n=12) did provide information they used inappropriate information focusing on physical aspects and giving patients information that they had not requested. Wilkinson suggests this was a way of maintaining control of the situation and avoiding emotionally loaded areas. A number of the sample (n=22) used a combination of facilitative and blocking behaviours and Wilkinson termed these nurses 'mixers'.

Overall, the nurses in the Wilkinson (1991) study were poor communicators. They gained little information from the patients with which to plan their care and Wilkinson (1991) argues that care planning must have been based largely on assumptions. A point of interest is that the nurses who had completed a communication skills course were no more effective in communicating than those who had no specific communications skills training. Wilkinson concluded from this that effective communication did not just depend on acquiring skills in communication and that the environment in which the nurses worked could be conducive to effective communication, particularly if a role model, such as the ward sister, was present who practised facilitative communication.

It may be that nurses attitudes towards cancer have an impact on their ability to provide information for people with cancer. Corner (1993) reported on a study carried out in the UK that involved interviews with 127 newly registered nurses. Each nurse was asked to complete a cancer attitude scale and in depth interviews were carried out with 68 of these nurses. A commonly occurring theme from the interviews was a feeling of inadequacy in their role as a cancer nurse particularly in communicating with people with cancer, with 54% of the nurses interviewed reporting such feelings. The nurses reported difficulties in knowing how much information to give patients and also what information the doctors would 'allow' them to give. Generally cancer was associated with negative feelings about death and dying. These findings are very relevant in considering the cancer patients need for information. If nurses have a negative attitude towards cancer and feel uncertain of their role in providing information then patients may not receive the information that they need to cope with the disease or to make decisions about their care and treatment.

Nurses may not be the only health care professionals who have difficulties in communicating with people with cancer. Difficulties have also been reported in the information exchange between doctors and patients. Siminoff et al (1989) examined the communication process that took place between doctors and women with breast cancer in discussing adjuvant therapy. The communications of 100 women and 16 doctors were examined as part of the study. Most of the women (60%) overestimated their chances of cure with adjuvant therapy and there was poor agreement between doctors and the women on the likely side effects of treatment. The women's comprehension of the benefits and risks of adjuvant therapy was limited. Siminoff et al speculated as to why this was the case and suggested that the women may have been overwhelmed by the information given, the women may not have asked for information, and the doctors may not have given specific information unless it was asked for.

Siminoff et al (1989) suggested that the women may not have asked for information because they did not want to hear bad news. An alternative suggestion may be that the women did not know what to ask or did not feel comfortable in taking the time of a busy health professional. Siminoff et al further reported that the doctors made recommendations about therapy and the women followed those recommendations. This is not surprising if insufficient information is given on alternatives and likely side effects of treatment.

Health care professionals may also make assumptions about the information that service users need based on demographic factors. Amir (1987) looked at the factors that doctors took into account when giving information to cancer patients in a study involving 104 general surgeons in Israel. Patients who were perceived as intelligent and asked questions were given exact information. If the patient was perceived as intelligent, but did not ask questions they were given minimal information and in fact were given less information than a less well educated person regardless of whether they asked questions or not. It appears that assumptions were being made about level of intelligence and desire for information by the doctors in the Amir study.

It has been reported that individuals with lower levels of education underestimate the seriousness of their condition (Mackillop et al 1988) emphasising that these people may not be receiving accurate information. Mackillop et al (1988) interviewed 100 cancer patients (24 with breast cancer) to determine how they perceived their illness and how this compared to their doctor's perception of their illness. Eleven of 33 patients with metastatic disease believed that their cancer was localised while 16 out of 48 patients receiving palliative treatment believed that they were being treated for cure. Doctors in this study failed to recognise these misconceptions. This study has implications for involving patients in decision making. If individuals are not given appropriate information so that they have an accurate understanding of their illness then they may choose toxic or aggressive forms of treatment in the mistaken belief that they are being treated for cure.

Information as a Component of Patient Teaching and Education

Nurses and other health care professionals may feel it is an important part of their role to provide information and, as such, they need to be equipped with the necessary skills to impart that information. Care should be taken in assuming that heath care professionals necessarily have the skills to carry out effective patient teaching and education (Luker and Caress 1989).

In a general sense patient teaching has been defined as the provision of information and knowledge in order to aid understanding (Wilson-Barnett, 1983) while patient education involves a more in depth assessment of whether that information has been received and understood (Luker and Caress, 1989).

Health care professionals can provide information for individuals by, for example, handing out written information leaflets, but this cannot be regarded as patient teaching if the information did not aid understanding and it can not be regarded as patient education if there was no assessment of the impact of that information on service users. The provision of information to service users can, therefore, be considered a component of patient education and teaching. While the focus of this thesis is on the importance of information from the service users perspective and not on the concepts of patient teaching and education as such, it is important in the literature review to examine studies that have examined the role of the nurse in effecting patient teaching and education programmes in order to further understand how service users may perceive their own role as receivers of information from health care professionals.

It has been suggested that it may be unrealistic to expect nurses to be able to carry out effective patient education when teachers in educational establishments undertake a course of study for a number of years to acquire such skills (Luker and Caress 1989). Certainly no large amount of time is included in the nursing curriculum for developing teaching skills. Luker and Caress (1989) suggest that patient education should become the responsibility of specialist nurses who would have both the interest and the specialist knowledge to develop effective education programmes. In terms of providing information this may have an impact on how information is received by service users. If nurses are not skilled in providing information then the service user may receive inappropriate or conflicting information.

A Canadian study (Tilley et al 1985) reported that nurses felt limited in their abilities to implement effective patient education programmes due to unexpected discharge of patients and a lack of control over the discharge procedure. If the provision of information is a component of a patient education programme then service users may be disadvantaged by being discharged home before necessary information has been provided.

There is an underlying assumption here that if health care professionals have the skills to impart information effectively then the service user will benefit and there is some evidence to suggest that this is the case. A study carried out in Australia (Poroch, 1995) aimed to show the effectiveness of preparatory patient education (in terms of providing information) in reducing anxiety and improving satisfaction during the course of radiation treatment for 50 individuals with cancer. Rather than presenting technical information which individuals may have found difficult to recall, the importance of providing sensory information was stressed (including a description of feelings commonly associated with various procedures) as well as procedural information (descriptions of what the patient can expect to happen). Attention was also paid to the way in which information was presented. Rather than nurses waiting for the patients to ask for information, the information was given as part of a structured education programme (Poroch, 1995).

The Poroch (1995) study used a quasi-experimental design and collected data at three time points from an experimental group (n=25) who received the patient education programme (presented by a clinical nurse) and a control group (n=25) who did not. Although sample size was small, Poroch (1995) found that the experimental group were more satisfied than the control group and were more satisfied with the answers to their questions. The experimental group showed a significant decrease in anxiety over time whereas the control group maintained a high level of anxiety throughout.

Poroch (1995) also stressed the importance of early contact with a nurse and the importance of maintaining that contact over time to facilitate the information giving process. Although Poroch (1995) does not say how far from diagnosis the participants in her study were, it may be assumed that, if they were receiving radiation therapy, the majority would probably have not been in the early stages of diagnosis. This may have aided the retention of information in that the ability to concentrate and direct attention may not have been as limited at this time.

The programme described by Poroch (1995) provided encouraging results, highlighting that the provision of information as part of a structured patient education programme could be effective. Similar findings have been reported in a study carried out in the USA where an experimental group of 30 male cancer patients and their spouses, and a control group of 30 patients with cancer and their spouses, were involved in a patient education intervention programme (Derdiarian, 1989). The experimental group received individualised formal information, counselling and referral, a packet of written literature specific to their information needs, a list of names, contacts and resource persons, and a list of times when people could call. Although sample size was small, Derdiarian (1989) found that patient satisfaction with information was significantly higher for the experimental group. However, satisfaction also increased for the control group, although this was a non significant increase. It may have been that the interaction with a health professional was of benefit as well as the intervention.

Although there is evidence of the positive impact of providing information through structured patient education programmes it is not clear if nurses, or other health professionals, have the necessary time and skills needed to implement these programmes. There is also a danger of implementing the health care professional's agenda for these programmes rather than responding to the information needs specified by individual patients. However, it seems clear that nurses consider the provision of information to be an important part of their role and an important component of an effective patient teaching or education programme. However, given the importance of service users perspectives it seems important to establish how service users perceive their need for information.

Type of Information

In a review of over 200 clinical papers relating to communication issues for cancer patients from 1966-1986, Northouse and Northouse (1987) found that one of the major communication issues for patients was seeking information. They described how information reduced uncertainty and was a means of increasing control over a situation. Information has also been described as building hope and freeing individuals from the anxieties and fears associated with cancer (Cassileth et al 1980).

However, Northouse and Northouse (1987) comment that the literature does not present a clear picture on how much information patients need and what kind of information they prefer. In order to be responsive to the information needs of individuals it would seem important to have an understanding of the amount and type of information that people need.

There is evidence to suggest that, rather than making an assessment of individual information needs, some health professionals are assuming that they know what individuals will want to know. For example, Tierney et al (1992), in a study carried out in the UK, interviewed 60 women receiving chemotherapy for breast cancer, using semi structured interviews and postal questionnaires. All the women reported being given information about chemotherapy but Tierney et al reported that the women's knowledge was limited; for example 83.3% of the women knew how many treatments were planned but only 18.4% had any knowledge of the drugs involved.

Each woman in the Tierney et al (1992) study was asked which side effect of chemotherapy she expected to be the most problematic. All the women recalled being warned about hair loss and 58.3% expected this to be the most problematic side effect. In fact hair loss did not prove to be the major problem as anticipated by both patients and nurses and only 21.7% experienced this as the most problematic side effect. In comparison only 50% of the women recalled being told to expect tiredness as a side effect when 18.3% of the women reported this as the most troublesome side effect. The women experienced more side effects than they had been warned to expect with individuals reporting being told about a mean of 3.7 side effects per person whereas reported side effects amounted to a mean of 5.4 per person.

In a follow up postal questionnaire the women in the Tierney et al (1992) study were asked if the information they had been given was adequate and 64.7% of the sample expressed satisfaction with the information provided. For those women who did not express satisfaction two main problems emerged; not enough information was being provided on the different side effects that may occur and not enough practical advice was being given on what to do about the side effects that did occur.

The Tierney et al (1992) study highlights the importance of not making assumptions about what individuals will need to know and emphasises the need for individualised attention to information needs. While providing information on all the possible side effects of chemotherapy may increase anxiety for some women, other women may welcome more detailed information. It may be that nurses do not feel they have the necessary knowledge base from which to impart information and this is likely to present problems in meeting the information needs of individuals.

Few studies have attempted to examine the specific types of information needed by service users and those studies that have been carried out in this area tend to originate from the USA and Canada.

An early attempt to examine the types of information needed by people with cancer was carried out in the USA (Cassileth et al 1980). Cassileth et al (1980) examined the information needs of 256 cancer patients (24% of the sample were women with breast cancer) using an Information Styles Questionnaire where individuals had to describe their information preferences on a five point Likert scale ranging from 1 (no more detail than needed) to 5 (as many details as possible) (Cassileth et al 1980). Cassileth et al (1980) demonstrated that demographic and treatment variables may have some impact on information need in that individuals who wanted more detailed information were younger, better educated, and had their disease diagnosed more recently. The type of information considered to be most useful was information on side effects, the aim of treatment, diagnosis, cure and the spread of the disease.

A more recent study carried out in the USA examined the information needs of 60 women recently diagnosed with cancer and divided information into four main categories: disease (including information on treatment, prognosis, diagnosis and investigations), personal (including information on physical well being, psychological well being and plans and goals), family (considering the effect on the individual's spouse, children, parents and siblings), and social relationships (involving career, leisure and the future) (Derdiarian, 1986). This American study found that disease related information was perceived as being the most important, particularly information on treatment and prognosis and, although personal information came second in importance, information about physical well being was considered to be the most important item within the personal category.

A descriptive study carried out in the USA investigated the information needs of 50 mastectomy patients and their husbands (Northouse, 1989). This study is worthy of mention as it involved a longitudinal approach with study participants being interviewed at two points in time; in the hospital and one month later. As part of the study individuals were asked 'to describe their greatest concerns about the illness'.

The greatest concern for both patients and their husbands at both time points centred around surviving the disease. Northouse quotes one husband as saying:

> *"My greatest concern is to keep her in my life. As far as the loss of the breast, loss of the hair and chemotherapy goes, they're insignificant compared to having her."*
>
> *(Northouse 1989, p278)*

Three specific concerns were noted at the first time point when the women were in the hospital: worry about the extent of the cancer, fear about recurrence, and worry about a shortened life. Other less important concerns mentioned were the ability to return to their previous lifestyle (returning to work, household responsibilities), family concerns (young children to care for, wanting to see children grow up), and coping with the emotional aspects of the disease, such as the loss of the breast. At the second time point, one month later, survival issues remained important but concern about the extent of the disease had decreased while concern about the recurrence of the breast cancer had increased. Although concerns were somewhat different at the two different stages of the disease it is interesting that the focus of concern at both stages was mainly on physical issues. Although being concerned about an item may not equate to wanting information about that item the study provides useful insight into the perceived concerns of women with breast cancer.

Similar findings of the importance of survival issues were reported in a Canadian study that examined the specific types of information considered to be important to 74 Canadian women who were all within 131 days of a diagnosis of breast cancer. Bilodeau (1992) presented nine items of information using a paired comparison approach to produce a hierarchy of information needs. The nine items of information included information on the likelihood of cure from breast cancer, the spread of the disease, the effect on social life, the effect on family, self care, sexuality, treatments, genetic risk and side effects of treatments. Bilodeau (1992) found that the most important item of information was information about how far the disease had spread. This was followed by information concerning the likelihood of cure and information on different types of treatment. Concern centred mainly around physical aspects of the disease.

In summary, although it appears that health care professionals see the provision of information as an important part of their role, it is not clear how effective health care professionals are at providing information or if service users perceive health care professionals to be useful sources of information. There is evidence to suggest that health care professionals are assuming an awareness of information needs of individuals but these perceptions may be different to what individuals perceive their own needs to be.

What seems to be missing from the literature are methodologically sound studies carried out in the UK to indicate what British women perceive their information needs to be as well as an investigation into when certain types of information become important. Most studies have focused on one time point or have used sample sizes that are too small to allow for analysis of the data in terms of time from diagnosis. Few studies have taken a longitudinal approach and have favoured a cross sectional study design.

SUMMARY OF THEMES EMERGING FROM THE LITERATURE REVIEW

- Breast cancer effects a large number of women and health care professionals are likely to come into contact with these women at different stages of the disease trajectory.

- While patient participation is being encouraged by health care professionals it is not clear from the literature whether consumers of health care feel comfortable in the role of decision maker.

- Increasingly women with breast cancer are being asked to make choices about treatment options and evidence suggests that the availability of choice may be beneficial to service users in terms of decreasing psychological morbidity.

- Recall and retention of information may be limited at times of stress and crisis, such as a diagnosis of breast cancer, and evidence suggests that overloading women with information at one time point may not be appropriate.

- Evidence is inconclusive regarding the impact of demographic and treatment variables on both the decision making process and information need.

- Although nurses see themselves as playing a key role as providers of information it is not clear if they have the necessary skills or knowledge to provide this information nor if service users perceive health care professionals to be useful sources of information

- Few studies have examined the specific types of information that are important to service users. Evidence suggests that women with breast cancer may be concerned about the physical aspects of care and treatment, particularly in the early stages of the disease, but there is little evidence in the literature to suggest that information need may change over time.

CHAPTER 2

THEORETICAL FRAMEWORK

The theoretical framework for this study is based on two distinct but linked theoretical perspectives. The first is based on the work of two Canadian nurses (Degner and Beaton, 1987). The main thrust of their work concerned an understanding of how decision making took place in a life threatening situation and an understanding of the importance of information in enabling the decision making process. The second perspective has its origins in the work of a nurse researcher from the USA (Derdiarian 1987) who investigated the possibility of establishing a hierarchy of information needs.

DECISION MAKING IN A LIFE THREATENING SITUATION

A four year qualitative study carried out in Canada aimed to show how consumers of health care made decisions in a life threatening situation (Degner and Beaton, 1987). This Canadian study explained the complexities of the health care system that often make if difficult for service users to understand the system or to have any input into its workings. Many individuals may also feel that they have no right to be involved in the functioning of the health care system. Degner and Beaton argue that, given the appropriate information, individuals can learn to participate in making choices about their treatment and that a lack of information is an inhibiting factor in participation.

The Canadian researchers utilised a number of different approaches to gathering data including participant observation, a close examination of case notes and records and in-depth interviews with key participants. The decision making process was examined from the view of health care professionals and service users in 14 health care settings in Manitoba.

From their data Degner and Beaton (1987) described four patterns of control over the decision making process: provider controlled, patient controlled, family controlled and joint controlled. They stated that the person who has control determines the selection of treatment, but acknowledge that participation does not necessarily imply control. Indeed in many cases health care professionals may have control over the presentation of treatment options and, while participation may be encouraged, it may also be limited by the withholding of information on certain alternatives. In this scenario the individual would be asked to participate but the health care professional would retain control over the presentation of choices.

Provider-controlled Decision Making

In provider-controlled decision making health care professionals exert final control over treatment decisions. This may be due to the physical condition of the patient, in that they are unable to make decisions for themselves, or the patient may express a desire not to make decisions but to defer that responsibility to a health care professional. An alternative explanation would be that the health care professional does not present treatment options in the first instance but states what treatment will be carried out and believes a paternalistic approach to be best practice.

If a health care professional decides to present information on only one type of treatment, when other options are available, then it may be difficult for a patient to participate when they are unaware of the existence of alternatives. In this case patients are disadvantaged by a lack of information and are unaware that they are being denied access to information.

Degner and Beaton (1987) comment that the usual justification health care professionals give for not involving individuals in a participatory role is that the individual may experience feelings of guilt, at a later date, if they make a wrong decision. There is an argument that this sort of attitude warrants certain assumptions on the part of health care professionals. It assumes that people are likely to make decisions that they will regret at a later date and may not be capable of making rational decisions. It further implies that a wrong decision could be detrimental to the individuals well being. This encompasses a paternalistic approach in that individuals are not being 'allowed' to make a mistake and are being protected from this. However, a decision made by a health care professional could also be seen as a 'mistake' from the service users point of view if more information subsequently became available. Individuals could then equally regret decisions made by health care professionals as decisions made by themselves. Although, it could be argued that guilt would more likely be associated with personal decisions than with a decision that was not within the individual's control.

For some individuals deferring the decision making responsibility to a health care professional will be preferred despite a full disclosure of treatment options. It can be argued that if full information is provided and the individual prefers not to participate in decision making then this preference should be accepted if the rights of the individual are to be respected. A need for information may not equate to an active role in decision making and individuals may want a great deal of information but prefer to defer decision making responsibility to someone else.

Patient-controlled Decision Making

In patient-controlled decision making the patient is actively involved and engaged in the decision making process. This approach assumes that treatment options are presented to individuals and that they have been provided with the necessary information from which to make an informed choice. If treatment options are not presented then some assertive individuals may achieve a certain degree of control over the decision making process by, for example, withholding consent to treatment. However, if individuals have not been made aware of alternative options then they may be likely to assume that all the relevant information has been presented to them.

Family-controlled Decision Making

With family-controlled decision making the family may make decisions about an individual who is unable to make a decision due to the severity of their condition. This can place a burden on families who are trying to respect a family members wishes or who do not know what that family members wishes would be in the circumstances. Degner and Beaton (1987) describe how families can exert some control over the decision making process by withholding consent to treatment. They further describe how some health care professionals hope that families will become involved in the decision making process so that they can be released from the burden of making difficult decisions, such as when to switch off life support systems.

Jointly-controlled Decision Making

Jointly-controlled decision making involves a sharing of the decision making responsibility between the patient and the health care professional. Degner and Beaton (1987) describe this as the most appropriate form of decision making for a positive outcome as it avoids any feelings of guilt and future regret on behalf of both the patient and the health care professional.

The Importance of Information

Degner and Beaton (1987) described information as having a vital role in enabling the decision making process and stated:

> *"Knowledge and information are the substance of life-death decision making"*
>
> *(Degner and Beaton 1987, p39)*

Health care professionals were found to rate information as differing in importance. In making decisions for patients, health care professionals rated information on age, stage of disease, previous response to treatment and quality of life as important items of information. Younger people were thought to represent a greater loss if they died and to have greater potential for recovery. If the disease was advanced then treatment was sometimes thought to be largely ineffective, but a previous positive response to treatment was seen as a good reason to believe that a future response to treatment would also be positive.

Health care professionals can have a great deal of control as regards access to information and can, if they choose, withhold information. Patients in the Degner and Beaton (1987) study found it very upsetting if information was deliberately withheld or if they were given conflicting information. Degner and Beaton described how an individual's knowledge base started from their own personal experience and when people developed a serious illness they did not know what questions to ask to get the information they needed to make decisions. This emphasises the importance of information in the decision making process.

A HIERARCHY OF INFORMATION NEEDS

Drawing on theories of coping, appraisal, information seeking, information needs and hierarchies of needs, Derdiarian (1987) described how a hierarchy of information needs could be established based on the relative importance of different items of information to an individual.

Lazarus' theory of coping formed the main component of this framework (Lazarus, 1966). Lazarus (1966) described how individuals respond to threat (anticipated harm) or harm by first making a judgement, or an appraisal, of that event. This involves a consideration of the actual or anticipated harm and the resources available to counteract that harm or threat. Coping efforts are then made in response to this appraisal. A cancer diagnosis can be considered to be a stressful life event that necessitates an individual appraising the threat and harm that the diagnosis invokes, followed by the implementation of coping strategies dependent on the resources available to that individual.

Information seeking has been identified as one of the main modes of coping (Cohen and Lazarus, 1979). In this respect information seeking exists in response to a noxious stimulus or stressful event and is aimed at reducing emotional distress through a problem solving approach. The individuals environment, including person and situation related variables, will also impact on the information seeking process (Derdiarian, 1987). Information was seen by Derdiarian as a form of mediator between the individual (including appraisal and coping processes) and a stressful event that enabled that individual to employ effective coping mechanisms.

Seeking information implies that there is a lack of information and a need for information (Derdiarian, 1987). Drawing on Maslow's (1973) work on human motivation, Derdiarian described how individuals had priorities in terms of information need with some items of information being considered more important than other items of information. Maslow described humans as having a hierarchy of needs that included, in order of priority, basic physiological needs (for example, the need for air, food, warmth and water), safety needs (for example, security, protection and order), love, affection and belonginess needs, esteem needs and self actualisation (the need for self fulfilment). These needs had to be satisfied in order of priority and until basic physiological needs had been met it was pointless trying to satisfy other needs. This can be viewed in a nursing context. For example, there is little point in aiming at full mobility for an individual if that individual is in pain. The need for pain relief must be satisfied as a priority before other aims can be realised.

Derdiarian's (1987) framework can be seen as relevant to any study that aims to establish priority information needs for individuals. While Derdiarian's (1987) main focus of attention was on the stressful period at time of diagnosis it was acknowledged that coping was an ongoing process and was not limited to this one time point.

THE RELEVANCE OF THE TWO THEORETICAL PERSPECTIVES

The models of decision making (Degner and Beaton, 1987) and information need (Derdiarian 1987) described in this section of the thesis demonstrate how information can play an important role in enabling the decision making process.

The diagnosis of breast cancer can be considered a stressful life event which necessitates appraisal of the situation and instigation of coping mechanisms. Getting information is a way of coping with a stressful experience such as a diagnosis of breast cancer. The individuals personal experience may be the only knowledge base from which they function initially, although it is likely that information will accompany the presentation of treatment choices. It is within this context that choices are presented.

Health care professionals may consciously or unconsciously influence the choices they present depending on certain person and situation variables, for example type of disease, attitudes about cancer, belief that demographic variables such as age and level of education are important predictors of preference, and a belief that paternalism is best practice. The individual may need more information on which to make a choice and may have a hierarchy of information needs to be satisfied in order to make an informed choice. This information need may lead to information seeking behaviour and information may be sought from professional or non professional sources.

Assuming a full disclosure of necessary information, the individual's decision making preference may be provider controlled, patient controlled, jointly controlled, or family controlled. Family controlled decision making is mentioned in this context for completeness although Degner and Beaton (1987) primarily described this pattern of decision making for individuals who were unable to respond to the presentation of treatment choices due to the severity of their illness. While it is appreciated that some individuals may prefer their families to make decisions for them the majority of women diagnosed with breast cancer are conscious and able to interact with health care professionals.

In conclusion, the two perspectives described will provide a suitable framework from which to examine service users perceptions with regard to decision making preferences and information need.

CHAPTER 3

THE STUDY AIMS AND HYPOTHESES

INTRODUCTION

This study investigated the treatment decision making preferences, information needs and sources of information for women with breast cancer. As most decisions regarding treatment are made around the time of diagnosis a sample of women were selected who could be considered "newly diagnosed".

For comparison purposes the decision making preferences and information needs of a sample of women with benign breast disease was included. These women were considered an appropriate comparison group because they would likely have experienced anxiety about a potential cancer diagnosis and so had a "near miss" as far as cancer was concerned. In a Canadian study it was found that asking individuals to project themselves into the role of a cancer patient was not particularly useful and produced markedly different findings, in terms of decision making preferences, to individuals who had a diagnosis of cancer (Degner and Sloan, 1992). Therefore, in this study, rather than comparing the women with breast cancer to women who had never had a diagnosis of cancer, it was considered more meaningful to choose a sample of women who may have had similar feelings initially about their breast problems.

The study also investigated how decision making preferences and information need changed over time for women with breast cancer. In this context it was decided to target the newly diagnosed sample at a time point further from diagnosis producing a longitudinal design.

AIMS

The aims of the study were:

1. To investigate the degree of involvement that women newly diagnosed with breast cancer, and a comparison group of women with benign breast disease, would want in the treatment decision making process and to determine how these preferences were influenced by time since diagnosis for the women with breast cancer.

2. To construct profiles of information needs for women newly diagnosed with breast cancer, and for a comparison group of women with benign breast disease, reflecting priority information needs, and to investigate how these profiles changed over time for women with breast cancer.

3. To explore the relationship between treatment decision making preferences and information need. That is, to investigate if decision making preferences influenced the type of information needed for women with breast cancer and women with benign breast disease.

4. To examine the professional and non-professional sources of information available to women with breast cancer and to explore the usefulness of these information sources at two different time points in the breast cancer experience.

HYPOTHESES

From the study aims, 6 null hypotheses of no differences (H_0) and 6 alternative hypotheses (H_1) were generated and are listed below.

1. H_0: There are no differences between the treatment decision making preferences of women newly diagnosed with breast cancer and women with benign breast disease.

   H_1: There are differences between the decision making preferences of women newly diagnosed with breast cancer and women with benign breast disease.

2. H_0: There are no differences between the decision making preferences of women newly diagnosed with breast cancer and the same women at a point further from diagnosis.

   H_1: There are differences between the decision making preferences of women newly diagnosed with breast cancer and the same women at a point further from diagnosis.

3. H_0: There are no differences between the information needs profile for women newly diagnosed with breast cancer and women with benign breast disease.

   H_1: There are differences between the information needs profile for women newly diagnosed with breast cancer and women with benign breast disease.

4. H_0: There are no differences between the information needs profile of women newly diagnosed with breast cancer and the same women at a point further from diagnosis.

   H_1: There are differences between the information needs profile of women newly diagnosed with breast cancer and the same women at a point further from diagnosis.

5. H_0: There is no relationship between treatment decision making preferences and information need for women newly diagnosed with breast cancer, women with benign breast disease, and women with breast cancer further from diagnosis.

   H_1: There is a relationship between decision making preferences and information need for women newly diagnosed with breast cancer, women with benign breast disease, and women with breast cancer further from diagnosis.

6. H_0: There are no differences between the usefulness of different sources of information for women with breast cancer at either the newly diagnosed stage or at a time point further from diagnosis.

H_1: There are differences between the usefulness of different sources of information for women with breast cancer at the newly diagnosed stage and at a time point further from diagnosis.

CHAPTER 4

THE STUDY DESIGN

INTRODUCTION

The main study was a two stage process. Stage 1 involved an assessment of the treatment decision making preferences and information needs of a sample of women newly diagnosed with breast cancer and a sample of women with benign breast disease. Stage 2 of the study involved a comparison between the women who had been involved in the study when newly diagnosed with breast cancer and the same women approximately two years from diagnosis.

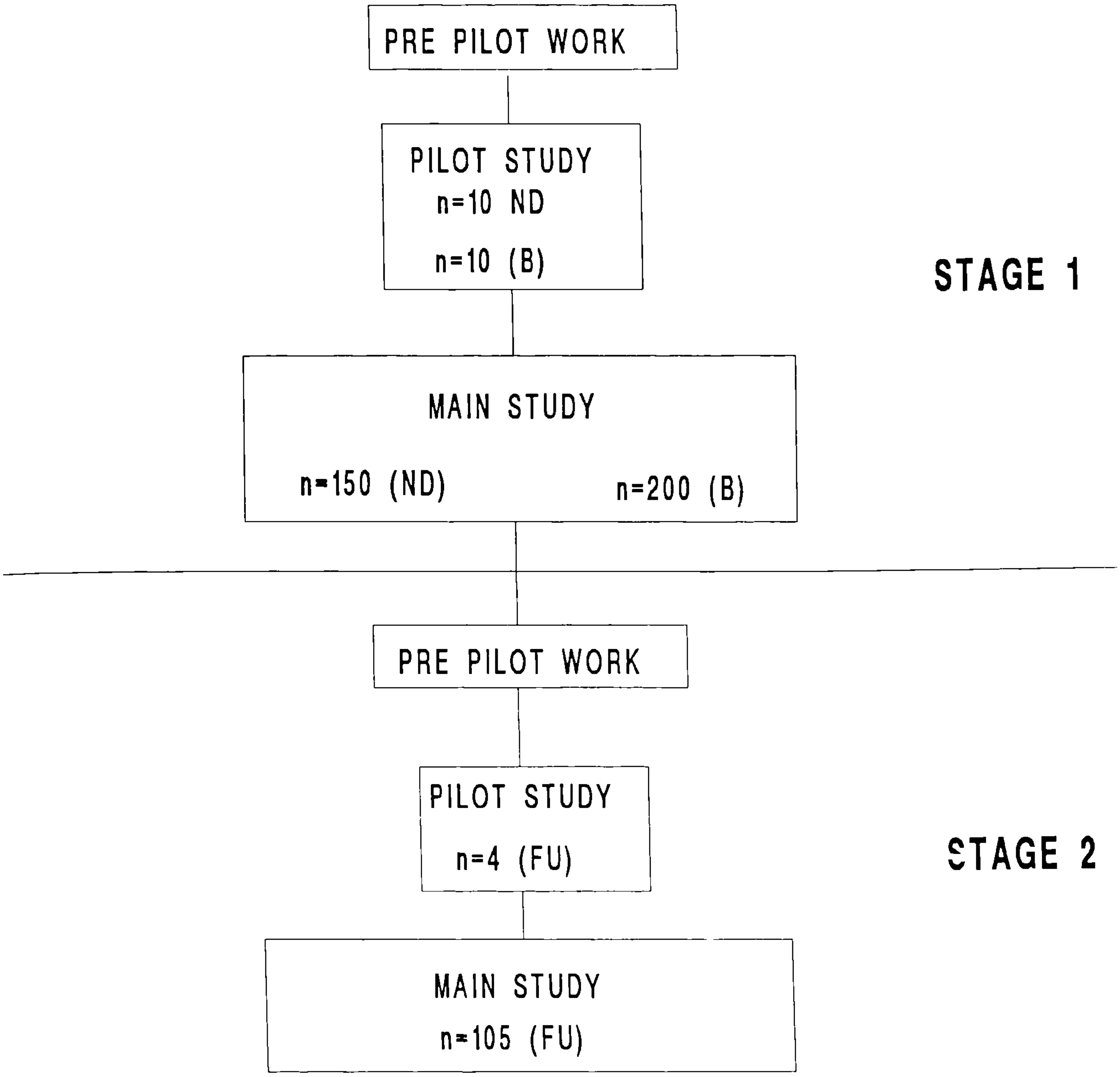
The prospective longitudinal design in the present study was considered to be an appropriate research design for collecting high quality data. Menard (1991) stated that:

> *"......... for the description and analysis of dynamic change processes, longitudinal research is ultimately indispensable. It is also the case that longitudinal research can, in principle, do much that cross-sectional research cannot, but that there is little or nothing that cross-sectional research can, in principle, do that longitudinal research cannot." (p68)*

Menard (1991) also noted that longitudinal research was not without problems. For example, he noted that interviewer bias may be more of a problem in longitudinal research than in a cross-sectional design as there is increased contact between the researcher and his/her subject. Also, there may exist "panel conditioning" where the subject may change as a result of the study and the repeated measurements rather than as a result of any study variables. Also, a longitudinal design may suffer from high attrition rates which may make data less amenable to high powered statistical analysis and findings less meaningful. Taking these points into consideration in this study, it was considered that interviewer bias and panel conditioning should not present a major problem as the women with breast cancer would only be interviewed on two occasions and there would be a significant period of time between the two occasions. Although the same interviewer carried out all the interviews, which could arguably present a systematic interviewer bias, a structured approach to the interviews was taken and interview schedules were designed to standardise the questions asked. Attrition rates could not be predicted in advance and could well be a study limitation if a high attrition rate was obtained for Stage 2 of the study.

A period of exploratory or pre-pilot work was planned to assess the feasibility of both stages of the study, to determine the instruments to be used to measure the central concepts of the study, and to determine the most appropriate means of data collection. Two pilot studies were undertaken. A pilot study was carried out prior to commencement of Stage 1 of the main study to assess the appropriateness of instruments and the limitations of the proposed study design. A second pilot study was carried out prior to commencement of Stage 2 of the main study to reconfirm the appropriateness of the measures used in Stage 1 of the study and to observe for any further limitations on the study design. Figure 1 shows a graphical representation of the study design.

Figure 1. The Study Design



B= Benign, ND= Newly Diagnosed, FU= Follow Up

PRE-PILOT WORK

To investigate the feasibility of the study an initial period of two to three weeks was set aside to carry out a period of exploratory work. The aims of the pre-pilot work were:

1. To allow the researcher to determine the best approach to meeting the aims of the study.

2. To identify the study site and make introductions to health care professionals who would be encountered on a regular basis for the duration of the study.

3. To investigate the role of key health care personnel and the way in which service users presented or were referred to the breast care service.

4. To consider access to the study samples which would determine the most appropriate format for data collection.

5. To determine the main measurement tools for the study based on a review of alternative instruments designed to measure decision making preferences and information need.

The Study Site

To meet the aims of the study it seemed appropriate to carry out the study in an environment that offered a specialist breast care service. This would ensure that all women in the study samples had access to the same high quality service provision. The study site chosen was a large 836 bedded university teaching hospital where a wide range of breast care services were available. This facility had the benefits of a breast specialist consultant and two breast care nurses.

During the pre-pilot work the researcher was able to familiarise herself with the layout of the study site and to introduce herself to the following key health care personnel.

The Breast Specialist Consultant

The breast specialist consultant at the study site granted unlimited access to his patient population and offered full co-operation in meeting the aims of the study. At the time of the pre-pilot work the breast specialist was seeing 350 new cases of breast cancer per year and had the highest workload of any surgeon treating benign and malignant breast diseases in Merseyside and Cheshire. On the basis of this it seemed likely that a large population of women with breast cancer and benign breast disease would be available from which to sample, further justifying the choice of study site.

The Clinical Nurse Specialists in Breast Care

Two breast care nurses were employed at the study site, one in full time employment as a breast care nurse and the other working half time on an acute general surgical ward and half time as a breast care nurse. The breast care nurses worked exclusively in the one speciality and were able to offer home visits to patients, if necessary, as well as being available to both in-patients on the hospital wards and out-patients in the clinic situation.

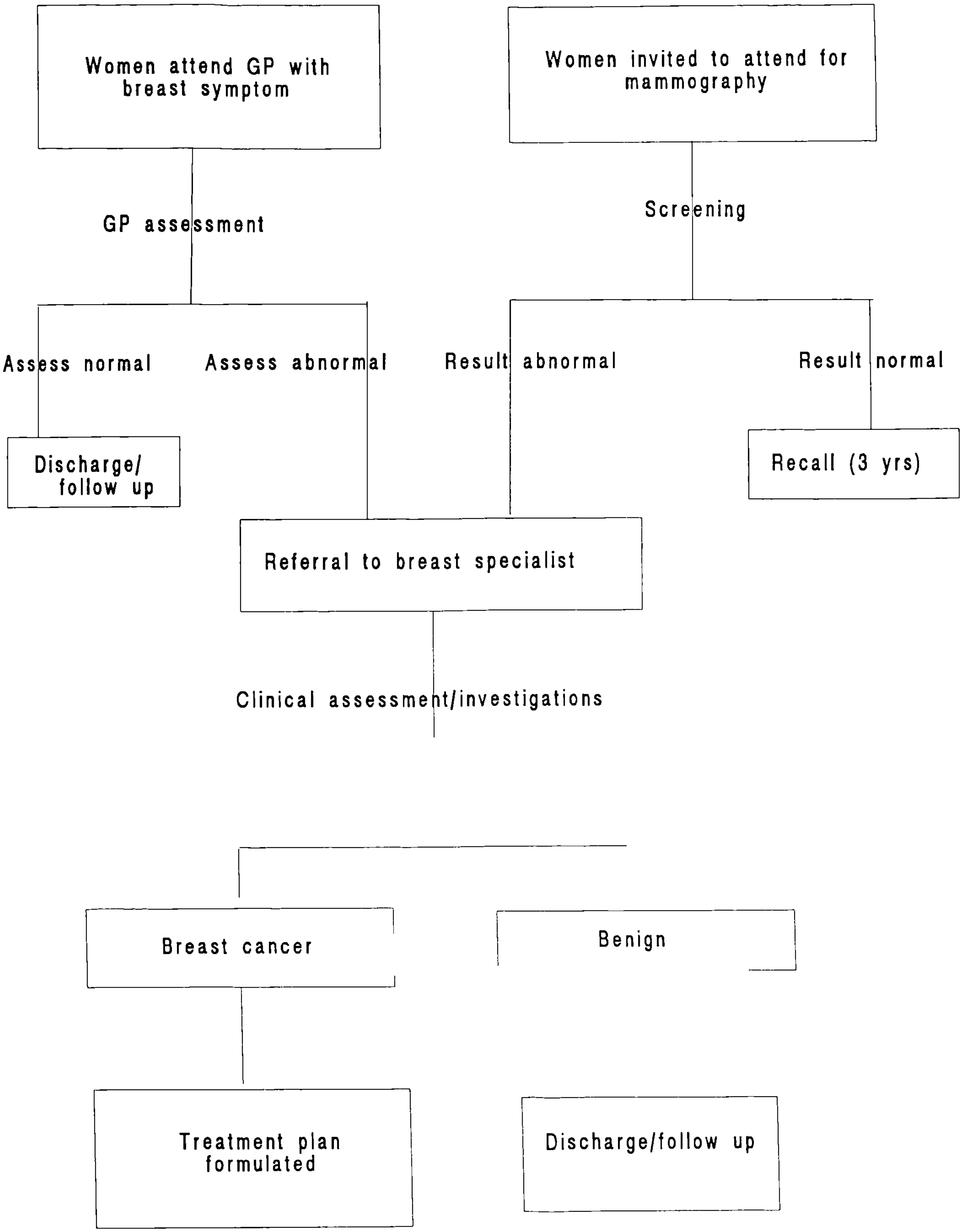
Both breast care nurses were willing to co-operate with the researcher and agreed to allow the researcher to shadow their movements for a day. This was an excellent opportunity to gain valuable insight into the workings of the breast specialist service and to gain information about accessing the study groups.

Referral Pattern and Access to the Newly Diagnosed Study Sample

Through observation of the breast care service it became apparent that there were two major routes of access for women with breast problems. The National Health Service Breast Screening Programme (NHSBSP) for the region served by the study site was in full operation in 1990. The NHSBSP called women aged 50-64 years for screening every three years. Women with abnormalities were referred to the breast specialist centre at the study site. Alternatively, women had presented to their general practitioner (GP) with a breast symptom (eg. a breast lump) and had been referred to the breast specialist consultant with letters of referral marked "routine" or "urgent" depending on the GP's assessment of the cause of the breast symptom. Figure 2 outlines the two main referral patterns for women with breast abnormalities.

Confirmation of diagnosis was carried out in either the Breast Assessment Unit (where mammographic equipment was available) or in a breast clinic in the Out Patient Department (where on the spot cytological testing was available). Both facilities were on-site. The breast specialist saw all new referrals with the breast care nurse so that if a diagnosis of cancer was made the women were already familiar with these key health care personnel pre-diagnosis.

Figure 2. The Referral Patterns for Women with Breast Abnormalities



Both the breast specialist consultant and the breast care nurses explained to the researcher that they encouraged patient participation in treatment decision making. The breast specialist aimed to give a choice between lumpectomy and radiotherapy, and mastectomy where possible. If this choice was not available due to the type, position or location of a tumour then a choice of whether or not to have reconstructive surgery was available. The breast specialist was able to carry out this procedure at the time of primary surgery.

If a treatment plan was formulated that involved surgery then a date for admission was arranged at the time of diagnosis. This date was usually two weeks hence. Two weeks was allocated for the woman to begin to come to terms with the diagnosis, to think about the treatment choices available, and to allow the breast care nurse time to make a home visit if this was what the woman wanted. Following an admission date being given, the breast care nurse would take each woman with a cancer diagnosis into a private room to discuss further the treatment plan and any questions that the woman may have at this time. Relatives and friends were encouraged to be present at the time of diagnosis. Home visits with the breast care nurse were arranged at this time.

On admission to hospital, usually the day prior to surgery, the women were seen on the consultant's ward round where the decision regarding treatment was finalised. The breast care nurse would try to co-ordinate her visit to follow on from the ward round but, due to a large case load, this was not always possible and the ward nursing staff were relied upon to contact the breast care nurse if any problems developed that they could not adequately cope with. The researcher was introduced to the ward staff on three surgical wards where the majority of the consultant's patients were admitted. The study aims were explained to ward staff who were available at the time of the researcher's visit and she was received warmly and with interest. The researcher familiarised herself with the layout of the wards, (mainly six bedded bays with a small number of side rooms), and the location of hospital notes, nursing records, admissions lists and theatre lists.

By observing the pattern of referral for the women with breast cancer and the way in which they moved through the system it was possible to identify a suitable time point for accessing the newly diagnosed group. The time of diagnosis itself was considered much too stressful to consider approaching these women, and also at this time they had not had the opportunity to think about treatment options or what items of information they might consider useful. It seemed much more sensitive, and appropriate in terms of the study aims, to wait until the women had been admitted onto the hospital ward before approaching them and asking them to take part in the study.

Referral Pattern and Access to the Sample of Women with Benign Breast Disease

During the course of the pre-pilot work the researcher observed two breast clinics. A large number of women were seen in two 5 hour clinic sessions that lasted from approximately 8am through to 1pm. On occasion the clinics would continue until 2pm or later depending on the number of appointments. During the course of a clinic session over a hundred women were seen and the researcher was informed that on occasion the number could be as high as two hundred. The realisation that the clinics were of such a large size, and would presumably be extremely busy, caused concerns in accessing the benign study sample.

All the consulting rooms were utilised by the breast specialist consultant and his surgical team. The breast care nurses had their own consulting room where they could conduct private discussions with women newly diagnosed with breast cancer. A treatment room was available, but this was utilised by either medical students taking detailed case histories of newly referred patients or by the breast care nurses inserting saline into the expanders of women who had breast reconstruction.

The problem of where to interview the benign sample was discussed with the breast care nurse and the nurse in charge of the out patient department. From observation the researcher considered that the clinic was the only feasible environment for obtaining a sample of women with benign breast disease. Following their negative results these women were usually discharged and had no further contact with the breast care service. If the women were not approached at the time of the clinic visit then there would not be a further opportunity to access this study sample. The breast care nurse suggested that the researcher share her own consulting room as there were usually only one or two confirmed breast cancer diagnoses in a clinic session and the room would likely be available for most of the clinic session. Although not ideal, the researcher decided to accept this offer and to assess the suitability of the arrangements during a pilot study.

Summary of Findings Regarding Access to Study Samples

The pre-pilot work made it clear that the most appropriate time to access the newly diagnosed sample would be on their admission to the hospital ward for treatment. On average the women would have had a period of approximately two weeks since their diagnosis to consider treatment options and to start to come to terms with their diagnosis. They would have also had the opportunity to communicate with the breast care nurses and to ask questions about any aspects of their future care and treatment as well as to discuss any anxieties and concerns. In order to meet the aims of the study it would be useful that the women would have had time to think about treatment options and when the subject was introduced by the researcher it would not be unfamiliar territory. Also, in having time to think about the diagnosis, the women may have formulated areas of concern that would provide invaluable information in determining information need.

The benign study sample would need to be accessed in the out patient clinic as this was the point of entry for the majority of these women into the breast care system. Once negative results were given this sample would be lost to the researcher as no follow-up was normally planned.

Inclusion Criteria for the Study Samples

After careful regard to the study aims and observations made at the study site during the pre-pilot work inclusion criteria were developed for the newly diagnosed and benign study samples and are described below.

Inclusion criteria for the newly diagnosed group

As all women would be accessed from only one study site the sample would be taken from the practice of the one breast specialist consultant. Although other general surgeons at the study site treated a small number of women with breast cancer, given the time available, bias from different consultant's approaches needed to be avoided.

The women in this study sample needed to be close to the time of diagnosis and, as the study aimed to examine women who were "newly diagnosed", women who had been diagnosed with a previous breast cancer were excluded. Following observation at the study site it was apparent that the majority of women would be approximately two weeks from diagnosis at the time of their hospital admission, the time when the study sample would be accessed. So that valuable data would not be lost from women who were over this two week time period from diagnosis the inclusion criteria "allowed" women to be up to four weeks from diagnosis. Any further time from diagnosis and women were excluded as a lack of homogeneity would be apparent in the study sample.

As the study was concerned with the treatment decision making preferences and information needs of a sample of women with breast cancer the women would need to be aware of their diagnosis. Women who were uncertain about their diagnosis, women who claimed to be unaware of their diagnosis and women who appeared to be using denial as a coping strategy would not be entered into the study. Communication with ward staff and referral to patients' medical notes may reveal if a woman was aware of her diagnosis. If ward staff were unaware or medical notes were not explicit about the awareness of the woman of her diagnosis then the researcher would carefully assess each patient by asking them to describe their condition and say what was wrong with them. In fact this approach was thought to be useful generally with all women in this study sample to prevent causing unnecessary anxiety. In summary, the inclusion criteria for the newly diagnosed sample were:

1. Treatment was being carried out by one breast specialist consultant at one centre.

2. A malignancy had been confirmed no longer than 4 weeks prior to inclusion in the study.

3. No previous history of breast malignancy was apparent.

4. Each woman was aware that she had breast cancer.

Inclusion criteria for the benign group

For consistency the benign group were referred to the same breast specialist consultant at the same centre as the newly diagnosed group. They had concerns about their breast problems and had presented to the consultant with a specific breast problem such as a lump that may have aroused suspicions of malignancy in the women. Women with a past history of breast problems or breast pain would not be included in this sample. Each woman would also need to be aware that her breast problem was non-malignant when asked to participate in the study. In summary, the inclusion criteria for the benign group were:

1. Treatment was being carried out by one breast specialist consultant at one centre.

2. A breast symptom had been reported (eg. a breast lump) with no previous history of breast disorders.

3. A non-malignant diagnosis had been given at the time of entry into the study of which each woman was aware.

Data Collection

As women newly diagnosed with breast cancer can be said to be in a crisis situation (Parry, 1990) it was apparent that the most sensitive way of obtaining data for the study would be through a face to face structured interview with the women. It seemed insensitive and inappropriate to attempt contact by postal questionnaire at this acute stage in the disease trajectory. The interview would need to be carried out by someone who had many years experience of dealing with the problems of breast cancer patients and would know how to access services if the women had any needs that had been unmet by other health care professionals.

The researcher was a psychology graduate and a registered nurse with many years experience of dealing with the problems of breast cancer patients on a number of different general surgical wards in a large District General Hospital. More specifically, the researcher had spent a six month secondment in breast and stoma care which involved dealing with the problems of breast cancer patients in a wide variety of settings, including out patient departments, hospital wards and patient's own homes.

To facilitate the interviews an interview schedule was designed to examine the concepts central to the study that would incorporate measures of decision making preferences and information need.

The Measures

In order to provide a foundation to the development of the interview schedule the measures for establishing treatment decision making preferences and information need were first determined. Gilbert (1993) stated that to test a theory there had to be a way of measuring each concept and these measures or indicators needed to be as good as possible. They should be valid, accurately measuring the concept, and reliable, consistent from one measurement to the next.

Decision Making Preferences

In establishing decision making preferences it seemed likely that individuals would have a variety of preferences. For this reason it was important to consider preferences as a continuous rather than as a dichotomous variable. For example, participation versus non participation may not be effective at encompassing the range of preferences that individuals may have and indeed may have been a limitation in other studies of decision making preferences (Cassileth et al 1980, Blanchard et al 1988).

A procedure that allowed individuals to consider a range of preferences was also thought superior to the "pick one" approach in that it allowed for more opportunity to compare and contrast different decision making roles. However, if too many roles were presented individuals may have become confused. Also, the procedure of ranking a large number of items may prove problematic for individuals. Therefore, the establishment of a preference order over a limited number of items rather than a single preferred item was seen as important in the choice of a measure of treatment decision making preferences.

To establish what role women with breast cancer wanted to play in treatment decision making a Control Preferences Scale (CPS) was used which had been piloted and tested in two Canadian studies (Degner & Russell, 1988; Degner & Sloan, 1992). This measure was chosen because of its sound methodological basis and its inclusion of an array of decision making preferences.

A four year qualitative study exploring the way in which health care service users and health care providers make treatment decisions formed the foundation for the development of the measurement scale (Degner and Beaton, 1987). This study was carried out in Canada and four patterns of control over treatment decision making were identified: provider controlled, patient controlled, family controlled and jointly controlled decision making. From this inductive approach patients were hypothesised to have preferences about the degree of control they wanted over treatment decision making that corresponded to keeping, sharing or giving away control over decision making.

The theoretical findings about how individuals made treatment decisions formed the basis for the development of a measure of decision making preferences. Degner and Russell (1988) used a card sort procedure that included four vignettes describing various degrees of control over the decision making process. The measure was developed to encompass a range of decision making preferences and was piloted in a Canadian study of 60 ambulatory cancer patients (Degner & Russell, 1988). Four decision making preferences were used in this Canadian study and are listed overleaf.

A. After learning my diagnosis, I explore possible treatment options and then select a doctor who proceeds with the treatment I feel is appropriate for my disease.

B. After my doctor explains the various treatment options available for my illness, I have the major responsibility for selecting which treatment will be used.

C. After my doctor explains the various treatment options, the selection of any therapy is a joint decision between myself and my doctor.

D. My physician decides which treatment would be best for me without discussing all the available treatment options.

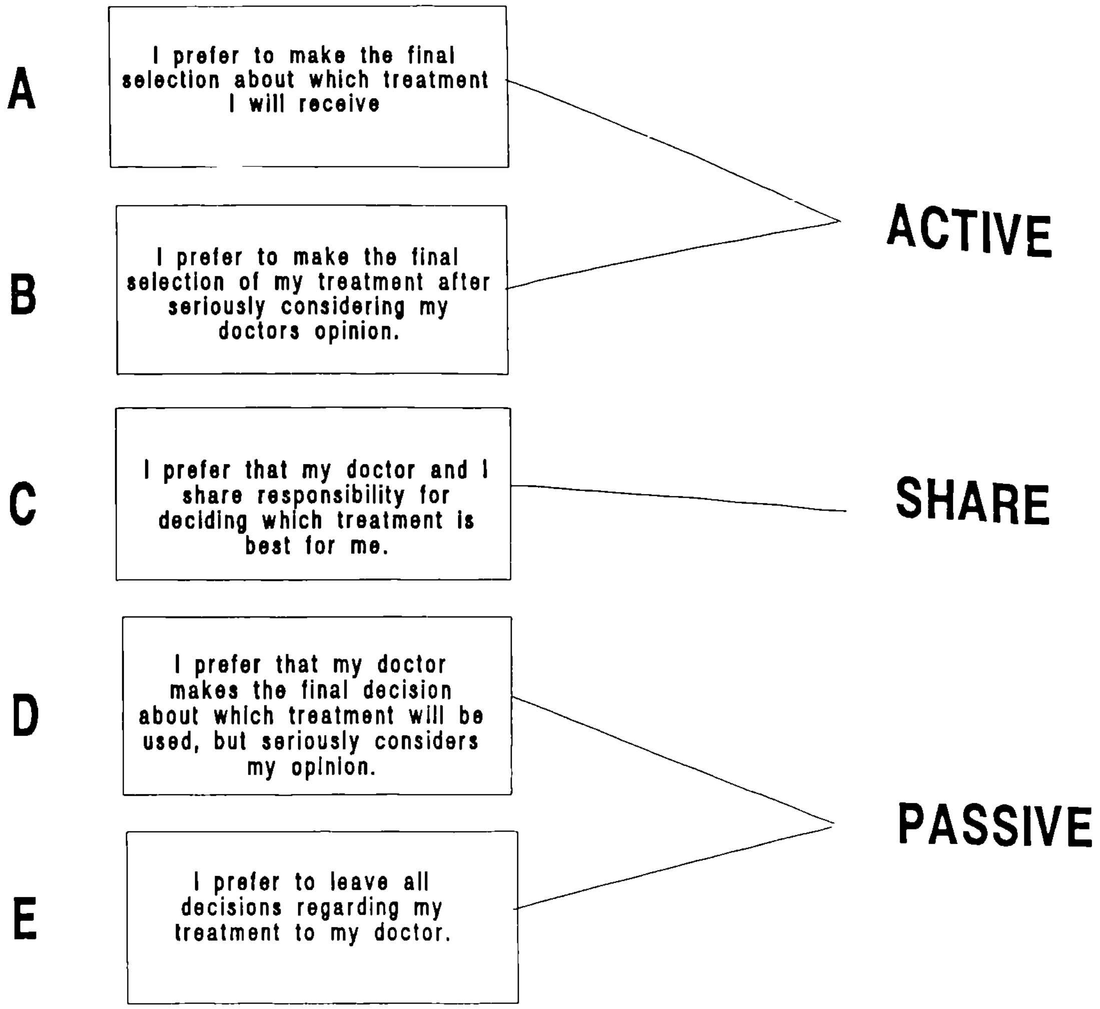
(Degner & Russell, 1988)

A preference order over all four roles was obtained by presenting the cards two at a time and asking each individual to state a preference between the two cards. This process continued until a preference order over all four cards was established. The measurement model applied to the data was Coombs' unfolding theory (Coombs, 1964). This model assumed that a psychological dimension existed onto which each individual's preference order could be placed. For example, in the Degner and Russell (1988) study the unfolding model showed that there existed a dimension of control that ranged from keeping control, through sharing control, to giving away control. The existence of the dimension could be tested for directly without having to rely on indirect tests of dimensionality such as alpha or factor analysis. Degner subsequently refined the measure and card A was omitted as it did not appear suitable for a Canadian audience (Degner & Sloan, 1992). Card A certainly did not appear suitable for a British audience under the current National Health Service system. Also, the word "physician" would be unsuitable for a British audience.

The refined version of the CPS consisted of five decision making roles and was implemented in a large study of decision making preferences of 436 newly diagnosed cancer patients and 482 members of the general public (Degner and Sloan, 1992). The CPS proved to be easily administered and a valid measure of preferred roles in treatment decision making. Validity here was in terms of a direct test of dimensionality using Coombs' unfolding theory. The CPS has also been shown to have clinical relevance, being used as an assessment tool as part of a nursing intervention study that aimed to provide patients with decisional support (Neufeld, Degner and Dick, 1993).

The refined CPS consisted of five cards with each card describing a potential role that could be played in treatment decision making. The roles ranged from keeping control and playing an active role through sharing control and playing a collaborative role to giving away control and playing a passive role. All five roles are displayed in Figure 3. Each role was allocated a letter ranging from A to E (see Figure 3) and when the preference order over all five roles was established it was recorded using these letters, for example ABCDE. This preference order would be the most extreme active role while a preference order of EDCBA would be the most extreme passive role.

Figure 3. Decision Making Roles



I prefer to make the final selection about which treatment I will receive

I prefer to make the final selection of my treatment after seriously considering my doctors opinion.

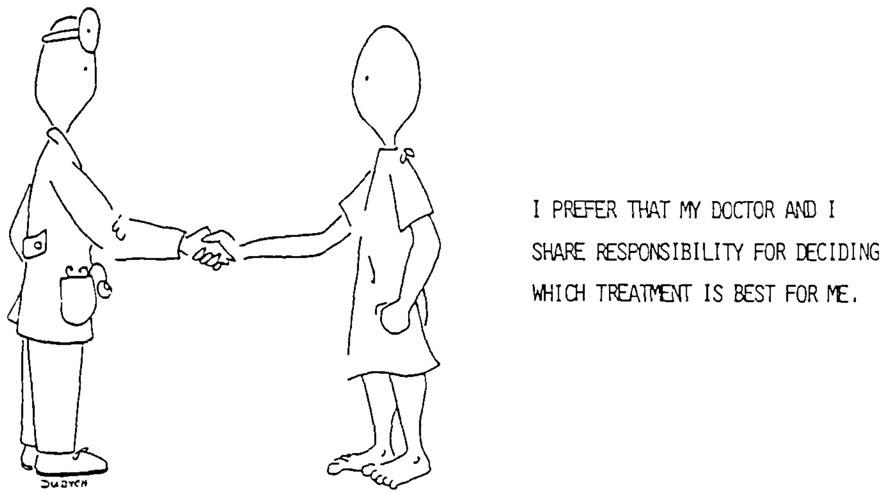
I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.

I prefer to leave all decisions regarding my treatment to my doctor.

Each statement on the cards was accompanied by a cartoon which aimed to make the statements easier to understand as shown in Figure 4 (all five decision making cards are displayed in Appendix 1). This refined measure was found to be suitable for a Canadian audience and Coombs' unfolding theory again allowed for a direct test of the dimensionality. Because of the similarities between the health care systems of Canada and the UK it was considered that the refined CPS could be piloted, without modification, on a British audience. A more in depth review of unfolding theory would ascertain if the model could be used to represent the British data.

Figure 4. Card C - Sharing Responsibility


I PREFER THAT MY DOCTOR AND I SHARE RESPONSIBILITY FOR DECIDING WHICH TREATMENT IS BEST FOR ME.

Administration of the CPS

Three alternative means of administering the measure were available. All possible combinations of two of the five cards could be presented to each individual. This procedure, while being the most thorough approach in terms of comparing all possible combinations of decision making roles, would require an extensive period of training on the part of the researcher in keeping check on what orders had been presented. Also, time was considered to be a potential limiting factor in Stage 1 of the study and any procedure that was too lengthy would limit the number of questions that could be incorporated into the interview schedule.

An alternative approach would be a fixed order presentation where the five cards were always placed in the same order at the start of the procedure. Although this procedure would standardise the administration of the CPS in that all individuals would be presented with the same initial subset of cards it could introduce bias into the measure. Deciding on an order of presentation would also present difficulties in preventing bias. Unfolding theory would aim to directly test the dimensionality of the scale. However, if there was not support for the psychological dimension of control ranging from keeping control to giving away control and individuals were choosing cards at random they may, for whatever reason, prefer cards at the beginning of the presentation rather than cards at the end or vice versa. This procedure was not considered appropriate for the present study because of the problems of bias.

The third alternative was a random order presentation of the cards to prevent any bias in the presentation sequence. The cards were shuffled at the outset and presented to individuals in subsets of two. Each participant was asked to state a preference between the two and this process continued until a preference order over all five roles was established. This procedure was considered most appropriate for the present study in that it maximised the time available (the procedure was relatively quick to carry out) and it prevented any bias in the order of presentation. An example may clarify this procedure.

Example: The cards are shuffled and cards B and D are placed in front of the study participant. A preference for card D is expressed and so card D is placed on top of card B (D>B). Card A is randomly selected from the pack and the participant is asked to choose between cards A and D. A preference for card D is again expressed and so card D is turned over and the participant is now asked to express a preference between cards A and B. A preference for card B is expressed and so card B is placed on top of card A and card D is replaced on top of card B (D>B>A). Another card is randomly introduced from the pack and this procedure is continued until a preference order over all five roles is established, for example CDEBA (C>D>E>B>A).

Actual Role

To distinguish between preferred role and perceived role the CPS could also be used to establish what role the women in the study actually believed they had played in decision making. Sutherland et al (1989) examined the perceived role played in decision making of 52 cancer patients using an adapted version of a five item decision making preference scale devised by Strull et al (1984). This preference scale bore remarkable similarities to the CPS but used a "pick one" approach. To establish the actual role played in decision making in the present study it was decided to use the CPS as a measurement tool and to incorporate a "pick one" approach for this part of the procedure. It seemed sensible that in this scenario the women would be stating a "fact" rather than a preference, which would be better represented by one item than an ordering of items.

Information Need

To determine the important information needs of women with breast cancer a paired comparison approach was used derived from Thurstone's Law of Comparative

Judgement (Dunn-Rankin, 1983; Thurstone, 1974). This methodology allowed for the scaling of a set of items so that a profile of information needs could be constructed to reflect a priority order for a series of items.

Many previous measures of information need have suffered from "ceiling" effects with individuals expressing a wish for maximum information rather than specifying the importance of each item of information. For example, Cassileth (1980) used an "Information Styles Questionnaire" consisting of twelve items with cancer patients. For each of these items individuals were asked to state whether they "absolutely needed", "would like to have" or "do not want" the information. Information on seven of the twelve items was seen as absolutely necessary for more than half of the study sample. The study was valuable in highlighting the importance of information to cancer patients although this categorical approach to rating information did not clearly define any priority to the items of information.

Similarly, Sutherland et al (1989) adapted the Information Styles Questionnaire to produce an Information Seeking Questionnaire containing 18 linear analogue self assessment scales, thirteen of these scales relating to different kinds of information a cancer patient may wish to acquire. The median scores on this questionnaire ranged from 77.0 to 95.5 (with 100 being the maximum) which showed that cancer patients wanted a lot of information but did not specifically highlight the priority information needs.

The Thurstone scaling approach to assessing preferences for information has been seldom used in health care probably due to the complex nature of the analysis and the unavailability of a computer software package to analyse the data to produce scores for the information needs profiles. However, this approach has been successfully used in two studies relating to health care in Canada and the UK (Bilodeau, 1992; McKenna et al 1981).

McKenna et al (1981) carried out a study to weight the seriousness of perceived health problems using Thurstone's method of paired comparisons. The study illustrated the method by the use of five statements relating to problems associated with sleep patterns. Each individual was asked to make a choice between two statements, a much easier task than placing all five statements in order. Each statement was seen with every other statement (n(n-1)/2) to give a total of 10 paired comparisons. The investigators found that they could produce scale values to reflect the degree of seriousness attached to each of the five items and found that individuals had no problems with the paired comparison procedure. McKenna et al recommended that the method should be considered for use in health care settings where the rating of items was required.

Bilodeau (1992) used the paired comparison approach to produce profiles of information needs for women newly diagnosed with breast cancer. She used nine items of information that had been identified as being important to women with breast cancer (Degner, Farber & Hack, 1989). To identify the items of importance a number of researchers had been involved in reviewing the literature for evidence of items of information considered to be important to people with cancer. Over 200 relevant articles were reviewed. Following on from this, a second review was carried out to specifically isolate the items of information that were considered important to women with breast cancer. The ensuing nine information needs covered physical, psychological and social aspects of care and treatment.

A Canadian researcher (Degner, 1991) devised a questionnaire (The Information Needs Questionnaire) that incorporated these nine items of information and suggested that Thurstone methodology could be an appropriate way in which to present the items and analyse the data in terms of producing scale values that would reflect the relative importance of each item of information. The Information Needs Questionnaire was subsequently tested in a sample of 74 Canadian women newly diagnosed with breast cancer (Bilodeau, 1992).

Bilodeau (1992), in a small pilot study in Canada, presented the nine items of information to women with breast cancer in subsets of two with each item being seen with every other item (n(n-1)/2). A total of 36 pairs of items were presented. On presentation of each pair of items the women were asked to state which of the two items had the greater importance in terms of gaining information. Kendall's coefficients of consistency and agreement were used to show that individuals were consistent in their judgements and were not making random choices, and that consistency or agreement existed between individuals in choosing items. The coefficient of consistency (Kendall's zeta) in the Bilodeau (1992) study was 0.99 showing that individuals were consistent in their judgements. The coefficient of agreement, u, was found to be 0.34 indicating agreement between individuals. The nine items and the specific wording associated with each item are listed below.

1. Information about the diagnostic stage of the disease and the extent of involvement of the disease.

2. Information about the likelihood of cure from the disease.

3. Information about how the treatment may affect my ability to carry on my usual social activities (sports or hobbies etc).

4. Information about how to handle the physical and emotional impact of the disease on the family and significant others.

5. Information about caring for myself at home (for example: nutrition, support groups, home care, social worker, mental health worker).

6. Information about how the treatment may affect my usual feelings of physical and sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery)

7. Information about different types of treatment (surgical, chemotherapy, radiotherapy) and the possible benefits and risks associated with each treatment.

8. Information about how at risk my children and/or other family members are of developing the disease.

9. Information about possible unpleasant side effects of treatment (for example: nausea, pain, change in physical appearance).

The Information Needs Questionnaire was considered an appropriate tool in meeting the aims of the study and producing profiles of information needs. However, the measure had been designed for a Canadian audience and the researcher realised that it would need some revision before being considered suitable for a British audience.

Modification of the Information Needs Questionnaire

As the Information Needs Questionnaire had been developed for a Canadian population the wording of the items needed to be carefully scrutinised to check for readability and understanding in a British sample of women. The nine information needs were shown to the breast specialist consultant and the breast care nurses at the study site and, based on their experiences of communicating with women with breast cancer, they were asked to assess the items for readability and understanding. A consensus opinion was then reached on instigating certain changes to some of the items. Items 2, 3, 6 and 9 were essentially unchanged as they were felt to be readable and readily understandable.

Item 1 talked about the "diagnostic stage of the disease" and "the extent of involvement". These expressions were considered to be too technical and were replaced by simpler expressions of "how advanced" the disease was and "how far it has spread".

Item 4 was also thought to be too technical and complex in its language. The expressions "physical and emotional impact" and "significant others" were replaced and the expressions "affected" and "friends" were introduced.

Item 5 itself was considered to be acceptable, but two of the examples given in brackets following the item were thought to be more appropriate for a Canadian audience. Therefore, "nutrition" was changed to "diet" and "mental health worker" was changed to "counsellor". Although it was appreciated that a mental health worker and a counsellor were not the same thing it was thought that the item would be more meaningful to British women if "counsellor" was included.

Item 7 mentioned "the possible benefits and risks associated with each treatment" whereas the expression "the advantages and disadvantages of each treatment" was thought to be clearer and more readily understood.

Item 8 concerning family risk was made clearer and more concise by stating "breast cancer" in the item rather than just "the disease".

The revised list of nine items considered suitable for the women to be interviewed in the present study are listed in Box 1.

Box 1. The Nine Information Needs

1. Information about how advanced the disease is and how far it has spread.
2. Information about the likelihood of cure from the disease.
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports or hobbies etc).
4. Information about how my family and close friends may be affected by the disease.
5. Information about caring for myself at home (for example: diet, support groups, help at home, social worker, counsellor).
6. Information about how the treatment may affect my feelings about my body and my sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).
7. Information about different types of treatment (surgical, chemotherapy, radiotherapy) and the advantages and disadvantages of each treatment.
8. Information about whether my children or other members of my family are at risk of getting breast cancer.
9. Information about unpleasant side effects of treatment (for example: nausea, pain, change in physical appearance).

Administration of the Information Needs Questionnaire

The nine items of information that formed the Information Needs Questionnaire were administered in the same way as in the Bilodeau (1992) study. Pairs of items were presented to individuals and for each pair an individual was asked to say which item they would prefer to have information about at that moment in time. A total of 36 pairs of items were presented. The items were presented in such a way as to prevent any selection bias (Ross, 1974).

To ensure that all relevant information needs had been included in the measure, and to provide a further check on the validity of the measure, all individuals were asked, on completion of the Information Needs Questionnaire, if there were any other information needs which they felt were important to them but which had not been included in the measure.

Training

The author of the decision making preferences card sort and the Information Needs Questionnaire (Lesley Degner) provided the researcher with a period of training on how to administer the measures. This period of training proved valuable in reducing the likelihood of error when administering the measures.

Development of the Interview Schedule

Observations at the study site put certain limitations on the number of questions that could be included in the interview schedule. Development of one interview schedule for use with the newly diagnosed and benign study groups and a separate schedule for use with the follow up group was suggested by these observations. Time would be a limiting factor in the busy hospital environment for the newly diagnosed and benign groups. Because of this limitation many closed questions were included in the schedule to focus the interview. The schedule was divided into a number of sections to gather data on socio-demographic details, treatment plans, decision making preferences and information need. The interview schedule for the newly diagnosed and benign study groups, including the Information Needs Questionnaire, is shown in Appendix 2.

Socio-demographic Details

Socio-demographic details were thought to be important as other studies had suggested that variables such as age, level of education and severity of illness may influence decision making preferences (Cassileth et al 1980, Ende et al 1989). This being the case information was obtained on a wide range of socio-demographic and treatment variables in order to assess their potential impact on decision preferences and information need (see Appendix 2).

Age

Each individual was asked their age at their last birthday. In this way the variable "age" could be considered as a continuous or categorical variable depending on the subsequent analysis being undertaken. As the NHSBCSP commenced breast screening for women at age 50 years, due to the increased risk of developing breast cancer from this age onwards, it would be useful to examine the major concepts of the study for women who were 50 years or greater and women who were younger than 50 years.

As the incidence of breast cancer increases with age it was expected that the age of the women newly diagnosed with breast cancer would be higher than the age of the women in the benign study group. In this respect it was considered useful to have information on age as this may prove a confounding factor if the ages of the newly diagnosed and benign women showed a great deal of disparity.

Level of education

It was considered likely that age would be associated with level of education. Younger women may have had more educational opportunities than older women. If this was found to be the case and older women were over-represented in the newly diagnosed group then information on level of education would be useful in making comparisons between study groups.

Formal qualifications were taken as a proxy for level of education in the absence of any alternative means of assessing level of education and information on formal qualifications such as "O" levels, "A" levels, "GCSE's", diplomas, degrees and post graduate qualifications was collected. It was realised that some women may have qualifications that did not fit into the above categories, such as shorthand and typing. Although it was appreciated that subsequent analysis may require educational groups to be collapsed if sample sizes were small in certain educational subgroups it was considered important at the outset to collect as much accurate information as possible. For these reasons four categories of education were included on the interview schedule; no qualifications, "O" levels, "A" levels, and qualifications since the age of 18 years. Women who were included in the "qualifications since age 18" category were asked to specify what qualifications they held and the interviewer would write down the qualifications to allow for subsequent coding of the data.

Marital Status

The presence or absence of a permanent partner was considered to be an important variable with regard to the concepts central to the study. Women who did not have a partner may well have had different decision making preferences and different information needs to women who had a partner. Data on marital status were collected in six categories; married, common law/co-habiting, widowed, divorced, separated and never married. Although it was appreciated that in subsequent analysis some of these subgroups may need to be collapsed if sample sizes were small it was considered important to collect as much accurate data as possible at the outset.

Social Class

Social class was derived from Standard Occupational Classification manuals (Employment Department Group, 1991, 1990a, 1990b). This classification system used a structured approach to categorising individuals into five separate classes based on the occupation of the individual. The five classes are listed below.

I	Professional occupations
II	Managerial and technical occupations

III	Skilled occupations (non-manual and manual)
IV	Partly skilled occupations
V	Unskilled occupations

Individuals were asked to state their current or most previous occupation and the current or most previous occupation of their partner, if they had a partner. The highest level of social class, of the woman or her partner, was taken as representative of the social class of each woman in this study. Although this may create bias in that the social class of the study sample may be artificially inflated it was considered to be the most appropriate and consistent approach, and women who referred to themselves as "housewives" could be categorised based on their partners occupation.

This method of categorising individuals could be foreseen to present problems for women who were without a partner and had no occupation at the present time or were in full time education. However, the system was the most comprehensive available and the general accuracy of the approach seemed to outweigh any minor problems in categorising individuals.

Ethnic Group

It was unclear what the makeup of the study groups would be in terms of ethnic group although it was appreciated that different beliefs and cultures could certainly influence decision making preferences and information need. Thirteen ethnic groups were included in the interview schedule and as a further precaution against excluding any of the study participants a category labelled 'other' was also included in case the wide range of categories did not prove to be all inclusive (Appendix 2).

Relatives with Breast Cancer

It was considered important to collect data on family history of breast cancer. Women who presented with a family history may well have different information needs and more concerns about their families than women with no family history of breast cancer. Women were asked if they were aware of any relative with breast cancer. This did not necessarily have to be a relative the women were in contact with. Some women may have been aware of a relative with breast cancer who had died or who they had never met.

Knowing Someone with Breast Cancer

It was appreciated that contact with another breast cancer sufferer may well influence decision making preferences and information need. The emphasis here was on knowing someone with breast cancer. Knowing of someone with breast cancer was not considered synonymous with having actual contact with a breast cancer sufferer. The person that the women knew with breast cancer could also of course be a relative. The importance of this variable was in the contact that the women had with someone else with breast cancer regardless of whether that person was a relative or not. In this way the variable could be distinguished from having a relative with breast cancer which collected information on actual family history.

Stage of Disease

Although information about the stage of disease could not be obtained at the time of initial interview, as treatment had not yet commenced for the newly diagnosed women and so histological reports were not yet available, this information would be useful for Stage 2 of the study were women would be interviewed at a time point further from diagnosis. The stage of disease may well influence decision making preferences and information need at a later date. For this reason it was decided to collect histological data when it became available, usually ten days after surgery.

Following discussions with the breast specialist consultant and members of the Pathology department it was decided that the researcher would make a list of the histology reports that she required on a monthly basis. The reports would be made available by the Pathology department and the breast specialist consultant would grade the reports in the presence of the researcher so that the researcher could ask questions about any of the reports that were unclear. The Tumour size-Node-Metastasis classification (TNM) (Spiessl et al 1992) system was used to stage the breast cancer tumours (see Appendix 3).

Location of Items in the Interview Schedule

Questions on socio-demographic history were included at the outset of the interview schedule. In this way the interview could commence with fairly straightforward questions to which the women would feel comfortable responding. The CPS and

Information Needs Questionnaire would follow on from the socio-demographic history. The CPS preceded the Information Needs Questionnaire as it took only a short time to administer and would introduce women to the concepts of the study in a simple way before progressing to the longer and more detailed Information Needs Questionnaire. Data pertaining to the actual role women felt they had played in decision making were obtained immediately following the administration of the CPS as women would be familiar with the cards and the concept of decision making.

Conclusions from Exploratory Work

The findings from the exploratory work enabled decisions to be made about the location of interviews. The women in the newly diagnosed sample would be most accessible at the time of hospital admission just prior to surgery. Women with benign breast disease would be accessible in the out patient department breast clinic. The decision on where to interview the follow up study sample would be made at a later date during the exploratory work prior to Stage 2 of the study.

The exploratory work also allowed the researcher to familiarise herself with the breast care system in operation at the study site and to meet key health care personnel involved in the care of women with breast problems. It was also a useful experience for identifying the referral patterns for the women with breast problems to aid a more fuller understanding of the working of the system.

Measures were chosen to establish decision making preferences (CPS) and information need (Information Needs Questionnaire). The interview schedule was developed to include these measures although it was appreciated that certain modifications may be needed following the pilot study.

THE PILOT STUDY: STAGE 1

Prior to the main study a pilot study was undertaken on a small sample of individuals to assess the suitability and acceptability of the selected measures, namely the CPS and the Information Needs Questionnaire, and to highlight any problems in accessing the study samples. The aims of the pilot study were:

1. To test the decision making and information needs measures in a British context and assess if the revised wording and refinements in the Information Needs Questionnaire were suitable for British women.

2. To assess if the interview schedule designed for Stage 1 of the study included relevant questions and to assess if any questions had been excluded that would provide essential data for the study.

3. To investigate if the design of the study was appropriate in terms of accessing the study samples and to highlight areas that may prove problematic to the study.

4. To familiarise the researcher with carrying out the interviews and administering the measures.

Ethical Approval

Ethical committee approval to carry out this study was obtained by the breast specialist consultant at the study site. A protocol that included the aims of the study and data collection details had been produced and was available to the breast specialist consultant when seeking approval.

Population/sample

The population for the pilot study were women referred to the breast specialist unit at the study site. A sample of ten women were interviewed who had been newly diagnosed with breast cancer and met the inclusion criteria for that particular study group (see page 89). A sample of ten women with benign breast disease were also interviewed who met the inclusion criteria for the benign study group (see page 91). The women in the newly diagnosed group were older than the women in the benign study group, having a mean age of 54 years as opposed to a mean age of 41 years for the benign group and this result was expected in view of the fact that the incidence of breast cancer increases with age. Matching samples for age would be a complex process and sample accrual for the benign study sample would probably be limited if this criteria were enforced. For this reason samples were not matched for age and it was realised that this could prove to be a study limitation.

Method

The women newly diagnosed with breast cancer were interviewed on the hospital ward on the day of their admission and the day prior to surgery. The interview schedule, including the CPS and the Information Needs Questionnaire, was administered and any problems were noted. Problems with access to this study group were also assessed. The women with benign breast disease were interviewed in the out patient department clinic following their negative or non-malignant results. Any problems with the interview schedule or access to the study sample were again noted.

Consent

Verbal consent was obtained prior to commencement of the interview. The aims of the study were explained, stating that there were no right or wrong answers and the researcher was interested in the opinions of each participant. Anonymity was assured. It was explained that only the researcher carrying out the interviews would be aware of individual names and corresponding numbers on the interview schedule. It was also explained that entry to the study was voluntary and that at any time during the proceedings they were free to discontinue the interview.

Findings from the Pilot Study

Testing the Measures

The first aim of the pilot study was to test the measures and assess if the revised wording and refinements were suitable for British women. With the decision making card sort no major problems were encountered either in the administration of the measure or in the individuals understanding of the measure. The cartoon that accompanied each decision making role did appear to make the statements easier to understand.

On occasion individuals encountered difficulty in choosing a card if they felt that two cards were similar in meaning and difficult to distinguish. Card C ("I prefer that my doctor and I share responsibility for deciding which treatment is best for me") and card D ("I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion") appeared to be close in some individuals' assessments. In this case the researcher would try to distinguish between the meanings of the two cards for the individual and again ask if the individual could try to make a choice. All twenty individuals in the pilot study were able to complete the measure and a preference order was obtained for each individual.

The preference orders obtained in the pilot study for the newly diagnosed and benign study groups are shown in Table 2. Observation of the preference orders showed that a wide range of different preference orderings had been obtained (14 different orders) with the most active (ABCDE) and passive (EDCBA) orders being represented. The orders have been presented in Table 2 according to the order of data collection.

Table 2. Decision Making Preference Orders for the Newly Diagnosed and Benign Study Groups (Pilot Study)

Newly Diagnosed (n=10)	**Benign (n=10)**
ABEDC	DECBA
ABCDE	CDBEA
EDCBA	CDEBA
BCADE	BCDAE
CEDBA	CEDBA
CBADE	BCDEA
EDCBA	DCEBA
CDBEA	DECBA
DCBAE	CDEBA
ABCDE	CBDAE

Thurstone scaling was not carried out on the Information Needs Questionnaire because of the small sample size but it was interesting to find that none of the twenty women interviewed felt that the measure had excluded any important items of information.

The Information Needs Questionnaire was found to be somewhat intimidating in length for many individuals. An initial assessment of the number of pages in the questionnaire led to many comments suggesting that it would take a substantial amount of time to complete. The questionnaire ran over a number of pages (see Appendix 2) but it was explained that once the first page had been completed there was a lot of repetition in the measure and it could be completed in a short space of time. The researcher did not specify how long the questionnaire should take to complete as she did not want to put pressure on individuals to feel that they were in some way inadequate for not filling in the questionnaire as quickly as others had done. However, most individuals managed to fill in the questionnaire in approximately five or ten minutes.

The fact that items were repeated in the measure (for example, item 1 would be seen with item 2, item 1 would also be seen with item 3 and with item 4, and so on) often needed further explanation once the individual had completed the first page of the questionnaire. It was at this stage that individuals realised that they had seen certain items before and wanted to know why they were seeing the same pair of items. Some individuals were insistent that the pairings were identical to previous pairings and had to be shown the first page of the questionnaire again to establish that all the pairings were in fact different even if the particular items were seen repeatedly.

The need for further instruction and explanation in completing the Information Needs Questionnaire justified the use of an interview approach. A postal questionnaire would not have allowed for discussion or explanation if the individual was confused about certain aspects of the questionnaire and responses may well have been biased by a lack of understanding.

As a result of the pilot study the measures were deemed suitable and acceptable. The revisions in the wording on the Information Needs Questionnaire presented no problems for individuals in either the newly diagnosed or benign study samples and the only minor problem was in having to further explain the measure when repetition of the items occurred. Encouragement was also needed about the time taken to complete the measure, especially with the benign study group who were keen to return home after waiting in clinic for a number of hours.

Testing the Interview Schedule

The pilot study also aimed to assess if the interview schedule included relevant questions and to assess if any questions had been excluded that would provide essential data for the study.

Socio-demographic questions were asked at the start of the interview and the position of these questions in the schedule seemed appropriate in that they provided a general introduction to further dialogue. General details on age, level of education and occupation were obtained before the interview became more specific and asked about referral patterns and treatment plans (for the newly diagnosed group).

Obtaining socio-demographic details was generally not problematic although gathering data on occupation to derive social class did present some minor problems. Some women reported that they had no occupation nor did they have a partner on whom to base social class. This problem had been anticipated and it was accepted that some data on social class would inevitably be "missing". Generally the occupational classification system proved effective for women who were able to report on an occupation for themselves and/or their partners.

Access to Study Samples

The third aim of the pilot study was to investigate if the design of the study was appropriate in terms of accessing the study samples and to highlight areas that may prove problematic to the study.

The newly diagnosed women were admitted onto the wards at the study site on two days each week. Information about admissions was available on an admissions list that each ward was provided with by the breast specialist consultant's hospital secretary. The researcher visited the wards on a monday morning to view the admissions list and read the medical notes to decide which women met the inclusion criteria for the study. It seemed immediately apparent that if the researcher had her own copy of the admissions list this would be a useful reference for planning the interviews for the entire week. Through communication with the hospital secretary it was arranged that the researcher would collect a copy of the admissions list each week.

The numbers of women who met the inclusion criteria for the study varied considerably from week to week, based on information from the admissions lists. However, this variability would probably not be significant if data collection was continued for a sufficient time period.

Ten women newly diagnosed with breast cancer were approached and asked to consent to taking part in the pilot study. All ten women were willing to be interviewed and the interviews lasted between twenty and thirty minutes. In terms of sample accrual for the main study these results were very encouraging.

Finding a suitable time slot in which to interview the newly diagnosed sample proved problematic. A great deal of time was spent waiting for potential participants who had been admitted to the ward but who were now in the X-ray or the ECG department having pre-operative tests and assessments. The researcher also found other competitors for each woman's time, for example ward nurses making assessments and completing nursing notes, the breast care nurse making a pre-operative visit, medical students taking detailed case histories, house officers clerking in patients, the breast specialist consultant carrying out his ward round, the anaesthetist making a pre-operative assessment as well as relatives and friends and interruptions due to meal times.

Identifying suitable candidates for interview and obtaining consent to interview did not present any major problems but being in the right location at the right time to interview the study participants was time consuming. The researcher found that she was spending a great deal of time waiting in corridors for other health care professionals to complete their assessments or travelling from ward to ward in order to find somebody who was available for interview. No solution to this problem was apparent. The most important point was that the women were consenting to the interview. To ensure that data would not be lost the researcher would have to accept that access to the women may be frustrated and repeated attempts at contact may need to be made.

It was important that the interview was uninterrupted so that the women could concentrate on the questions they were being asked and in this respect the interview was of adequate duration in meeting this aim. If the interview had included further questions, or more open ended questions, which would have stimulated further discussions, then interruptions would have been more likely.

The women with benign breast disease were interviewed in the out patient department. Eleven women were approached and asked to participate in the study and ten of these women consented. One woman stated that she had a prior commitment and, as she had been in the out patient department for a number of hours, could not stay any longer. This response rate was encouraging in terms of sample accrual although problems were encountered in accessing the study sample.

The researcher attended the breast clinic in the out patient department and waited for a negative diagnosis to be announced by the pathologist, following which the consultant would confirm this diagnosis with the patient and introduce the researcher. However, the pathologist tended to examine a number of specimens of breast tissue before announcing the results to the breast specialist consultant. By doing this a number of women were available for interview at one time point. The consultant would introduce the researcher to a potential study participant and then immediately move on to inform another individual of their negative results. By doing this the researcher was only able to access one individual out of each group of possible study participants. It would be insensitive to ask potential participants to wait for a further hour or more in the clinic before being interviewed when they had already waited a number of hours for their test results.

Also, the number of women fulfilling the inclusion criteria for the benign study sample varied quite widely from week to week with no means of predicting how many women would fulfil the inclusion criteria on any given day. The location of the interview also proved to be problematic. The researcher had arranged to share a consulting room with the breast care nurse but on occasion the researcher was interrupted during the interview when the breast care nurse needed to talk to women newly diagnosed with breast cancer. The breast care nurse was given priority on these occasions but it was disruptive to the interview as the researcher had to try and locate a quiet corner of the waiting area to complete the interview, not always an easy task in such a busy clinic.

These practical problems had no obvious solution and, as no other point of access for the benign study sample was apparent and no other consulting room was available, the frustrations caused by these practicalities would have to be accepted. The pilot study made it clear that the researcher would need to be available for the duration of the clinic in order to accrue sufficient numbers for the main study sample. As the availability of women who met the inclusion criteria for the benign sample would be variable then by maximising the amount of time spent in the clinic situation sufficient data could be gathered for the main study.

Conducting the Interview

The fourth aim of the pilot study was to familiarise the researcher with carrying out the interviews and administering the measures. After conducting twenty interviews the researcher felt confident in her ability to carry out the interview effectively. Health care professionals at the study site co-operated and were agreeable to answering questions about potential study participants and study participants were generally willing to consent to interview. The women in the newly diagnosed study group did not appear distressed by the questions they were asked, even at this acute stage in the breast cancer experience. However, some women were concerned that what they said would influence their care. Further emphasis needed to be given when obtaining consent to the fact that only the researcher would be aware of the women's responses and that their comments would in no way influence their care or treatment.

Conclusions from the Pilot Study

The Control Preferences Scale (CPS) and the Information Needs Questionnaire were considered appropriate instruments to test the study aims. The changes to the wording in the Information Needs Questionnaire made the questionnaire suitable for a British audience and no problems were evident in completing the questionnaire. The length of the questionnaire caused concern for some study participants and the repetition in the measure needed repeated explanation. However, as the design of the study incorporated an interview approach these problems could be overcome by the interviewer with careful explanation and encouragement.

The practical problems of accessing the study samples were frustrating but were not considered to be a study limitation. Collecting data for the main study would involve a great deal of negotiation and communication with other health care professionals to arrange access to women at suitable times.

THE MAIN STUDY: STAGE 1

Population/sample

The population for the main study were women referred to the breast specialist centre at the study site who met the inclusion criteria of the two main study groups, that is women newly diagnosed with breast cancer and women with benign breast disease.

Sample size

Data collection was planned to extend for approximately one full year and was commenced in December 1992 and completed in February 1994. With an estimated availability of 350 new cases of breast cancer a year in the study centre it was considered that one year would be sufficient to gather adequate numbers of cases for statistical analysis. A sample size calculation was also carried out using the ARCUS™ statistical package which showed that a minimum of 108 women newly diagnosed with breast cancer and 108 women with benign breast disease would be needed in each of the two study groups (Appendix 4).

Method

Data were collected by means of a structured interview which included questions on socio-demographic details as well as the CPS and Information Needs Questionnaire. The interview lasted approximately twenty to thirty minutes. The women in the newly diagnosed group were interviewed on the hospital ward the day of their admission, the day prior to commencement of treatment. Women in the benign group were interviewed in an out patient clinic.

Consent

Verbal consent was obtained prior to commencement of each interview. The main aims of the study were explained, stating that there were no right or wrong answers and the researcher was interested in the opinions of each participant. Anonymity was assured as only the researcher carrying out the interviews would be aware of individual names and corresponding numbers on the interview schedule. It was explained that entry to the study was voluntary and that at any time during the proceedings they were free to discontinue the interview. The newly diagnosed group were also informed that their responses to the questions would in no way influence or prejudice their care and treatment but it was hoped that their answers to the questions would be of assistance in aiding health care professionals care for other women with breast cancer in the future.

Sample Accrual

Interviews were carried out with 150 women who were newly diagnosed with breast cancer and 200 women with benign breast disease who met the inclusion criteria for the study and consented to interview.

Newly Diagnosed Group

A total of 167 women were approached as possible study participants with 150 women being entered into the study. Seventeen women were, therefore, not included in the study sample and the reasons for this are summarised in Table 3.

Table 3. Reasons for Non-inclusion in Newly Diagnosed Study Sample

Reason for non-inclusion	**Number of individuals**
Previous surgery for breast cancer	4
Refused consent	5
Unaware of diagnosis	3
More than 4 weeks from diagnosis	3
Unable to complete measures	1
Excessive missing data	1
Total	17

The four women who had previous surgery for breast cancer had no notes available on the hospital wards when the researcher arrived to carry out interviews. Ward staff were unable to inform the researcher if the women had any previous history of breast cancer. All four women were approached and the researcher introduced herself explaining that she would like to talk to women who were in hospital for the first time with breast problems. The women were willing to elaborate on their experiences and from their comments it was clear that they did not meet the inclusion criteria for the newly diagnosed study group.

Five women refused consent to the study. Four of these women refused consent at the outset stating that they were too anxious to answer any questions. One woman agreed to take part in the study but became very distressed when the researcher asked her to complete the Information Needs Questionnaire and refused to carry on any further. The researcher discontinued the interview at this point.

Three women were unaware of their diagnosis. In these cases the medical notes were not available at the time of interview and the researcher asked the women if they could say why they had been admitted to hospital. Two women seemed somewhat confused and were unable to say why they had been admitted or what treatment was planned. The researcher did not proceed further. Another woman stated that she knew there was a possibility of cancer cells but that they had not been confirmed although subsequent reading of the medical notes for this woman stated that a malignancy had been confirmed.

Three women were too far from diagnosis to be considered "newly diagnosed". These women were 16, 25 and 26 weeks from diagnosis. Their medical notes had been unavailable and they had been approached as possible study participants. All three women had received pre-operative chemotherapy prior to admission for surgery. All three women were keen to talk to the researcher about their experiences and time was spent with each of these women although they were not asked to consent to the study.

One woman was unable to complete the Information Needs Questionnaire. She seemed to find it extremely difficult to make choices. Even though she could point out the information needs that were not important to her she could not decide which needs were more important than others. For example, she said that item 6, relating to sexual attractiveness, was not important to her. However, when asked to compare item 1 (information about the spread of the disease) to item 6, she could not say which item was more important than the other. The researcher discontinued the interview as the woman was becoming distressed about her inability to make choices.

Although the researcher tried to observe all participants when they were filling in the Information Needs Questionnaire one woman omitted 7 of the paired comparisons. This was considered excessive in terms of the data analysis and this participant was excluded from the study sample.

Benign Group

A total of 216 women were approached as possible study participants with 200 women being entered into the study. Sixteen women were, therefore, not included in the study sample and the reasons for this are summarised in Table 4.

Table 4. Reasons for Non-inclusion in Benign Study Sample

Reason for non-inclusion	**Number of individuals**
Prior engagement	13
Refused consent	2
Too distressed to continue	1
Total	16

Thirteen women who were approached and asked to participate in the study could not stay any longer to talk to the researcher as they had other appointments to keep. Two women refused to consent to take part in the study. They did not state a reason and the researcher did not press for an explanation. One woman, who consented to take part in the study, became distressed and the interview was discontinued by the researcher.

PRE-PILOT WORK: STAGE 2

Stage 2 of the study involved a second interview with the newly diagnosed group but at a time point further from diagnosis. A time point of approximately two years from diagnosis had been planned as part of the study design. The aims of the pre-pilot work were:

1. To determine the best approach to accessing the follow up study sample.

2. To design a second interview schedule that would be suitable for this follow up group.

Access to the Study Sample

Through observation in the out patient department the researcher ascertained that women who were approximately two years from a diagnosis of breast cancer, who had encountered no recurrence of disease or further breast problems, were now being assessed in the clinic approximately every 6 months. Few of these women now saw the breast specialist consultant. The majority of these women were reviewed by a more junior member of the specialist team, usually the registrar or senior house officer. There appeared to be four main routes of accessing the follow up sample and these are listed overleaf.

1. To co-ordinate the interview with the out patient department visit.
2. To ask women to make a special journey to the study site to be interviewed.
3. To interview women in their own homes.
4. To provide women with a choice of location and allow them to express a preference.

To assess the feasibility of interviewing all the women in the follow up group at the time of their out patient appointment the study site's computer system was accessed to provide a list of all out patient appointments for the study sample. Unfortunately, it appeared that the computer system only recorded appointments made with the breast specialist consultant's team. A substantial number of women, who had lumpectomy and radiotherapy as their primary treatment, were now being followed up by a radiotherapist. Although the radiotherapist carried out his clinics at the study site he was based at the local specialist oncology centre and his appointments system was managed by his secretary at that location. These appointments were on a separate computer system to which the researcher had no access. Following discussion with the radiotherapist's secretary a list of appointments was obtained for a number of women, but the list was incomplete.

An examination of the clinic appointments revealed that it would be impractical and probably impossible to co-ordinate the clinic appointments with the interview for the follow up group. Some women had appointments that were one year hence when, by which time, they would be approximately three years from diagnosis. The design of the study involved interviewing women with breast cancer at two specific time points.

If there was too much variation in the time from diagnosis for each individual then sample sizes within separate time cohorts would be too small for adequate statistical analysis. The researcher had ascertained that the follow up group needed to be interviewed within approximately a six month time period to ensure that all women would be as close to the same time point from diagnosis as possible.

To ask women to make a special journey to the study site to be interviewed may cause inconvenience. Also, as sample size would be limited by the number of women in the newly diagnosed group, it seemed more likely that individuals would be less willing to become involved in the study if it involved travelling some distance to the study site or having to make arrangements regarding work or children.

Interviewing women in their own homes was considered the most practical solution. The interview would, hopefully, be uninterrupted and more time would be available to ask women about the breast cancer experience. Also, the women would feel more at ease in their own home environment and may be more willing to share details of their experiences. It was appreciated that this approach would involve a great deal of travelling on the part of the researcher and it was not certain how many interviews could realistically be carried out in a day and this would need investigation in the pilot study for Stage 2 of the study.

Providing women with a choice of location was also a viable option although the practical limitations of interviewing women in the clinic situation, such as finding access to a private room, could be a study limitation. A compromise was decided upon. Women would be asked to consent to an interview in their own homes. It would also be stressed that if, for any reason, this was inconvenient the interview could be carried out at the study site or at the researcher's base.

Consent

As the women in the follow up sample would be approximately two years from diagnosis it was likely that a number of potential study participants would not remember the first interview. The hospital computer system was used to obtain addresses for the study sample but only a small number of telephone numbers were available. The researcher did not want women to feel obliged or pressured into agreeing to take part in the study on a second occasion, which may be the case if telephone contact was established. A letter of introduction would remind women of the previous study and put the onus on them to respond should they wish to do so.

A letter was drafted that explained who the researcher was and what the study was about (see Appendix 5). Confidentiality was assured and the letter reminded each individual of where and when they had previously been interviewed by the researcher. Reimbursement was offered for postage or phone calls that would be needed to get in touch with the researcher. Telephone numbers were given where the researcher could be contacted as well as an address for correspondence. A second letter was also drafted to be sent to non-responders (Appendix 5). This letter included a second request for an interview and a sheet of paper that allowed individuals to tick a box if they did not wish to be contacted again or to provide their telephone number if they wanted the researcher to contact them. A stamped addressed envelope was also included on this occasion. No further attempt at contact was planned if no response was received to the two letters. A letter was also drafted to thank respondents once the follow up interview had taken place (Appendix 5).

The Interview Schedule

Interviewing women in their own homes would allow more time for women to express themselves. With more time available more questions could be included in the interview schedule than in the schedule designed for the acute hospital setting. Also, more open questions could be included to allow free expression by the women about their experiences. The measure of decision making preferences (CPS) and information need (Information Needs Questionnaire) would be included in this interview schedule for consistency and to allow a comparison of the changes in decision making preference and information need over time. To assess if information needs were being met at this follow up stage all women were asked if there was any information they still needed but had not received.

Socio-demographic details were taken to note any changes that had occurred in the intervening period. Treatment details were also recorded. More open ended questions were included about the decision making process, the impact of the disease on family and friends and problems encountered. The interview schedule for the follow up group is presented in Appendix 6. The Information Needs Questionnaire is not presented in the interview schedule in Appendix 6 to avoid repetition (see Appendix

2 for the Information Needs Questionnaire). However, in carrying out the interview the questionnaire was presented following the assessment of decision making preferences and prior to questions regarding sources of information.

Sources of Information

The second interview schedule also focused on the sources of information that the follow up group used. The first interview had taken place at the time of diagnosis before treatment had commenced. Women were not asked about their sources of information at this time point as the breast cancer experience was new to them and, arguably, they would not have had time to determine what sources of information were available and how useful they were. This part of the study would involve retrospective questions as the women would be asked, at the follow up stage, about the sources of information they found useful at the time of interview as well as the sources of information they had found useful around the time of diagnosis and treatment.

In devising a list of potential sources of information consideration was given to both professional and non-professional sources of information. The professional sources represented the primary health care team as well as the hospital breast specialist service. From observations made at the study site and from discussions held with health care professionals as well as breast cancer sufferers the main potential professional sources of information that were available to women with breast cancer were the breast specialist consultant, the breast care nurse, hospital ward nurses, clinic nurses and the General Practitioner (GP). Breast cancer has become a popular media focus in recent years and so it seemed appropriate to include women's magazines, radio, television and newspapers as non-professional sources. Family and friends were also considered to be a non professional source of information for women with breast cancer (Northouse and Northouse, 1987).

The researcher discussed with the breast care nurses the written sources of information that were provided to women with breast cancer. The breast care nurse provided leaflets on different treatment options and different treatment regimes. The leaflets were included as a separate source of information as women may have found the breast care nurse a useful source of information but not have been impressed with the written material or vice versa. Medical books and journals were included to determine if some women wanted more technical and detailed information in a written format.

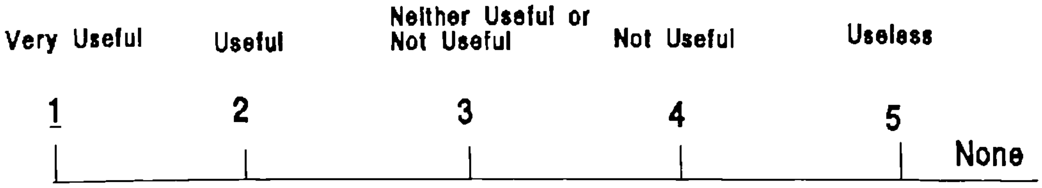
Voluntary sector organisations are gaining in popularity in the current health care system and for this reason "support groups" were included as a potential source of information. The sources of information that would be included in the interview schedule are listed in Box 2.

Box 2: Sources of Information

- Hospital consultant
- Breast care nurse
- General Practitioner (GP)
- Nurses on wards and clinics
- Leaflets
- Women's magazines
- Television/radio
- Newspapers
- Medical book/journal
- Family/friends
- Support groups/volunteers

The women in the follow up study were asked if they had received any information from the above sources around the time of diagnosis and at the present time. Each item was accompanied by a five point scale. Points 1 to 5 indicated how useful they had found the information with a score of 1 being the most useful and a score of 5 being the least useful. Each individual also had the option of stating that they had received no information from a particular source, this was indicated by circling zero at the end of the scale (Figure 5). Getting no information from a particular source was not automatically assumed to be any worse than getting useless information as it's position in the scale may be taken to indicate. The scale simply allowed a yes/no response to having obtained information and a rating of how useful information was to the individual.

Figure 5. Rating the Sources of Information



THE PILOT STUDY : STAGE 2

A pilot study was carried out once access to the study sample had been determined and the interview schedule had been developed. The aims of the pilot study were:

1. To test the interview schedule, including the CPS and Information Needs Questionnaire.

2. To determine if the questions on the schedule were appropriate for the follow up study sample and to determine how long each interview would take to complete.

Population/sample

The population for this pilot study were women with breast cancer who had been treated for breast cancer at the study site and were more than one year from diagnosis. In the main study the population would be all the women in the newly diagnosed group who had been interviewed on a previous occasion. As this was a limiting factor to the sample size of the follow up group the pilot study involved carrying out interviews with a small number of women who had not been interviewed on a previous occasion. These women were approached in the out patient department and interviews were carried out there. In this way, if the interview schedule needed modification, valuable data from study participants would not be lost.

Method

Four women who had not been part of Stage 1 of the study were approached and consented to be interviewed in a breast clinic in the out patient department of the study site. Although it may have been more appropriate to interview some of these women in their own homes the researcher did not want to create unnecessary anxiety in a sample of women who may have been concerned as to why they had been singled out for individual attention. It seemed more sensible to approach women who were attending a breast clinic for a routine out patient appointment. This would cause less inconvenience to the women and would hopefully not cause any undue distress. The researcher explained that she would be very interested in the opinions of the women on the interview schedule that had been designed and that all responses would be treated with strict confidentiality. All four women consented to the researcher progressing through the full interview schedule.

Findings of the pilot study

The interviews carried out in the outpatient clinic were of approximately one hour's duration. Although an interview room had been provided there were still occasional distractions and interruptions, a problem that would presumably not be so evident when interviews were carried out in the women's own homes. On the basis of this observation the decision to interview women at home, if possible, seemed justified.

As more time would be available for the follow up interviews than those carried out in the acute hospital setting, the researcher's timetable allowed for one interview to be carried out in a morning, afternoon or evening session. Therefore, a maximum of three interviews could be carried out in any one day, although practically it was felt that to prevent fatigue on the part of the interviewer a maximum of two interviews in any one day would be a more realistic target.

Minor alterations were made to the interview schedule to make the data more meaningful. For example, marital status had been included on both interview schedules but for comparative purposes a question was added to the interview schedule for Stage 2 of the study regarding change in marital status following the diagnosis of breast cancer. A question that asked if the participant had school age children was also added as it was thought inadequate to ask women if they had children without qualifying the age of the children. As many of the sample would be over sixty years of age many of the women's "children" would now be adult (see Appendix 6).

No problems were encountered with the administration of the measures and the women involved in the pilot study did not have any problems in understanding the measures. The researcher asked if any of the women were distressed by any of the questions or felt that they were too intrusive. None of the four women expressed any distress and did not object to discussing the more intimate details of their experiences.

As the four women in the pilot study had not been part of the newly diagnosed group in Stage 1 of the study, data from these women was disregarded prior to commencement of the main study.

THE MAIN STUDY: STAGE 2.

Stage 2 of the study sought to examine how decision making preferences and information need were influenced by time since diagnosis. The design of the study involved a second interview with the original sample of newly diagnosed women but at a point further from diagnosis.

Population/sample

The population for this stage of the study were all the women who had been interviewed on one previous occasion when they had been newly diagnosed with breast cancer. Of the 150 women in the original sample, 140 were available for interview as far as the researcher could ascertain. Information about deaths was recorded on the hospital computer system but only if the individual had died while a patient in the hospital. Eight of the sample had died (5.33%) according to the computer system.

The researcher noticed that the address of one woman was that of a nursing home. On contacting the nursing home the researcher was informed that this woman was very confused and would not be suitable for interview. One woman had received a benign diagnosis following the first interview. The researcher was not party to the reasons for this. The medical notes had indicated a malignancy and the individual concerned stated that she had breast cancer. This individual was not re-contacted and was not excluded from the newly diagnosed study sample as she had believed that she had breast cancer when the interview had been carried out.

Method

All 140 women who were potentially available for a second interview were contacted by letter and a second letter was sent to non-responders at a later date. Interviews were arranged with 105 women who contacted the researcher (i.e 75% of the available sample, 70% of the original sample). The majority of these 105 women had responded to the first letter (91.4%, 96/105) with a smaller number responding to the second letter (8.6%, 9/105).

Letters were sent out to the follow up group each week, ten at a time. Two telephone numbers had been included in the letter so that if the researcher was not available a secretary was available to take a message. An entire morning, afternoon or evening was allocated for each interview so that women would not be rushed or hurried. Interviews were arranged at times and locations convenient to the study sample.

The interview schedule was administered and ample time was available to allow the women to express any concerns or anxieties. Women with problems that warranted attention were referred to either the breast specialist consultant, the breast care nurses or their own GP. The researcher had the co-operation of the breast specialist consultant and the breast care nurses in this matter.

Consent

Responding to the written communications sent out by the researcher implied consent to take part in the study. However, on meeting with each study participant the researcher reminded women of the study in which they had taken part on a previous occasion and explained the reasons for a second interview. All participants were informed that anonymity would be assured with only the researcher being able to identify individual names from the identification number on the interview schedule. All the women who agreed to be interviewed were informed that they could discontinue the interview at any stage should they wish to do so.

Location and Sample Accrual

The majority of women were interviewed in their own homes as Table 5 indicates. Some women requested to be interviewed at the study site as they could co-ordinate the interview with an imminent out patient appointment. On these occasions the interview was planned and a private location was arranged and booked in advance. Two women preferred to have the interview conducted in the researcher's office as the location was convenient for them. Two women preferred to be interviewed at their place of work as they had their own private location where the interview could take place uninterrupted.

Thirty five women who had been contacted by the researcher and asked to take part in the follow up study were not entered into the study. The reasons for this are summarised in Table 6.

Table 5. Location of Interview for the Follow Up Group

Location	**Number**
Own home	95
Study site	6
Researchers office	2
Place of employment	2
Total	105

Table 6. Women Not Entered into the Follow Up Study

Reason	**Number**
No response to letters	21
Responded but unable to arrange interview	6
Responded but refused consent	4
Interview discontinued	3
Died	1
Total	35

Twenty one women did not respond to either the letter of introduction or the reminder. Six women were willing to be interviewed but the researcher could not arrange a suitable time or location to carry out the interview. For example, one woman had moved to a different part of the country and one woman worked night shifts. Four women responded but on talking to these women they were reluctant to agree to interview. The researcher further emphasised that entry to the study was voluntary and that consent to the first interview did not imply consent to a second interview. These four women decided that they would prefer not to be interviewed on a second occasion.

Three interviews were discontinued by the researcher. On one occasion a woman received some distressing personal news during the interview and the interview was terminated at that point. On another occasion a woman refused to continue with the Information Needs Questionnaire and instead preferred to talk about the historical aspects of the study site. Despite an attempt to refocus the interview the woman would not continue with the interview schedule but was quite happy to continue talking to the researcher about matters unrelated to the breast cancer experience. On another occasion it was apparent that the study participant was extremely distressed and unhappy about the breast cancer experience as she explained to the researcher her feelings of extreme depression and anxiety. Due to the level of distress shown by this woman the interview was terminated and a referral to the breast specialist consultant with a view to consultation with a clinical psychologist was made.

The daughter of one of the previous study participants contacted the researcher to relay the news that her mother had recently died. The researcher apologised for having troubled the family at such an upsetting time.

In total 105 completed data sets were available for analysis.

Data Entry and Coding of Data

All data were entered using the SPSS-PC+ Data Entry system. Two forms were created within the data entry system that presented variables in the same order as those presented in the two interview schedules used in this study. In this way data could be readily transferred from the interview schedule into the data entry system with minimal time wastage.

All data were coded as numerical variables with the exception of the decision making preference order. As this information would be transferred to a SAS computer programme this data was required to be entered as a string variable.

CHAPTER 5

ANALYSIS

INTRODUCTION

In examining the data from this study both descriptive statistics, used to summarise and describe the data, and inferential statistics, used to draw inferences and conclusions from the data, were employed.

To test the hypotheses for this study a number of statistical tests and procedures were carried out on the data. Where a normal distribution could be ascertained or assumed in the data and where the level of measurement was at the interval level, parametric techniques were employed. For data that conformed to categorical or nominal levels of measurement non-parametric techniques were utilised.

For all statistical tests carried out as part of this study a significance level of 5% was employed. There are two types of error that may occur in deciding about whether to accept or reject a null hypothesis (Siegel and Castellan, 1988). A Type I error involves rejecting the null hypothesis when it is, in fact, true, whereas a Type II error involves accepting the null hypothesis when it is, in fact, false. The significance level indicates the probability of committing a Type I error. In this study, the null hypothesis would be rejected in favour of the alternative hypothesis if a statistical test gave a value equal to or less than 0.05. That is, a one in twenty chance of making a Type I error would exist.

All hypotheses and predictions made in this study were considered to be non-directional or two tailed. The researcher did not wish to try and make predictions about the direction of changes and influences in the data.

CONFIDENCE INTERVALS

The use of confidence intervals in social science research has gained in popularity. It has been suggested that, if appropriate for a particular study, they should be used when reporting major findings (Gardner and Altman, 1992). Confidence intervals allow the researcher to give an indication of the range of results that would be expected if the population had been involved in a particular study rather than a sample. That is, the researcher would have a certain level of confidence (usually 99%, 95% or 90%) that a population difference would lie within a particular range of values.

In the present study confidence intervals have been used where it was considered relevant to particular sections of the data. For example, where distributions of decision making preferences are presented, confidence intervals as well as p values are displayed as the clinical relevance of applying findings to a population are appreciated. In all cases where confidence intervals have been utilised in this study a confidence level of 95% has been instigated.

PARAMETRIC STATISTICAL TESTS

T-Test

The pooled variance T-Test was used to test the differences between the means of two independent groups where a normal distribution in the data could be assumed. For example, Case V of Thurstone's law of Comparative Judgement assumed that data were normally distributed (Thurstone, 1974). The T-Test in this scenario was used to compare scale values from the information needs profiles across different groups and subgroups within the data to examine if variables such as age and level of education influenced the information needs profiles.

Analysis of Variance

Where it was necessary to test the differences between the means of more than two independent groups Analysis of Variance (ANOVA) techniques were employed.

NON PARAMETRIC TESTS

Chi-Square Test

The Chi-square test was used for analysing data that fell into various categories and that involved two or more independent groups. The technique is one of 'goodness of fit' and looks to see if there is a significant difference between an observed number of responses in a certain category and the expected number of responses in a certain category, based on the null hypothesis (Siegel and Castellan, 1988).

The McNemar Test

The McNemar test was used where two samples were matched or related in some way. The test is used to show changes of a "before" and "after" nature.

RANK ORDER CORRELATION

Correlation coefficients were used to show the degree of association between variables. As many of the variables in this study were of a categorical nature it was not possible to carry out the parametric Pearson's correlation. The non-parametric Spearman's rank order correlation was used instead and data were ranked prior to the calculation of correlation co-efficients. Spearman's *rho* gives values that range from -1 to +1. A value of 1 (minus or plus) would indicate a perfect correlation between two variables. A value of 0 would indicate no correlation or association between two variables. Care needs to be taken when assessing the relevance of correlation coefficients. Although many variables can be shown to be associated it is the degree of association that is important and it is important to remember that correlation does not imply causation.

ANALYSIS OF DECISION MAKING PREFERENCES

Analysis of the decision making preferences of the study groups related to the first aim of the study, that is :

To investigate the degree of involvement that women newly diagnosed with breast cancer, and a comparison group of women with benign breast disease, would want in the treatment decision making process and to determine how these preferences were influenced by time since diagnosis for the women with breast cancer.

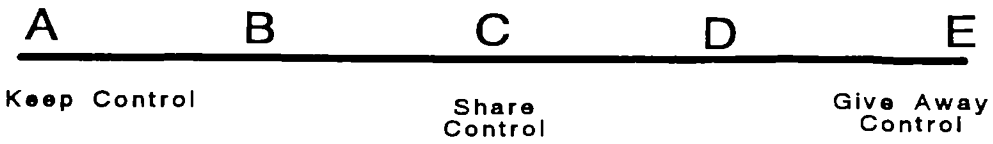
This part of the analysis involved the use of Coombs' unfolding theory (Coombs, 1964).

Unfolding Theory

This scaling method was based on the theory of preferential choice which involved preferential choice data being converted to a rank ordering of preferences for a set of stimuli. That is, the decision making preference cards in the CPS would be placed in order of preference that ranged from most to least preferred. The card sort technique aimed to establish a preference order over 5 decision making roles by presenting stimuli in subsets of two.

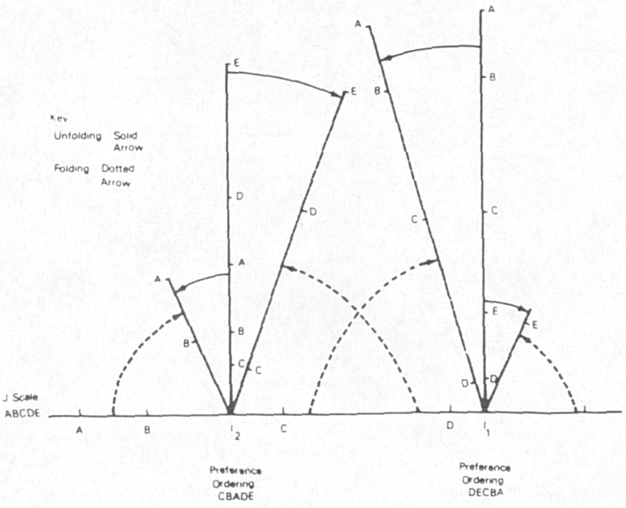
The unfolding model aimed to show the relationship between two sets of points, individual and stimulus points. As a geometric model it examined the relationship between an individuals "ideal point" and a dominant underlying psychological dimension. In the present study the aim of the unfolding model was to show the existence of an underlying dimension of control that ranged from keeping control through sharing to giving away control. These degrees of control related to an active, collaborative and passive role respectively (see Figure 6). The underlying dimension of control postulated for the present study can be referred to as the "ABCDE metric" with each individual preference order being displayed as a permutation of the five decision making roles (eg. BACDE).

Figure 6. Dimension of Control



Coombs termed each individual preference order an I scale. The I scale reflects the individual's ideal point on the dimension of control. For example, a preference order of BACDE would suggest that an individual had an ideal point between A and B on the ABCDE metric but was closer to B than A. Unfolding theory aimed to "unfold" each I scale onto an underlying dominant psychological dimension, termed a "Joint" or J scale. The J scale was a joint scale that reflected the relationship between the individual's preference order and the dominant dimension. The aim then was to show that a single J scale was consistent with a set of I scales. That is, that there is one dominant psychological dimension onto which each I scale can be fitted to reflect each individual's **ideal point** on that dimension. In the present study the unfolding model was used to validate the existence of the ABCDE metric, that is to show that individuals recognised the existence of an active-passive dimension in terms of treatment decision making. Figure 7 shows how I scales are unfolded to be consistent with a J scale.

Figure 7. How I Scales are Unfolded to Form a J Scale



(From McIver & Carmines 1991)

Coombs described two different types of J scale. A qualitative J scale described the relationship between stimulus points on the J scale in terms of their ordinal position on that scale. It reflected the position of each stimulus point and the order in which each point occurred. For 5 stimuli there are 16 preference orders that conform to a qualitative J scale (2^{n-1}) (McIver and Carmines, 1991).

Although a qualitative J scale provides information on the position of each stimulus on the scale it does not provide information regarding the distance between stimulus points. To gather information about distance a quantitative J scale is constructed. This scale consists of a subset of preference orders taken from the qualitative J scale.

Coombs stated certain criteria that the I scales had to meet before they could be considered to fit a quantitative J scale. The first and last preference orders had to be mirror images. For example, if a preference order of ABCDE existed then a preference order of EDCBA also had to exist. If no individual chose ABCDE or EDCBA then an immediate rejection of the unidimensional model would have to be made. No more than one set of mirror images were allowed to exist within the quantitative J scale. In moving from one preference order to the next only two of the stimuli must be reversed. For example, in moving from ABCDE to BACDE only A and B have changed order. The remainder of the preference order is unchanged.

There were eleven preference orders consistent with a quantitative J scale for 5 stimuli. This number was achieved by using the formula $\binom{n}{2}+1$ where n is the number of stimuli (McIver and Carmines, 1991). In the present study $n=5$ as there are 5 decision making preference cards. The number 2 in the equation refers to the size of the subset. That is, there are 5 stimuli in total but they are shown in subsets of two. However, n stimuli can be ordered in n! different ways (McIver & Carmines, 1991). So, 5 stimuli can be ordered in 5! different ways i.e $5 \times 4 \times 3 \times 2 \times 1 = 120$ different ways. But only $\binom{n}{2}+1$ of these orders can be represented on a single quantitative J scale. That is, $5!/[(2!(5-2)!] +1 =11$.

In the present study it was important to know about the distance between stimuli as information was needed on the midpoints between stimuli. For example, information was needed about where the midpoint was between B and C as this would indicate a change from an active to a collaborative role. A quantitative J scale was, therefore, constructed for the purposes of this study that allowed for the formation of eleven preference orders that would fit onto the ABCDE metric. The eleven preference orders are listed below.

ABCDE
BACDE
BCADE
BCDAE
CBDAE
CDBAE
CDBEA
CDEBA
DCEBA
DECBA
EDCBA

For any scale consisting of 5 stimuli there are a possible 120 different ordered permutations of those stimuli. The unfolding model proposed that to show the existence of a scale (the ABCDE metric in this study) only a small subset of these 120 permutations (I scales) should be valid. Validity here is in terms of an individual giving a response that is consistent with the ABCDE metric. It may be that the way in which individuals choose their preference orders is purely arbitrary and they may not 'see' the dimension that is hypothesised to exist. A number of dimensions exist but the aim was to show that a majority of the preference orders chosen by the study sample were consistent with one dominant underlying psychological dimension, the ABCDE metric. Obviously not all individuals' preference orders will fit onto the ABCDE metric and Coombs stated that 50% plus 1 of the individual preference orders were required to fit onto the dominant dimension to support a unidimensional model.

Coomb's model dates back to the 1960's when statistical techniques were not as advanced as they are today and computer technology was not readily available for the analysis of data. It is now possible to examine all the competing models that may form a dimension for the individual preference orderings (I scales). There are 60 possible models for a five point metric and computer programmes have been developed that can examine each of these models to determine if they are consistent with Coombs' criteria for a unidimensional model (Sloan and Yeung, 1994). The presence of a mirror image reversal is no longer thought to be critical in presenting support for a unidimensional model although it's existence does lend power to the validity of the model.

A SAS computer programme developed in Canada (Sloan and Yeung, 1994) was used in order to rank the competing models by the number of valid responses for each of the 60 models, to note whether a mirror image reversal existed for each of the 60 models, and to note the number of empty cells in each model, that is the preference orders that had not been chosen.

Ordinal scores ranging from 1 (for the preference order ABCDE) through to 11 (for the preference order EDCBA) could be allocated to the preference orders consistent with the ABCDE metric. The allocation of ordinal scores is shown in Table 7. These scores could be used in subsequent analysis to show differences between mean metric scores for the study groups indicating differences in decision making preferences.

Table 7. Ordinal scores allocated to the ABCDE metric.

Order	Score
ABCDE	1
BACDE	2
BCADE	3
BCDAE	4
CBDAE	5
CDBAE	6
CDBEA	7
CDEBA	8
DCEBA	9
DECBA	10
EDCBA	11

However, even though a direct test for dimensionality could be made and ordinal scores could be allocated to the preference orders consistent with the ABCDE metric there remained the problem that a lot of valuable data may be lost if findings were only reported for those individuals whose preference orders were consistent with the ABCDE metric. What about those preference orders that "fell off" the ABCDE metric? Coombs would have disregarded these orders but it seemed a more thorough approach to look at these preference orders where individuals made a "mistake" to see what items caused confusion within the measure. The present study reported on those preference orders that were consistent with the ABCDE metric as well as those orders that fell off the dominant dimension to further examine the complexities of the decision making process.

To enter the data into the SAS computer programme the individual preference orders were first entered into the SPSS-PC+ Data Entry system as string variables, for example ABCDE. Using the KEEP and EXPORT commands in SPSS-PC+ the relevant variables were saved and exported into the SAS system. SPSS was used as a means of data entry as the researcher was familiar with this computer software.

It was also considered useful to assign a categorical value to each preference order, as well as the ordinal scores assigned to each order consistent with the ABCDE metric, so that no information would be lost in an analysis of the distribution of preference orderings. In this way the most preferred card in the preference order was noted and used to assign categorical variables. Data were entered such that a category of 1 through 5 was allocated to each preference order reflecting a preferred first choice of A, B, C ,D or E respectively. Subsequent inferential statistics could then be applied to the data to show the impact of other variables on decision making preferences; categories could be collapsed to produce active (A and B), collaborative (C) and passive (D and E) preferences. Comparisons could be made between the ordinal scores for individuals consistent with the ABCDE metric and the categorical scores for all individuals to cross validate findings in reporting preference distributions for the total samples.

ACTUAL ROLE

Summary statistics were used to describe the data on perceived role in treatment decision making. A comparison between preferred role and perceived role was made to determine how many women showed congruence between the role they wanted to play in decision making and the role they perceived they played. Crosstabulations highlighted areas of incongruence where women may have, for example, wanted to play an active role in decision making but believe they had no opportunity to do so.

COMMENTS ON THE DECISION MAKING PROCESS

All the women with breast cancer were asked, at the follow up interview, how the decision regarding treatment had come about. Field notes were made on the women's comments. These notes were transcribed using a word processing package (WordPerfect 5.2). These comments were then classified according to whether women felt that the doctor had made decisions about their treatment, a shared form of decision making had taken place, or the women had made their own decisions about their treatment.

ANALYSIS OF THE INFORMATION NEEDS DATA

Analysis of the information needs data related to the second and third aims of the study, that is:

To construct profiles of information needs for women newly diagnosed with breast cancer, and for a comparison group of women with benign breast disease, reflecting priority information needs, and to investigate how these profiles changed over time for women with breast cancer.

To explore the relationship between treatment decision making and information need. That is, to investigate if decision making preferences influenced the type of information needed for women with breast cancer and women with benign breast disease.

This part of the analysis involved the use of Thurstone Scaling (Thurstone, 1974).

THURSTONE SCALING

Louis Thurstone, a psychologist at the University of Chicago, was one of the first psychologists to propose procedures for measuring attitudes (McIver and Carmines, 1991). Thurstone's Law of Comparative Judgment involved the rank ordering of a set of stimuli in order of preference or perceived importance. The model incorporated a paired comparison approach where individuals were asked to state a preference between only two items at any one time. The model assumed that when two stimuli were presented together they could be ranked by the individual in terms of a particular attribute, in this case importance.

Thurstone appreciated that the ranking of items would not be identical for different individuals or even for the same individuals at different points in time. However, it was assumed that for each item there would be a most commonly occurring response which Thurstone referred to as the "modal discriminal process". Case V of Thurstone's Law of Comparative Judgment assumes that the distribution of the discriminal processes produced by a particular stimulus would be normal. This normal distribution could then be described in terms of the mean and standard deviation; the mean, median and mode having the same values in a normal distribution curve. This mean discriminal process was then taken as the scale value for each individual stimulus or item. Thurstone's methodology encompassed individuals distinguishing between items in terms of a particular attribute, for example perceived importance, and giving each item a scale value to reflect it's relative importance.

The methodology reduced the likelihood of ceiling effects, where individuals would rate every item as of maximum importance, as a choice was being forced each time between only two items. If two items were in close proximity in terms of perceived importance then this would be reflected in their similar scale values.

To carry out the Thurstone scaling analysis the data were first coded from the Information Needs Questionnaire using the SPSS-PC+ Data Entry system. Data were coded such that if an individual chose the first item in a pair this item was coded "1" and if an individual chose the second item in a pair that item was coded "0". A total of 36 pairs of information needs were presented to each individual and each of these pairs was coded with a "1" or a "0".

A SAS computer programme was used to produce the scale values for the data (Sloan et al 1994), although the analysis could be carried out by hand. The researcher carried out some of the Thurstone scaling by hand to fully understand the principles and procedures involved. The following basic principles were adhered to as described by Sloan et al (1994):

1. A 9 x 9 matrix was established to locate each paired comparison. Table 8 shows the layout for the paired comparisons variables. In the layout **I23**, for example, would represent a comparison between **I**nformation needs **2** and **3**. The diagonal contains values of zero as items were not compared to themselves.

Table 8. Layout of the Paired Comparisons Variables

0	I12	I13	I14	I15	I16	I17	I18	I19
I21	0	I23	I24	I25	I26	I27	I28	I29
I31	I32	0	I34	I35	I36	I37	I38	I39
I41	I42	I43	0	I45	I46	I47	I48	I49
I51	I52	I53	I54	0	I56	I57	I58	I59
I61	I62	I63	I64	I65	0	I67	I68	I69
I71	I72	I73	I74	I75	I76	0	I78	I79
I81	I82	I83	I84	I85	I86	I87	0	I89
I91	I92	I93	I94	I95	I96	I97	I98	0

(From Sloan et al 1994)

2. The results for all the participants in each study group were added together so that a **frequency matrix** showed the number of times each item was preferred

over every other item. For example, the number of times that item 1 was preferred over item 2.

3. From the frequency matrix a **proportions matrix** was produced to show the percentage of times each item was preferred over every other item.

4. Each proportion in the proportions matrix was then translated into a standard normal score or z-score (without the aid of a computer programme to compute the z scores these would be derived from normal deviate tables).

5. The mean of the z scores for each item was the scale value for that item.

6. The scale values were then plotted to produce a profile of information needs that reflected a hierarchy of importance. The higher a score for any particular item the more importance was attributed to that item. A positive scale value meant that the item was preferred by more than 50% of individuals while a negative scale value indicated that less than 50% of individuals preferred that item.

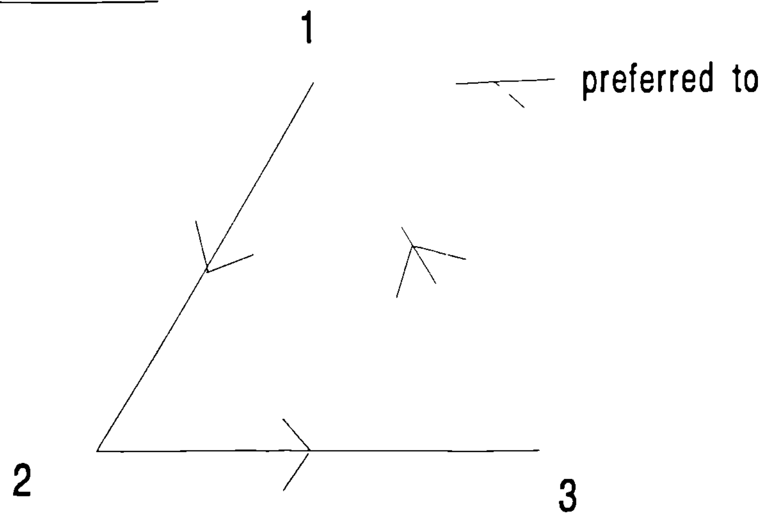
Appendix 7 shows an example of the matrices and how the final scale values were produced.

CIRCULAR TRIADS

In making paired comparisons individuals may be inconsistent in their choices. This may occur for a number of reasons. For example, an individual may not be able to distinguish between the items, the items may present problems with readability, the number of paired comparisons may be excessive and disinterest may develop, or the time taken to complete the measure may be excessive and a lack of concentration may ensue.

If an individual decided that item 1 was preferred over item 2, and that item 2 was preferred over item 3 ($1>2>3$) then logically it would be expected that item 1 would be preferred over item 3 ($1>3$). If, however, item 3 was preferred over item 1 ($1<3$) this would represent an inconsistency in the way the individual was making judgments about the items. This inconsistency is termed a "circular triad" where circular logic has been applied in making comparisons between a trio of items (Figure 8). Circular triads describe the internal consistency of individuals.

Figure 8. A circular triad



For every three items there is a possible eight different answer combinations (Table 9). Table 9 uses the example of comparing items 1, 2 and 3 in all possible combinations. A "1" means that the first item is the preferred item in the pair and a "0" means that the second item is the preferred item.

Table 9. The Potential Circular Triads That May Occur for a Trio of Items

Pairs	I12	I13	I23	Result
Possible preferences	0	0	0	consistent
	0	0	1	consistent
	0	1	0	**TRIAD**
	1	0	0	consistent
	0	1	1	consistent
	1	0	1	**TRIAD**
	1	1	0	consistent
	1	1	1	consistent

(Adapted from Sloan et al 1994)

For any set of items there are $\binom{n}{3}$ possible circular triads (Sloan et al 1994). Therefore, with nine items there are a possible 84 circular triads.

i.e $\binom{n}{3} = 9!/\ 3!(9-3)!$

$= 362880/\ 6(720)$

$=84$

Kendall (1948) developed a coefficient of consistence which would reflect whether the number of triads that an individual made was due to chance or indicated inconsistent logic. The maximum number of triads that an individual would be allowed to make before being considered inconsistent would be $(n^3 - n) / 24$ for an odd number of stimuli. For an even number of stimuli the equation would be $(n^3 - 4n) / 24$. Therefore, for 9 stimuli the maximum number of circular triads allowed would be 30. If d is the number of observed triads then Kendall's coefficient of consistence, zeta, can be worked out using the following equations:

When n is odd:

$$\zeta=1-\frac{24d}{n^3-n}$$

When n is even:

$$\zeta=1-\frac{24d}{n^3-4n}$$

If an individual did not make any triads (d=0) then the coefficient of consistence would be 1.00. If an individual made the maximum number of circular triads allowed then the coefficient would be 0. Kendall's zeta can, therefore, range between 0.00, indicating the maximum number of circular triads, and 1.00 indicating that no circular triads were made.

To find out the value of d a 9x9 matrix was created containing the numbers 1 and 0. If a row stimulus was judged more favourably than a column stimulus then a 1 was entered in the appropriate cell. If a column stimulus was judged more favourably than a row stimulus then a 0 was entered into the cell. The value a_i was then calculated for each row as the row sum of the matrix (Edwards, 1974). The number of circular triads observed, d, was then calculated from:

$$d=\left(\frac{1}{12}\right)n(n-1)(2n-1)-\frac{1}{2}\Sigma a_i^2$$

Once a value for zeta had been obtained this could be tested by using the χ^2 distribution, as long as n is equal to or greater than 7 items. The degrees of freedom for the statistic is:

$$\frac{n(n-1)(n-2)}{(n-4)^2}$$

A p value can then be obtained that demonstrates the probability of obtaining a certain value of zeta. For example, a p value of 0.90 would support that individuals were consistent in their judgments and were not simply picking items at random.

The SAS computer programme used in the present study was able to establish the number of circular triads made by each individual as well as identifying which items were involved in the triads. In addition the programme was able to compute Kendall's coefficient of consistency as well as giving χ^2 and p values.

Kendall's coefficient of consistence could be used to demonstrate consistency within each individual in their choices. However, even if all individuals were found to be consistent (with a coefficient of consistency approaching 1), there could still be inconsistencies between individuals. Kendall (1948) developed a coefficient of agreement to test for inconsistencies between individuals although the test often rejects the null hypothesis of random choices between individuals at low levels of agreement. The SAS computer programme was used to compute the degree of consistency between individuals and values were obtained for Kendall's coefficient of agreement (u).

ANALYSIS RELATING TO SOURCES OF INFORMATION

Analysis of the data on the sources of information related to the fourth aim of the study, that is:

To examine the professional and non-professional sources of information available to women with breast cancer and to explore the usefulness of these information sources at two different time points in the breast cancer experience.

Data relating to the sources of information were coded and entered into the SPSS-PC+ Data Entry system. Individuals were asked to rate each potential source of information as very useful, useful, neither useful or not useful, not useful, or useless. Numerical variable labels of 1 through 5 were allocated to these categories respectively. Alternatively, if individuals perceived that they had not received any information from the specified source then the interview schedule allowed the individual to circle "none" and a numerical value of 0 to be entered into the data entry system.

Analysis of the data on sources of information involved the use of descriptive and inferential statistics. Tables were produced to show the various sources of information and their perceived usefulness by the women in the study groups. Categories were collapsed to allow adequate power of statistical analysis in subsequent McNemars' tests for two related samples.

IMPACT ON PARTNERS, FAMILY AND FRIENDS

All women were invited to comment on the impact of breast cancer on their families and friends. Field notes were taken and were later transcribed using Wordperfect 5.2.

CHAPTER 6

CHARACTERISTICS OF THE STUDY SAMPLES

INTRODUCTION

The interview schedules incorporated socio-demographic, disease and treatment details in order to investigate if variables such as age, level of education, social class and type of surgery would influence decision making preferences or information need. A description of the characteristics of the samples follows to enable a comparison of the similarities and differences in terms of these variables.

AGE

The incidence of breast cancer increases with age and this was reflected in this study in that the women newly diagnosed with breast cancer were significantly older than the women with benign breast disease[1] ($t=13.05$, $p=<0.01$) (Table 10). Chi-square analysis showed that a significantly larger number of women in the newly diagnosed group were over the age of fifty years than in the benign study group ($\chi^2=98.09$, $df=1$, $p=<0.01$) (Table 11).

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[1] The follow up group were a subsample of the newly diagnosed group and were, therefore, the same women but approximately two years older. For this reason statistical comparison was not made, in terms of age, between the newly diagnosed and follow up groups.

Table 10. Mean Ages for the Study Samples

	Benign (n=200)	**Newly Diagnosed (n=150)**	**Follow Up (n=105)**
Mean (years)	39.2	54.8	56.02
Range (years)	18-70	32-84	35-80
SD	11.3	10.7	9.9

Table 11. Age Distributions for the Study Samples

Age	**Benign (n=200)**	**Newly Diagnosed (n=150)**	**Follow up (n=105)**
<50 years	84.0% (n=168)	32.0% (n=48)	24.8% (n=26)
≥50 years	16.0% (n=32)	68.0% (n=102)	75.2% (n=79)

LEVEL OF EDUCATION

Data on level of education was collected in four main categories (no qualifications, "O" levels, "A" levels and qualifications since age 18 years). However, due to the small sample sizes in some of these groups, which would have limited the power of statistical analyses, the data on level of education were analysed in two main groups; "qualifications" versus "no qualifications". Formal qualifications were taken as a proxy for level of education in this study in the absence of any simple alternative derivation of educational level.

Table 12 shows the distributions for level of education between the three study groups. Chi-square analysis showed that there were significant differences in level of education between the newly diagnosed and benign study groups (χ^2= 13.75, df=1, p=<0.01). Women with benign breast disease were more likely to have formal qualifications than the women newly diagnosed with breast cancer. As the follow up group were a subsample of the newly diagnosed group, and educational level had not changed for women in this group since they were interviewed for Stage 1 of the study, the follow up group were not entered into this part of the analysis. Also, the Chi-square test assumes that groups are independent which would not be the case if the newly diagnosed and follow up groups were compared.

Table 12. Level of Education for the Study Samples

Education	**Benign (n=200)**	**Newly Diagnosed (n=150)**	**Follow Up (n=105)**
No Qualifications	44.0% (n=88)	64.0% (n=96)	64.8% (n=68)
Qualifications	56.0% (n=112)	36.0% (n=54)	35.2% (n=37)

SOCIAL CLASS

Social class was derived from occupational classification to form five categories ranging from professional occupations (social class I) to unskilled occupations (social class V). For ease of analysis the data were condensed into three categories. Social classes I and II formed one category, social class III a second category and social classes IV and V the third category.

The social classes for the three study groups are shown in Table 13. There were no significant differences in terms of social class between the benign and newly diagnosed groups ($\chi^2=3.52$, df=1, p=0.17). Some data were missing for the benign and newly diagnosed groups as some women stated that they had no occupation, current or past, and were not living with a partner. Although highlighting a limitation of the occupational classification system, only a small percentage of women overall (6.4%, n=29/455) could not be allocated into one of the five social classes.

Table 13. Social Class for the Study Groups

Social class	**Benign (n=200)**	**Newly diagnosed (n=150)**	**Follow up (n=105)**
I & II	29.5% (n=59)	24.0% (n=36)	32.4% (n=34)
III	40.5% (n=81)	45.3% (n=68)	50.5% (n=53)
IV & V	18.0% (n=36)	27.3% (n=41)	17.1% (n=18)
Missing values	12.0% (n=24)	3.3% (n=5)	0.0% (n=0)

ASSOCIATION BETWEEN AGE, LEVEL OF EDUCATION AND SOCIAL CLASS

A rank order correlation was carried out to determine if there was an association between age, level of education and social class. The follow up group were not included in this calculation as they were a subset of the newly diagnosed group.

A good degree of association was found between level of education and social class ($r=-0.65$, $p<0.01$) with women having higher levels of education coming from higher social classes. A moderate degree of association was found between age and level of education ($r=-0.30$, $p=<0.01$) with younger women tending to have higher levels of education than older women. A weak association was found between age and social class ($r=0.13$, $p=0.02$).

The association between level of education and social class, and between level of education and age, was taken into account in subsequent analysis on the impact of age, level of education and social class on decision making preferences.

MARITAL STATUS

For ease of analysis the data on marital status was condensed into two categories, women who were living with a partner and women who were not. Although this meant that women who had been divorced, separated, widowed and never married were all in the same group, sample size would have been too small in some of these subgroups to produce meaningful results if all categories of marital status had been included in the analysis.

Table 14 shows the numbers of women living with and without a partner for the three study groups. Only two women had a change in marital status at the follow up interview. One woman had been divorced at the newly diagnosed stage and had re-married by the follow up stage. Another woman had previously been widowed and was now married. Only one woman had a change in relationship as a result of the breast cancer experience. This woman was involved in a relationship at the newly diagnosed stage but the relationship ended during the treatment period. A new relationship was established by the follow up stage.

Table 14. Marital Status for the Three Study Groups

Marital status	**Benign (n=200)**	**Newly diagnosed (n=150)**	**Follow up (n=105)**
Living with a Partner	62.5% (n=125)	64.7% (n=97)	66.7% (n=70)
Not living with a Partner	37.5% (n=75)	34.7% (n=52)	33.3% (n=35)
Missing values	0.0% (n=0)	0.7% (n=1)	0.0% (n=0)

Chi-square analysis was carried out to look for differences between the newly diagnosed and benign study groups in terms of having a partner or not. The follow up group were not included in this analysis as they were a subset of the newly diagnosed group and minimal changes had occurred in terms of having a partner or not between Stage 1 and Stage 2 of the study. No significant differences were found between the newly diagnosed and benign groups in terms of having a partner or not (χ^2= 0.25, df=2, p=0.62).

HAVING A RELATIVE WITH BREAST CANCER

Chi-square analysis was carried out to determine if there were differences between the newly diagnosed and benign study groups in terms of having a relative with breast cancer. The follow up group were not included in this analysis as they were not an independent group but a subset of the newly diagnosed group. Also, in looking at the number of women in the follow up group who had a relative with breast cancer the percentage of women was almost identical to women having a relative with breast cancer in the newly diagnosed group. No significant differences were found between women who had a relative with breast cancer and women who did not for the newly diagnosed and benign groups (χ^2=0.14, df=1, p=0.93) (Table 15).

Table 15. Having a Relative with Breast Cancer for the Three Study Groups

Relative with breast cancer	Benign (n=200)	Newly diagnosed (n=150)	Follow up (n=105)
Yes	20.5% (n=41)	22.0% (n=33)	21.9% (n=23)
No	79.5% (n=159)	78.0% (n=117)	78.1% (n=82)

KNOWING SOMEONE WITH BREAST CANCER

Chi-square analysis was carried out to determine if there were differences between the newly diagnosed and benign study groups in terms of knowing another individual with breast cancer. The follow up group were not included in this part of the analysis as they were not an independent group but a subset of the newly diagnosed group. No significant differences were found between women who had a relative with breast cancer and women who did not for the newly diagnosed and benign groups ($\chi^2=0.05$, df=1, p=0.82) (Table 16).

However, in looking at the number of women in the follow up group who knew someone with breast cancer it seemed apparent that more women knew someone with breast cancer at the follow up stage than at the newly diagnosed stage. To determine if this was a statistically significant difference, data on the 105 women in the follow up group were extracted from the newly diagnosed sample. In this way McNemar's test for related samples could be carried out to determine if significantly more women knew someone with breast cancer at the follow up stage than at the newly diagnosed stage. Significant differences were apparent between the newly diagnosed and follow up stages with more women knowing an individual with breast cancer at the follow up stage than at the newly diagnosed stage ($\chi^2=9.53$, df=1, p=<0.01) (Table 17). This could partly be explained in so far as the follow up group would have had more opportunity to make contact with other breast cancer sufferers.

Table 17 shows that, of the 105 women interviewed on two occasions, 63 women knew someone with breast cancer when they were first diagnosed with breast cancer and 81 women knew someone with breast cancer at the follow up stage. However, it should be noted that some women knew someone with breast cancer when they were first diagnosed but no longer had contact with that person or with any other breast cancer sufferer at the follow up stage. Twenty six women had no contact with a fellow breast cancer sufferer at the newly diagnosed stage but knew someone with breast cancer at the follow up stage while eight women knew someone with breast cancer at the newly diagnosed stage but did not have this contact at the follow up stage.

Table 16. Knowing Someone with Breast Cancer for the Three Study Groups

Knowing someone with breast cancer	**Benign (n=200)**	**Newly diagnosed (n=150)**	**Follow up (n=105)**
Yes	62.5% (n=125)	61.3% (n=92)	77.1% (n=81)
No	37.5% (n=75)	38.7% (n=58)	22.9% (n=24)

Table 17. Differences Between Women Who Knew an Individual with Breast Cancer at the Newly Diagnosed and Follow Up Stages

Newly diagnosed stage (n=105)

Follow up stage (n=105)		YES	NO	Total
	YES	55	26	81
	NO	8	16	24
	Total	63	42	105

YES: know someone with breast cancer.
NO: no knowledge of another individual with breast cancer.

TREATMENT

Women were asked at the follow up stage what treatment they had undergone. A majority of the women had conservative surgery in the form of lumpectomy followed by radiotherapy (Table 18). For the women who had mastectomy as their primary treatment (n=33), about half of these women had reconstructive surgery (45.5%, n=15/33). Most of the women had some form of adjuvant therapy in the form of radiotherapy, chemotherapy or hormonal treatment such as tamoxifen (Table 19). Some women also had more than one form of adjuvant therapy, for example radiotherapy and chemotherapy.

Table 18. Type of Surgery

Type of surgery	**Follow up group (n=105)**
Mastectomy	31.4% (n=33)
Lumpectomy	65.7% (n=69)
Other eg wire guided	2.9% (n=3)

Table 19. Adjuvant Therapy

Adjuvant therapy	**Follow up group**
Radiotherapy	46.7% (n=49)
Chemotherapy	16.2% (n=17)
Hormonal eg tamoxifen	82.9% (n=87)
No adjuvant therapy	5.8% (n=6)

STAGE OF DISEASE

Stage of disease was based on the grading of histology reports. Table 20 shows the stage of disease around the time of diagnosis, as histology reports became available approximately ten days after surgery. Stage of disease was not re-established at the follow up interview, other than to ask women if they had needed further treatment and why they had needed that treatment. Women in the newly diagnosed group would not have been aware of the stage of their disease at the time of interview, and so this variable could not have influenced decision making preferences or information need. Therefore, stage of disease was only considered in subsequent analysis for the follow up group.

Table 20. Stage of Disease

Stage of disease	**Follow up (n=105)**
Stage I	66.7% (n=70)
Stage II	30.5% (n=33)
Other eg Paget's disease	2.9% (n=2)

ETHNIC GROUP

Although a number of ethnic groups had been included on the interview schedule for the newly diagnosed and benign study groups (Appendix 2) the samples were predominantly white British. In the newly diagnosed group 99.3% (149/150) of the sample were white British. In the benign group 98% (196/200) of the sample were white British. It was, therefore, not possible to assess the impact of different ethnic groups on decision making preferences or information need.

SELECTION BIAS

Forty five women in the newly diagnosed group had taken part in Stage 1 of the study but had not been included in Stage 2 of the study. To investigate if any selection bias may have arisen this sample of women were compared to the 105 women in the follow up group to determine if there were any differences in terms of age, level of education, social class, marital status, having a relative with breast cancer, knowing someone with breast cancer, type of surgery and stage of disease. The analysis of these variables using the Chi-square test for independent samples is shown in Appendix 8. The only significant difference was in terms of social class. More of the women who had not been included in the follow up study were from higher social classes ($\chi^2=15.81$, df=2, $p=<0.01$). The reasons are unclear, but it is interesting to note, that women from higher social classes were less willing to respond to a request for a second interview.

SUMMARY

The benign study group differed from the newly diagnosed group in terms of age and level of education. The benign women were likely to be younger and have more formal qualifications. There were no differences between the study groups in terms of social class with the majority of women coming from social class III. There were no differences between the study groups in terms of having a relative with breast cancer, although when consideration was given to knowing someone with breast cancer the follow up group were more likely to know of a fellow breast cancer sufferer. Most of the women with breast cancer received conservative surgery (lumpectomy) and also received some form of adjuvant treatment.

CHAPTER 7

FINDINGS RELATING TO DECISION MAKING PREFERENCES

INTRODUCTION

The findings concerning decision making preferences related to the first aim of the study, that is:

To investigate the degree of involvement that women newly diagnosed with breast cancer, and a comparison group of women with benign breast disease, would want in the treatment decision making process and to determine how these preferences were influenced by time since diagnosis for the women with breast cancer.

The analysis involved the use of Coombs' unfolding theory (Coombs, 1964) as well as other statistical procedures such as Chi-square analysis for independent samples and McNemar's test for related samples.

UNFOLDING ANALYSIS

Applying Coombs' unfolding theory to the Control Preferences Scale (CPS) allowed for the formation of eleven preference orders that were consistent with the ABCDE metric. Coombs stated that 50% plus one of the preference orders were required to fall on the dimension to support a unidimensional theory.

Benign Group

The preference orders of 49% (98/200), [95% CI: 42%-56%], of women with benign breast disease were consistent with the ABCDE metric. This finding is shown graphically in Figure 9. All preference orders displayed above the level of zero on the vertical axis are those orders consistent with the ABCDE metric. The preference orders that fall below zero were not consistent with the ABCDE metric. The value of 49% did not meet Coombs' criterion of 50% plus one necessary to support the model of unidimensionality. However, the ABCDE metric was the only one of 60 possible scales to show the existence of a mirror image reversal between the first and last preference orders.

The unfolding analysis indicated that a competing scale may exist comprised of a dimension that ranged from some form of joint decision making to one primary decision maker, the woman or the doctor (a DCBAE metric). The preference orders of 39% (n=78/200) of women were consistent with this particular metric. However, a mirror image reversal did not exist between the first and last orders and many preference orders within this possible dimension had not been chosen. There was little evidence to support that a second dimension existed although a subscale of the ABCDE metric could be proposed as four of the preference orders in the subscale (CDBAE, CBDAE, BCADE, BACDE) were also included in the ABCDE metric (Table 21).

Table 21. The Two Competing Metrics for the Benign Group

ABCDE metric		**DCBAE metric**	
Order	Frequency	Order	Frequency
ABCDE	4	DCBAE	14
BACDE	5	CDBAE	15
BCADE	10	CBDAE	12
BCDAE	9	CBADE	22
CBDAE	12	BCADE	10
CDBAE	15	BACDE	5
CDBEA	7	BACED	0
CDEBA	12	BAECD	0
DCEBA	9	ABECD	0
DECBA	8	AEBCD	0
EDCBA	7	EABCD	0
Total	98	Total	78

Newly Diagnosed Group

The preference orders of 58% (87/150), [95% CI: 50%-66%], of women newly diagnosed with breast cancer were consistent with the ABCDE metric (see Table 22). This finding is displayed graphically in Figure 10.

The newly diagnosed women had systematic preferences about the degree of control they wanted over treatment decision making. The dominant dimension was one of keep, share, give away control (the ABCDE metric). The most commonly chosen preference order for the newly diagnosed women was EDCBA (14.8%, n=21), the most passive order.

Table 22. The ABCDE Metric for the Newly Diagnosed Group (n=150)

Order	Frequency
ABCDE	7
BACDE	2
BCADE	2
BCDAE	5
CBDAE	5
CDBAE	11
CDBEA	7
CDEBA	5
DCEBA	13
DECBA	9
EDCBA	21
Total	87

Follow Up Group

The preference orders of 69.5% (73/105), [95% CI: 60.5% - 78.5%], of the women at the follow up stage were consistent with the ABCDE metric (Table 23) These findings are displayed graphically in Figure 11. The women in the follow up group had systematic preferences about the degree of control they wanted over treatment decision making and the dominant dimension was one of keep, share, give away control over decision making. As with the newly diagnosed group the most common choice of preference order for the women at the follow up stage was EDCBA (18.1%, n=19/105), the most passive order.

Table 23. The ABCDE Metric for the Follow Up Group (n=105)

Order	**Frequency**
ABCDE	2
BACDE	2
BCADE	4
BCDAE	0
CBDAE	6
CDBAE	10
CDBEA	5
CDEBA	11
DCEBA	11
DECBA	3
EDCBA	19
Total	73

Figure 9. Unfolding Analysis for the Benign Group (n=200)

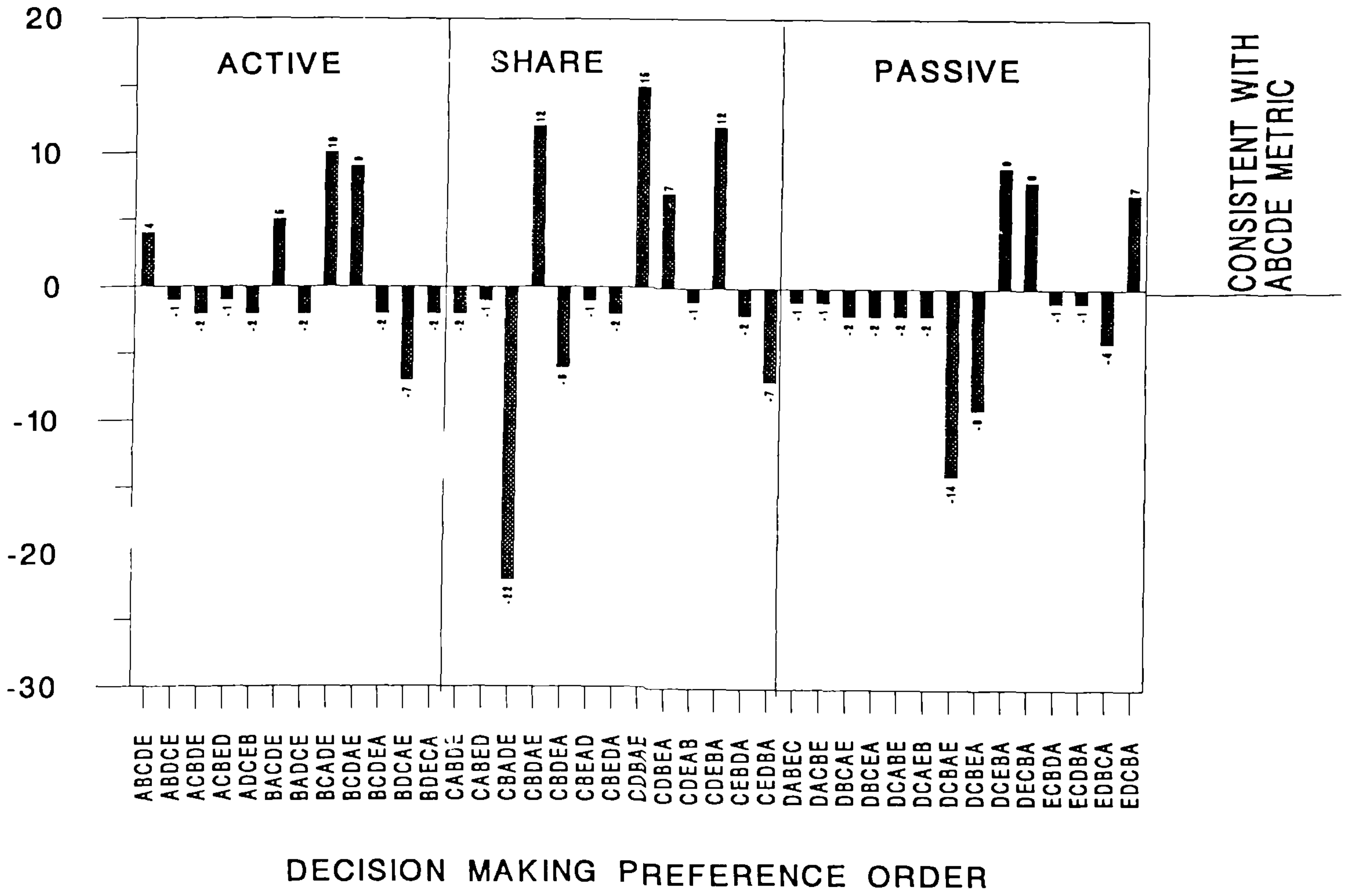


Figure 10. Unfolding Analysis for the Newly Diagnosed Group (n=150)

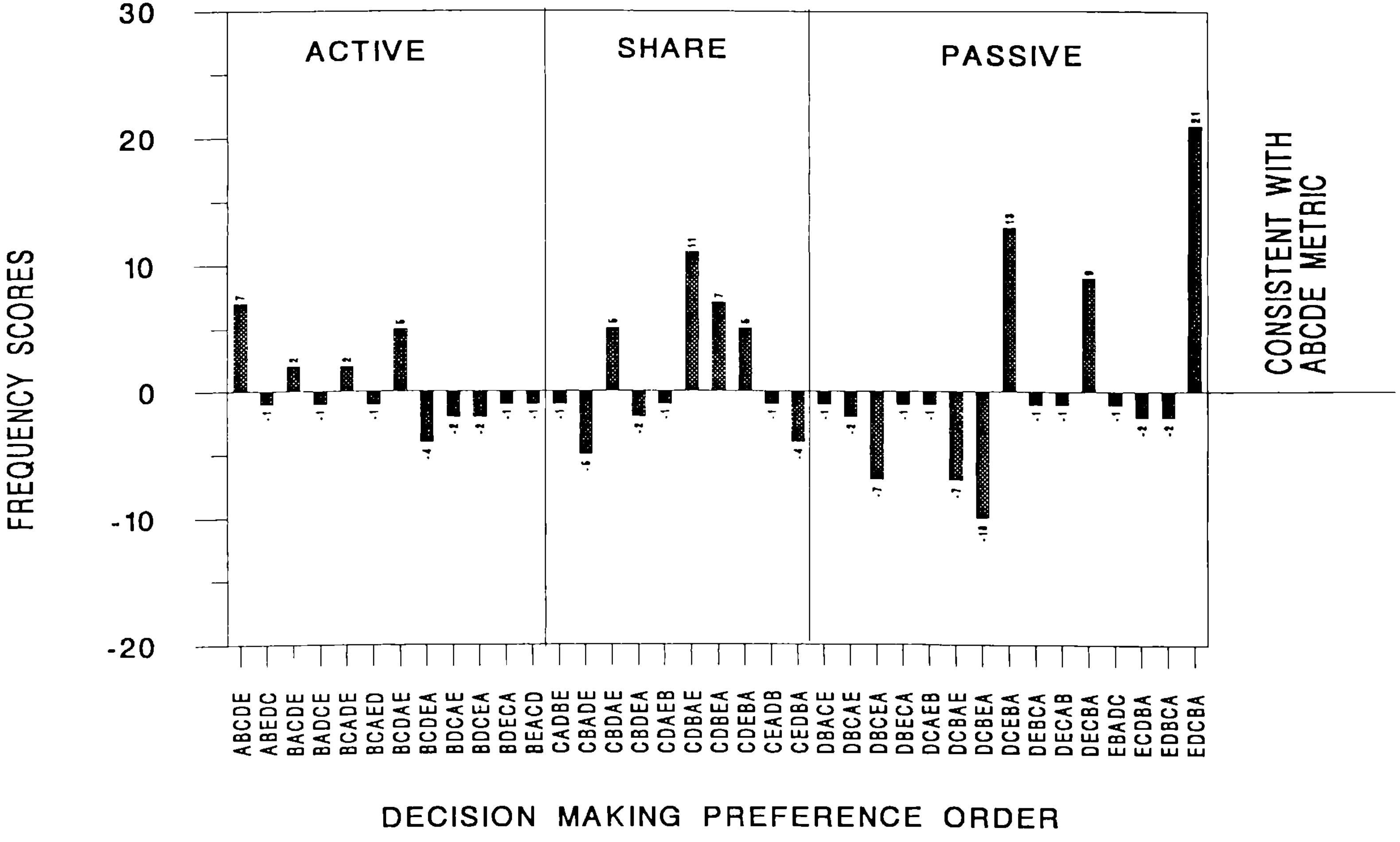
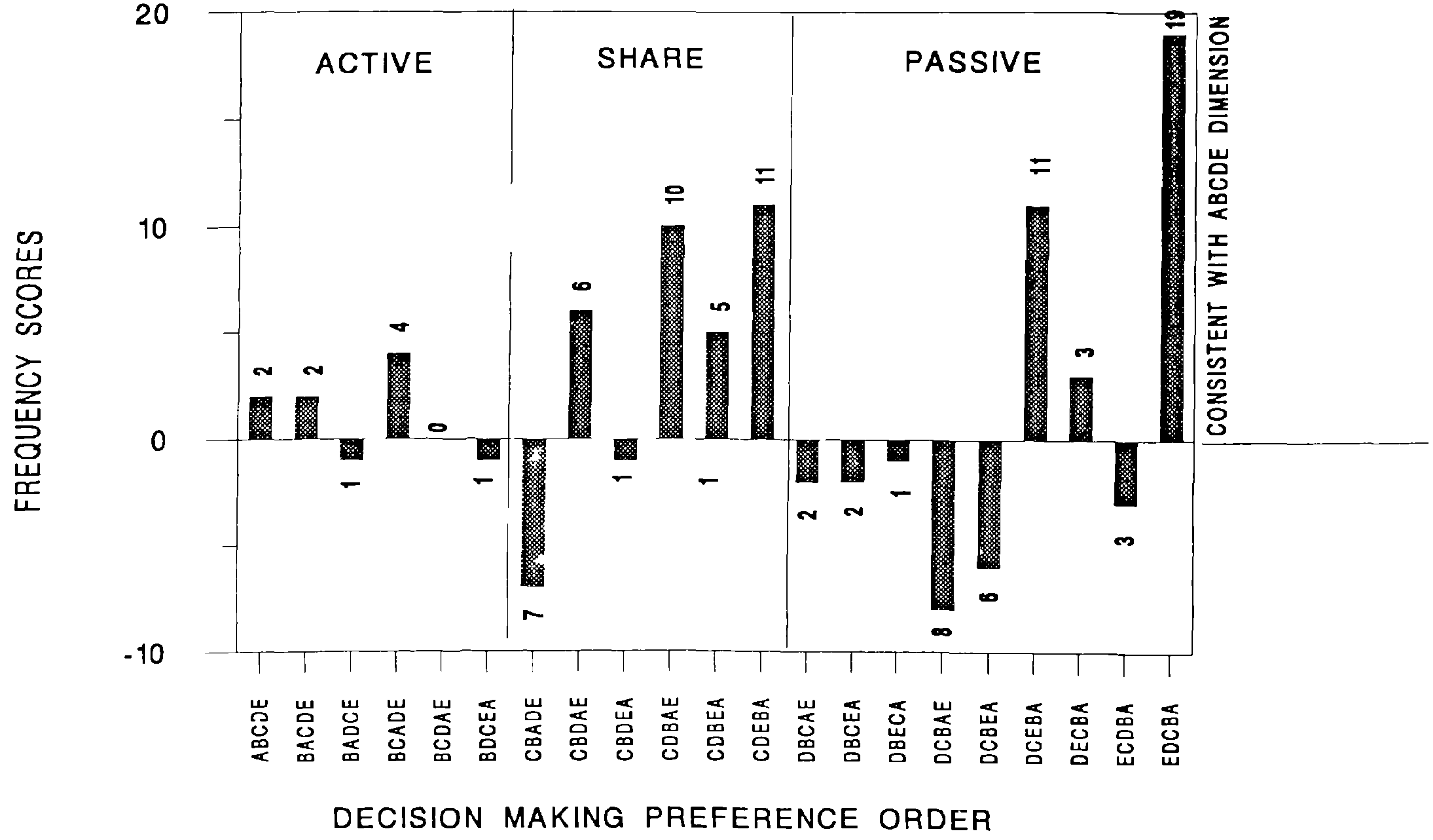


Figure 11. Unfolding Analysis for the Follow Up Group (n=105)



MEAN METRIC SCORES

Each preference order consistent with the ABCDE metric was allocated an ordinal score ranging from 1 through to 11. An ordinal score of 1 was allocated to the most active preference order, ABCDE, while an ordinal score of 11 was allocated to the most passive preference order, EDCBA. The allocation of scores are shown in Table 7 (p 165). The mean metric scores for each of the three study groups are shown in Table 24.

Table 24. Mean metric scores for the three study groups

Group	Mean metric score
Benign	6.3
Newly diagnosed	7.5
Follow up	7.8

Although the allocation of scores was at the ordinal level of measurement the scores could be assumed to be at an interval level of measurement to compare the means of the metric scores across study groups. The use of an interval level for the preference orders had been carried out successfully in a Canadian study of decision making preferences (Degner and Sloan, 1992). A t-test for independent groups was carried out to compare mean metric scores for the newly diagnosed and benign study groups. Significant differences were found between the two groups indicating that women newly diagnosed with breast cancer had ideal points on the ABCDE metric that were closer to the passive end of the scale than women with benign breast disease ($t=2.89$, $p=<0.01$).

A related t-test was carried out to compare metric scores for the newly diagnosed and follow up groups. This procedure involved an investigation of the women who had a metric score consistent with the ABCDE metric at both the newly diagnosed and follow up stages. A total of 48 women conformed to this criteria. The related t-test did not show any significant differences between the scores of the women newly diagnosed with breast cancer when compared to the same women at the follow up stage ($t=-0.64$, $df=47$, $p=0.53$). However, by carrying out this procedure and only including women who were consistent with the ABCDE metric a substantial amount of data was not being used. To examine preferences for decision making that would include the total samples it was necessary to examine the distribution of preferences by both metric and categorical scores.

DISTRIBUTIONS OF DECISION MAKING PREFERENCES

To examine the distributions of decision making preferences consideration was given to the first card in each individual's preference order with a categorical label of "active" (cards A and B), "share" (card C) or "passive" (cards D and E) being applied accordingly.

As this section of the analysis involved a consideration of the impact of variables such as age, level of education and social class on decision making preferences it was important to ensure that sample sizes were adequate for statistical analysis in subsets of these variables. If just those preference distributions that were consistent with the ABCDE metric had been considered then sample size would have been too small for some variable subgroups. In order to maximise sample sizes the distributions of preference orders were considered for individuals whose preference orders were consistent with the ABCDE metric as well as for individuals whose preference orders were not consistent with the ABCDE metric.

Additional support for the reporting of total distributions came from Chi square analysis that was used to compare the distributions of preference orders for the total samples, consistent and not consistent with the ABCDE metric, with the samples that were consistent with the ABCDE metric for the three study groups. No significant differences were found between the preferences for the total samples and the samples that were consistent with the ABCDE metric for the benign group ($\chi^2=1.67$, df=2, p=0.43), the newly diagnosed group ($\chi^2=0.47$, df=2, p=0.79) or the follow up group ($\chi^2=0.89$, df=2, p=0.64). Appendix 9 displays the relevant tables of distributions that were used in this analysis. The preference distributions for the benign, newly diagnosed and follow up groups are shown in Table 25.

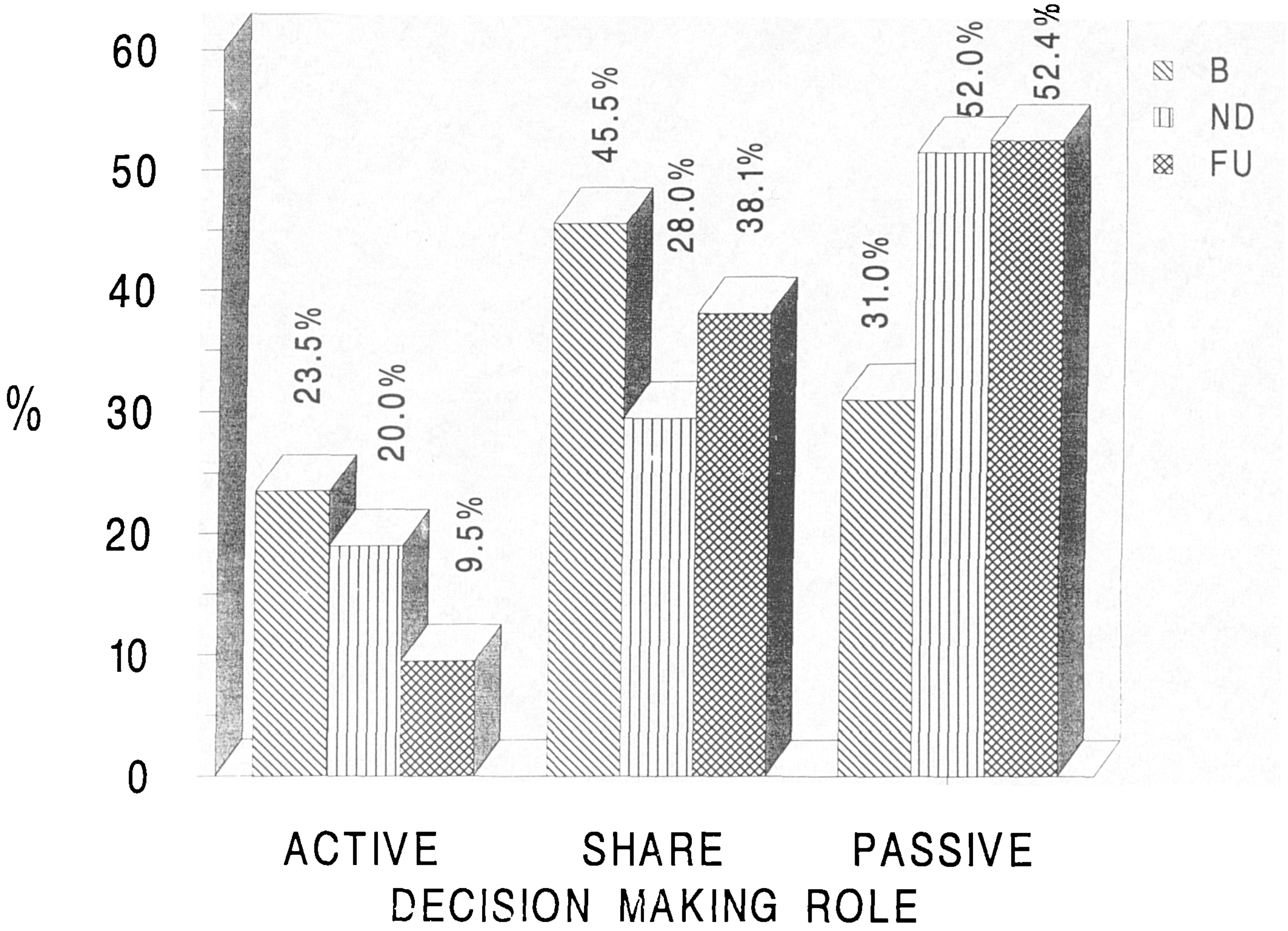
Table 25. The Distribution of Decision Making Preferences by Role for the Three Study Groups

	Active	Share	Passive
Benign (n=200)	23.5% (n=47)	45.5% (n=91)	31.0% (n=62)
Newly diagnosed (n=150)	20.0% (n=30)	28.0% (n=42)	52.0% (n=78)
Follow up (n=105)	9.5% (n=10)	38.1% (n=40)	52.4% (n=55)

These findings are shown graphically in Figure 12. Significant differences were found between the benign and newly diagnosed groups in terms of decision making preferences ($\chi^2=16.84$, df=2, p=<0.01). The women in the benign study group were significantly more likely to prefer a sharing role in decision making while the women in the newly diagnosed group were more likely to prefer a passive role in decision making.

McNemar's test for related samples was used to compare decision making preferences for the follow up group with the previous decision making preference when newly diagnosed with breast cancer. As McNemar's test involves entering data into a 2x2 table, the active and sharing categories were combined. This seemed the most logical way of collapsing categories as women who preferred some involvement in the decision making process would be compared to women who preferred the doctor to be the primary decision maker. All subsequent analysis involving McNemar's test and decision making preferences has been carried out in this way. There were no significant differences between the decision making preferences of the newly diagnosed and follow up groups, the main preference was for a passive role in decision making ($\chi^2=0.03$, df=1, p=0.87).

Figure 12. Distribution of Decision Making Preferences for the Three Study Groups



B: Benign group (n=200), ND: Newly diagnosed group (n=150), FU: Follow up group (n=105)

The most popular first choice of role for women newly diagnosed with breast cancer was card D (Table 26) : "I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion". This role was chosen by 34.7% (n=52), [95% CI: 26.9%-42.5%], of newly diagnosed women.

For the benign group and the follow up group the most popular first choice of role was card C (Table 26) : "I prefer that my doctor and I share responsibility for deciding which treatment is best for me". This role was chosen by 45.5% (n=91), [95% CI: 38.5%-52.5%], of the benign group and 38.1% (n=40), [95% CI: 33.4%-42.8%], of the follow up group.

Table 26. The Distribution of Preferences by First Choice of Card for the Three Study Groups

Role	Active		Share	Passive	
Card	A	B	C	D	E
Benign (n=200)	5% (n=10)	18.5% (n=37)	45.5% (n=91)	25.0% (n=50)	6.0% (n=12)
Newly Diagnosed (n=150)	6.0% (n=9)	14.0% (n=21)	28.0% (n=42)	34.7% (n=52)	17.3% (n=26)
Follow up (n=105)	1.9% (n=2)	7.6% (n=8)	38.1% (n=40)	31.4% (n=33)	21.0% (n=22)

SOCIO-DEMOGRAPHIC VARIABLES AND DECISION MAKING PREFERENCES

The impact of various socio-demographic and disease/treatment variables was investigated using the distributions of decision making preferences as defined by first choice of card in the preference order and categorising these preferences as relating to an active, sharing or passive role. In this way no data would be lost to the analysis.

The follow up group were a subset of the newly diagnosed group and so could not be considered an independent group for chi-square analysis. For this reason comparisons using chi-square analysis were only made between the benign and newly diagnosed groups. Analyses that involved comparisons between the newly diagnosed and follow up groups involved the use of McNemar's test for related samples.

THE IMPACT OF AGE ON DECISION MAKING PREFERENCES

Age was considered in two subgroups:

1. Less than 50 years of age.
2. Fifty years or greater.

The decision making preferences of the three study groups according to age are shown in Table 27.

Table 27. Age and Decision Making Preferences for the Three Study Groups

Group	Age	Active	Share	Passive
Benign (n=200)	<50 yrs	25.6% (n=43)	47.0% (n=79)	27.4% (n=46)
	≥50 yrs	12.5% (n=4)	37.5% (n=12)	50.0% (n=16)
Newly diagnosed (n=150)	<50 yrs	16.6% (n=8)	37.5% (n=18)	45.8% (n=22)
	≥50 yrs	21.5% (n=22)	23.5% (n=24)	55.0% (n=56)
Follow up (n=105)	<50 yrs	11.5% (n=3)	42.3% (n=11)	46.2% (n=12)
	≥50 yrs	8.9% (n=7)	36.7% (n=29)	54.4% (n=43)

Chi square analysis showed that age did not predict preferences within the newly diagnosed group (χ^2=3.18, df=2, p=0.20) or within the follow up group (χ^2=0.56, df=2, p=0.75). That is, younger women did not have significantly different decision making preferences to older women. However, within the benign group significant differences were apparent with younger women more likely to want to assume a collaborative role and older women more likely to want to assume a passive role (χ^2=6.93, df=2, p=0.03).

The younger age group was isolated (<50 years) and comparisons were made between study groups two at a time (Table 28). The only significant finding was that younger benign women were more likely to prefer a sharing role while younger newly diagnosed women were more likely to prefer a passive role. Fewer women at the follow up stage preferred an active role in decision making, although it was not possible from the McNemar's analysis to show if this was a significant difference as the active and sharing groups had been combined.

The older age group was isolated (≥50 years) and comparisons were again made between study groups two at a time (Table 28), although no significant differences were found.

Table 28. Comparison of the Three Study Groups for Different Age Groups

Age group	**Comparison**	χ^2	**P value**
<50 years	B & ND	6.05	0.05
	B & FU	4.64	0.10
	ND & FU	0.11	0.74
≥50 years	B & ND	2.91	0.23
	B & FU	0.39	0.82
	ND & FU	0.00	1.00

B= Benign group, ND= newly diagnosed group, FU= Follow up group.

A rank order correlation was carried out to ascertain how much of an association was evident between age and decision making preferences. Although an association was evident the correlation value was weak ($r=0.27$, $p<0.01$). When each individual study group was isolated the correlation between age and decision making preferences was weak for all three study groups (B: $r=0.16$, $p=0.02$; ND: $r=0.14$, $p=0.08$; FU: $r=0.26$, $p=<0.01$).

Summary

For women with breast cancer, both at the newly diagnosed and follow up stages, age did not appear to be a useful predictor of decision making preferences. For these women the preference was for a passive role regardless of age. Age did appear to have some impact for the benign group. In this group younger women wanted to assume a more collaborative role while older women were more likely to want to assume a passive role. However, the degree of association between age and decision making preferences was found to be weak overall.

THE IMPACT OF LEVEL OF EDUCATION ON DECISION MAKING PREFERENCES

Level of education was considered in two subgroups:

1. No formal qualifications.
2. Formal qualifications.

The decision making preferences for the three study groups according to level of education are shown in Table 29. There were no changes in level of education for women interviewed when newly diagnosed and further from diagnosis, apart from two women who had commenced GCSE courses but had not, at the time of the follow up interview, taken any formal examinations.

Table 29. Level of Education and Decision Making Preferences for the Three Study Groups

Group	**Education**	**Active**	**Share**	**Passive**
Benign (n=200)	No Quals.	21.6% (n=19)	43.2% (n=38)	35.2% (n=31)
	Quals.	25.0% (n=28)	47.3% (n=53)	27.7% (n=31)
Newly diagnosed (n=150)	No Quals.	17.7% (n=17)	25.0% (n=24)	57.3% (n=55)
	Quals.	24.1% (n=13)	33.3% (n=18)	42.6% (n=23)
Follow up (n=105)	No Quals.	2.9% (n=2)	33.8% (n=23)	63.2% (n=43)
	Quals.	21.6% (n=8)	46.0% (n=17)	32.4% (n=12)

Chi square analysis showed that level of education did not predict preferences within the benign group ($\chi^2=1.34$, df=2, p=0.51) or within the newly diagnosed group ($\chi^2=2.99$, df=2, p=0.22). That is, women with qualifications did not have significantly different decision making preferences to women without qualifications in these two groups. Women with benign breast disease preferred a sharing role in decision making while women newly diagnosed with breast cancer preferred a passive role. Within the follow up group significant differences were apparent as women with no qualifications were more likely to prefer a passive role and less likely to prefer an active role than women with qualifications ($\chi^2=14.04$, df=2, p=<0.01).

The group of women with no qualifications was isolated and comparisons were made between study groups two at a time (Table 30). There were significant differences between the benign and newly diagnosed groups as the benign group mainly preferred to play a sharing role in decision making while the newly diagnosed group preferred to play a passive role in decision making ($\chi^2=9.64$, df=2, p=<0.01). This finding was repeated when a comparison was made between the benign and the follow up groups ($\chi^2=17.11$, df=2, p=<0.01). These results mirrored the main findings for the study in terms of differences in decision making preferences between the study groups indicating that group membership may be influencing decision making preferences and not level of education.

McNemar's test for related samples showed that there were no significant differences between the decision making preferences of the newly diagnosed and follow up groups within the cohort of women with no qualifications ($\chi^2=0.62$, df=2, p=0.43). Fewer women at the follow up stage preferred an active role in decision making, although it was not possible from the McNemar's analysis to show if this was a significant difference as the active and sharing groups had been combined.

Isolating the women with qualifications and comparing study groups two at a time showed that there were no significant differences between the study groups in terms of decision making preferences (Table 30).

Table 30. Comparison of the Three Study Groups for Different Levels of Education

Education	Comparison	Chi Square (χ^2)	P value
No Quals.	B & ND	9.64	<0.01
	B & FU	17.11	<0.01
	ND & FU	0.62	0.43
Quals.	B & ND	4.17	0.12
	B & FU	0.36	0.84
	ND & FU	0.60	0.44

B= Benign group, ND= newly diagnosed group, FU= Follow up group.

A rank order correlation was carried out to ascertain how much of an association was evident between education and decision making preferences. Although an association was evident the correlation value was weak ($r=-0.22$, $p<0.01$). When each individual study group was isolated the correlation between education and decision making preferences was weak for the benign and newly diagnosed groups and somewhat stronger for the follow up group (B: $r=-0.11$, $p=0.12$; ND: $r=-0.22$, $p=<0.01$; FU: $r=-0.37$, $p=<0.01$).

Summary

Level of education did not appear to be a useful predictor of decision making preferences for the study groups. Findings mirrored the main study findings that the benign group preferred to play a sharing role in decision making and the newly diagnosed and follow up groups preferred to play a passive role in decision making.

Overall, the association between education and decision making preferences was weak.

THE IMPACT OF SOCIAL CLASS ON DECISION MAKING PREFERENCES

Social class was considered in three subgroups:

1. Social class I and II.
2. Social class III
3. Social classes IV and V.

The decision making preferences for the three study groups according to social class are shown in Table 31. There were no changes in social class between women interviewed at the newly diagnosed and follow up stages. A number of women had retired or given up work since their diagnosis of breast cancer but, based on the most recent occupation of head of household, there were no changes in social class.

No significant differences were apparent within the benign group in terms of decision making preferences and social class ($\chi^2=9.17$, df=4, p=0.06). However, there were significant differences between social class and decision making preferences at both the newly diagnosed ($\chi^2=14.52$, df=4, p=0.01) and follow up stages ($\chi^2=22.07$, df=4, $p=<0.01$). At the newly diagnosed stage women from social classes III, IV and V preferred a more passive role in decision making while women from social classes I and II preferred a sharing role. At the follow up stage this finding was even more pronounced as women from social classes IV and V preferred a passive role in 94.4% of cases.

However, for the chi-square analysis carried out on the follow up group, the expected values in 2 out of the 9 cells were less than 5 (22%). Siegel and Castellan (1988) recommended that no more than 20% of the cells in a chi-square analysis should have an expected value of less than 5 and so findings for the follow up group should be treated with caution. The small sample sizes in the active and share categories for the follow up group from social classes IV and V led the researcher to omit the follow up group from further statistical analysis on the influence of social class and decision making preferences. The descriptive finding that the vast majority of women from the lower social classes in the follow up group preferred a passive role in decision making was the main conclusion drawn from this data.

Table 31. Social Class and Decision Making Preferences for the Three Study Groups

Group	Social class	Active	Share	Passive
Benign (n=200)	I and II	25.0% (n=19)	44.7% (n=34)	30.3% (n=23)
	III	23.8% (n=20)	50.0% (n=42)	26.2% (n=22)
	IV and V	18.5% (n=5)	25.9% (n=7)	55.6% (n=15)
Newly diagnosed (n=150)	I and II	33.3% (n=15)	37.8% (n=17)	28.9% (n=13)
	III	12.7% (n=9)	23.9% (n=17)	63.4% (n=45)
	IV and V	17.9% (n=5)	25.0% (n=7)	57.1% (n=16)
Follow up (n=105)	I and II	14.7% (n=5)	58.8% (n=20)	26.5% (n=9)
	III	9.4% (n=5)	35.9% (n=19)	54.7% (n=29)
	IV and V	0.0% (n=0)	5.6% (n=1)	94.4% (n=17)

Isolating the women from social classes I and II for the benign and newly diagnosed groups showed that there were no significant differences in terms of decision making preferences ($\chi^2=1.04$, df=2, p=0.60). Women from social classes I and II mainly preferred to play a sharing role in decision making. Isolating women from social class III for the benign and newly diagnosed groups showed significant differences in decision making preferences ($\chi^2=22.80$, df=2, p=<0.01). Benign women from social class III were more likely to prefer a sharing role in decision making whereas women in the newly diagnosed group were more likely to prefer a passive role in decision making. These results mirrored the main findings for the study in terms of differences in decision making preferences between the three study groups and it seemed likely that group membership rather than social class was responsible for these findings.

Isolating the women from social classes IV and V showed that there were no significant differences between the benign and newly diagnosed groups in terms of decision making preferences ($\chi^2=0.01$, $df=2$, $p=0.99$). Women in the lower social classes predominantly preferred a passive role in decision making.

A rank order correlation was carried out to ascertain how much of an association was evident between social class and decision making preferences. Although an association was evident the correlation value was weak ($r=0.20$, $p=<0.01$). When each individual study group was isolated the correlation between social class and decision making preferences was weak for the benign and newly diagnosed groups but a good level of association was found between social class and decision making preferences for the follow up group (B: $r=0.06$, $p=0.45$; ND: $r=0.14$, $p=0.09$; FU: $r=0.50$, $p=<0.01$). However, due to small sample sizes in the active and sharing categories of decision making preferences for the lower social classes, findings from the follow up group should be treated with caution.

Summary

Women from social classes I and II tended to prefer a sharing role in decision making. Women in social class III who were in the benign group tended to prefer a sharing role while women in the newly diagnosed and follow up groups tended to prefer a passive role. Women in social classes IV and V preferred to play a passive role in decision making. Social class was weakly associated with decision making preferences with women from lower social classes preferring a more passive role in decision making.

ASSOCIATION BETWEEN AGE, LEVEL OF EDUCATION AND SOCIAL CLASS IN TERMS OF DECISION MAKING PREFERENCES

As a reasonable degree of association had been found between age and level of education, and between level of education and social class, the interaction between these variables and their combined influence on decision making preferences was considered.

A two way ANOVA was used to compare the metric scores for decision making preferences according to two independent variables. ANOVA is only applicable if both independent variables are between-subjects (Foster, 1992). In this analysis age, level of education and social class were considered independent variables. Age was examined in two groups, women who were under the age of 50 years and women who were aged 50 years and above. Level of education was considered in terms of having qualifications or not. Social class was considered in three groups; social classes I and II, social class III, and social classes IV and V. The dependent variable was decision making preferences with the metric scores ranging from 1 to 11 for individuals consistent with the ABCDE metric being entered into the analysis.

No two way interaction was found between age and level of education in terms of jointly influencing decision making preferences (F=0.80, p=0.37). Neither was there a two way interaction between level of education and social class in terms of influencing decision making preferences (F=1.76, p=0.18). Any influence exerted by these variables on decision making preferences appeared to be independent in nature. That is, age and education, and education and social class, were not jointly influencing decision making preferences.

THE IMPACT OF MARITAL STATUS ON DECISION MAKING PREFERENCES

Marital status was considered in two subgroups:

1. Women who lived with a partner (eg. married, co-habiting).
2. Women who did not live with a partner (eg widowed, divorced, never married).

The decision making preferences of the three study groups according to marital status are shown in Table 32.

Table 32. Marital Status and Decision Making Preferences for the Three Study Groups

Group	Marital status	Active	Share	Passive
Benign (n=200)	Partner	24.0% (n=30)	45.6% (n=57)	30.4% (n=38)
	No partner	22.7% (n=17)	45.3% (n=34)	32.0% (n=24)
Newly diagnosed (n=150)	Partner	25.5% (n=25)	24.5% (n=24)	50.0% (n=49)
	No partner	9.6% (n=5)	34.6% (n=18)	55.8% (n=29)
Follow up (n=105)	Partner	7.1% (n=5)	38.6% (n=27)	54.3% (n=38)
	No partner	14.3% (n=5)	37.1% (n=13)	48.6% (n=17)

Chi square analysis showed that marital status did not predict preferences within the benign group (χ^2=0.07, df=2 p=0.97), the newly diagnosed group (χ^2=5.75, df=2, p=0.06) or the follow up group (χ^2=1.21, df=2, p=0.55).

The women who lived with a partner were isolated and comparisons were made between study groups two at a time (Table 33). Significant differences were apparent between the benign and the newly diagnosed group, and the benign and the follow up group, in that women in the newly diagnosed and follow up groups mainly preferred a passive role in decision making while women in the benign group tended to prefer a sharing role. These findings mirrored the main findings of the study and suggested that group membership and not marital status may be influencing decision making preferences. Isolating women without a partner showed no significant differences when study groups were compared two at a time (Table 33).

Table 33. Comparison of the Three Study Groups for Marital Status

Marital status	**Comparison**	**Chi Square (χ^2)**	**P value**
Partner	B & ND	12.20	<0.01
	B & FU	13.55	<0.01
	ND & FU[2]	0.39	0.53
No partner	B & ND	8.04	0.02
	B & FU	3.52	0.17
	ND & FU	0.25	0.62

B= Benign group, ND= newly diagnosed group, FU= Follow up group.

A rank order correlation was carried out to ascertain how much of an association was evident between marital status and decision making preferences. Negligible association existed between marital status and decision making preferences for the three study groups (r=0.01, p=0.92). When each individual study group was isolated the association remained minimal for all three groups (B: r=-0.01, p=0.86; ND: r=0.11, p=0.20; FU: r=-0.03, p=0.73).

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[2] Two women at the follow up stage had a different marital status than at the newly diagnosed stage. In carrying out McNemar's test these women were excluded and results relate to 103 women.

Summary

Marital status did not appear to be a useful predictor of decision making preferences for the three study groups and the results confirmed the main study findings that women in the newly diagnosed and follow up groups were more likely to prefer a passive role in decision making while women in the benign study group were more likely to prefer a sharing role. Marital status as a variable had an almost negligible correlation with decision making preferences.

THE IMPACT OF HAVING A RELATIVE WITH BREAST CANCER ON DECISION MAKING PREFERENCES

The decision making preferences of the three study groups according to whether they had a relative with breast cancer or not are shown in Table 34. Chi square analysis showed that having a relative with breast cancer did not predict preferences within the benign group ($\chi^2=3.96$, df=2, p=0.14), the newly diagnosed group ($\chi^2=1.43$, df=2, p=0.49) or the follow up group ($\chi^2=0.93$, df=2, p=0.63).

The women who had a relative with breast cancer were isolated and comparisons were made between study groups two at a time (Table 35). No significant differences were found within these paired tests, the main preference being for a passive role in all three study groups.

The women who did not have a relative with breast cancer were also isolated and comparisons were made between study groups two at a time (Table 35). When comparisons were made between the benign and newly diagnosed groups, and between the benign and follow up groups, the benign group mainly preferred a sharing role while the newly diagnosed and follow up groups preferred a passive role, reflecting the main study findings.

Table 34. Having a Relative with Breast Cancer and Decision Making Preferences for the Three Study Groups

Group	**Relative with breast cancer**	**Active**	**Share**	**Passive**
Benign (n=200)	Yes	29.3% (n=12)	31.7% (n=13)	39.0% (n=16)
	No	22.0% (n=35)	49.1% (n=78)	28.9% (n=46)
Newly diagnosed (n=150)	Yes	27.3% (n=9)	24.2% (n=8)	48.5% (n=16)
	No	18.0% (n=21)	29.0% (n=34)	53.0% (n=62)
Follow up (n=105)	Yes	13.0% (n=3)	30.4% (n=7)	56.5% (n=13)
	No	8.5% (n=7)	40.2% (n=33)	51.2% (n=42)

Table 35. Comparison of the Three Study Groups for Having a Relative with Breast Cancer

Relative	**Comparison**	**Chi Square (χ^2)**	**P value**
Yes	B & ND	0.76	0.68
	B & FU	2.66	0.26
	ND & FU[3]	0.50	0.48
No	B & ND	17.16	<0.01
	B & FU	13.91	<0.01
	ND & FU	0.00	1.00

B= Benign group, ND= newly diagnosed group, FU= Follow up group.

A rank order correlation was carried out to ascertain how much of an association was evident between having a relative with breast cancer and decision making preferences. Almost no association existed at all between having a relative with breast cancer and decision making preferences for the three study groups (r=0.02, p=0.73).

Summary

Having a relative with breast cancer did not appear to be a useful predictor of decision making preferences for the three study groups although it could be suggested that having a relative with breast cancer was more likely to lead an individual to

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[3] One woman at the follow up stage was now aware of a relative with breast cancer who, at the newly diagnosed stage, had no relatives with breast cancer. For the McNemar's test this woman was omitted from the analysis and results relate to 104 women.

prefer a passive role in decision making regardless of which study group they belonged.

THE IMPACT OF KNOWING SOMEONE WITH BREAST CANCER ON DECISION MAKING PREFERENCES

The decision making preferences of the three study groups according to whether they knew someone with breast cancer or not are shown in Table 36. Chi square analysis showed that knowing someone with breast cancer did not predict preferences within the benign group (χ^2=0.45, df=2 p=0.80), the newly diagnosed group (χ^2=5.40, df=2, p=0.07) or the follow up group (χ^2=3.47, df=2, p=0.18).

The women who knew someone with breast cancer were isolated and comparisons were made between study groups two at a time (Table 37). Significant differences were found between the benign and newly diagnosed groups, and between the benign and follow up groups, in that women in the benign group preferred a sharing role in decision making while women in the newly diagnosed and follow up groups preferred a passive role, reflecting the main findings of the study. Isolating the women who did not know somebody with breast cancer did not produce any significant findings (Table 37).

Table 36. Knowing Someone with Breast Cancer and Decision Making Preferences for the Three Study Groups

Group	Know someone with breast cancer	Active	Share	Passive
Benign (n=200)	Yes	24.8% (n=31)	45.6% (n=57)	29.6% (n=37)
	No	21.3% (n=16)	45.3% (n=34)	33.3% (n=25)
Newly diagnosed (n=150)	Yes	19.6% (n=18)	21.7% (n=20)	58.7% (n=54)
	No	20.7% (n=12)	37.9% (n=22)	41.4% (n=24)
Follow up (n=105)	Yes	9.9% (n=8)	33.3% (n=27)	56.8% (n=46)
	No	8.3% (n=2)	54.2% (n=13)	37.5% (n=9)

Table 37. Comparison of the Three Study Groups for Knowing Someone with Breast Cancer

Know someone	Comparison	Chi Square (χ^2)	P value
Yes	B & ND	19.84	<0.01
	B & FU	16.61	<0.01
	ND & FU[4]	0.69	0.41
No	B & ND	1.01	0.60
	B & FU	2.08	0.35
	ND & FU	0.50	0.48

B= Benign group, ND= newly diagnosed group, FU= Follow up group.

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[4] Twenty six women had not known anyone with breast cancer at the newly diagnosed stage but knew someone with breast cancer at the follow up stage. Eight women knew someone when they were first diagnosed with breast cancer but no longer had contact with that person or any other person with breast cancer. These women were omitted from the McNemar's analysis for related samples and comparisons between the newly diagnosed and follow up groups relate to 71 women.

A rank order correlation was carried out to ascertain how much of an association was evident between knowing someone with breast cancer and decision making preferences. Almost no association existed at all between knowing someone with breast cancer and decision making preferences for the three study groups ($r=-0.06$, $p=0.23$).

Summary

Knowing someone with breast cancer did not appear to be a useful predictor of decision making preferences for the three study groups. Although some significant findings resulted they were once again to confirm the main study findings that women in the newly diagnosed and follow up groups were more likely to prefer a passive role in decision making while women in the benign study group were more likely to prefer a sharing role.

TYPE OF SURGERY AND DECISION MAKING PREFERENCES

Data on the type of surgery was analysed in two subgroups: women who had mastectomy as their primary surgery and women who had conservative surgery (Table 38). Although the newly diagnosed group were, on the whole, aware of the plan of treatment, the interview was conducted before treatment had been carried out. To examine the impact of type of surgery on decision making preferences it was important that women had already received their treatment and so this part of the analysis related to the follow up group only. Type of surgery did not have any significant impact on decision making preferences for the follow up group (χ^2=0.85, df=2, p=0.65).

Table 38. Type of Surgery and Decision Making Preferences

Type of surgery	**Active**	**Share**	**Passive**
Mastectomy (n=33)	6.1% (n=2)	42.4% (n=14)	51.5% (n=17)
Conservative (n=72)	11.1% (n=8)	36.1% (n=26)	52.8% (n=38)

A rank order correlation between type of surgery and decision making preferences showed no association between the two variables (r=0.00, p=1.00).

STAGE OF DISEASE AND DECISION MAKING PREFERENCES

Data on the stage of disease were coded in three subgroups based on the TNM classification of breast tumours (Appendix 3): Stage 1 (no evidence of spread to lymph nodes), Stage II (evidence of spread to lymph nodes) and other tumours that did not fit into the Stage 1 or Stage II categories such as Paget's disease (Table 39). As sample size was small in women who did not conform to the Stage I or Stage II categories these women were excluded from this part of the analysis. This part of the analysis was limited to the follow up group as women in the newly diagnosed group were not aware of the stage of their disease at the time of interview. Stage of disease did not have any significant impact on decision making preferences ($\chi^2=0.89$, df=2, p=0.64).

Table 39. Stage of Disease and Decision Making Preferences

Stage of disease	**Active**	**Share**	**Passive**
Stage I (n=70)	22.9% (n=16)	28.6% (n=20)	48.6% (n=34)
Stage II (n=33)	15.2% (n=5)	30.3% (n=10)	54.6% (n=18)
Other (n=2)	0.0% (n=0)	50.0% (n=1)	50.0% (n=1)

A rank order correlation between stage of disease and decision making preferences showed almost no association between the two variables (r=0.01, p=0.91).

FURTHER BREAST PROBLEMS AND DECISION MAKING PREFERENCES

The women in the follow up group were asked if any further breast problems had arisen following their initial treatment. This included women who had received further surgery for an incomplete excision of the original cancer or for a recurrence of the cancer, as well as women who had received further adjuvant treatment for recurrence, women who had complications with reconstructive surgery, and any other problems related to the breasts.

Initial treatment was considered to include both initial surgery and any planned adjuvant therapy, such as radiotherapy and/or chemotherapy. It was unclear as to whether further surgery for incomplete excision should be defined as a further problem or an ongoing problem. In this case the definition of further problems was left to the women to define. For some women surgery following incomplete excision was seen as part of the same treatment plan whereas for other women it was seen as a separate and new problem.

A large number of women (43.8%, n=46/105) said that they had experienced further problems with their breasts. This included problems of incomplete excision, recurrence of the cancer, pain and swelling due to the surgery, problems with the reconstructive surgery, problems with the prosthesis, wound infections and the occurrence of benign breast lumps. The problems reported by these women are described in Appendix 10.

The decision making preferences of the women who had further problems with their breasts and those who did not are displayed in Table 40. Women who had further problems with their breasts had significantly different decision making preferences to women who had no further problems with their breasts ($\chi^2=13.3$, df=2, p=<0.01). Although the main preference was for a passive role regardless of any further breast problems some differences were apparent at the active end of the scale. Women were more likely to want to be involved in the decision making process if they had experienced further breast problems. However, caution should be taken in drawing conclusions from this data as sample size was small for women who preferred an active role in decision making whether they had experienced further breast problems or not.

Table 40. Further Breast Problems and Decision Making Preferences

	ACTIVE	SHARE	PASSIVE
Further breast problems: 43.8% (n=46/105)	19.6% (n=9)	23.9% (n=11)	56.5% (n=26)
No further breast problems: 56.2% (n=59/105)	1.7% (n=1)	49.2% (n=29)	49.2% (n=29)

These findings did not apply to problems in general (Table 41). Women were asked if they had experienced any other problems at all, breast related or otherwise. Although 56.2% (n=59/105) of the women stated that they had experienced further physical or psychological problems, including both breast related and breast unrelated problems, there were no significant differences in terms of decision making preferences between those who had experienced problems and those who had not (χ^2=0.10, df=2, p=0.61). The tendency for some women to want to play a more active role in the decision making process seems to be specific to women who had experienced further breast related problems although, as stated, sample size was limited in the active category.

Table 41. Any Further Problems at All and Decision Making Preferences

	ACTIVE	SHARE	PASSIVE
Further problems: 56.2% (n=59/105)	11.9% (n=7)	35.6% (n=21)	52.5% (n=31)
No further problems: 43.8% (n=46/105)	6.5% (n=3)	41.3% (n=19)	52.2% (n=24)

RECURRENCE AND DECISION MAKING PREFERENCES

The women who had a recurrence of breast cancer were reinvestigated as a subsample of the women who had further breast problems. Seven women in the study had a recurrence of their breast cancer. In four of these individuals, decision making preferences had moved to the more passive end of the scale, in two individuals the preference remained the same and in one individual the preference was for a more active role than previous.

SHIFT IN DECISION MAKING PREFERENCES

To investigate if decision making preferences had changed over time the preference orders of the women in the follow up group were compared to their previous orders when newly diagnosed with breast cancer. In this way each order could be scrutinised, in terms of the first item in the preference order, to examine any change in decision making preference.

Table 42 shows the decision making preferences of the women in the follow up group compared to the decision making preferences of this same group of women when newly diagnosed with breast cancer. McNemar's test for related samples showed no statistically significant differences in terms of decision making preferences between the newly diagnosed and follow up stages ($\chi^2=0.03$, df=1, p=0.87). However, it is interesting to note that fewer women preferred an active role in decision making at the follow up stage than at the newly diagnosed stage. However, it was not possible to state this as a significant difference as the active and sharing categories had been combined for the purposes of analysis.

Table 42. Distribution of Preferences for Women in the Follow Up Group Compared to the Preferences of the Same Group of Women When Newly Diagnosed With Breast Cancer

ROLE	ACTIVE	SHARE	PASSIVE
NEWLY DIAGNOSED (n=105)	19.0% (n=20)	29.5% (n=31)	51.4% (n=54)
FOLLOW UP (n=105)	9.5% (n=10)	38.1% (n=40)	52.4% (n=55)

Table 43 shows how decision making preferences changed over time for the 105 women in the follow up group.

Table 43 : Shift in Decision Making Preferences Over Time (n=105)

PREFERENCE AT NEWLY DIAGNOSED STAGE	PREFERENCE AT FOLLOW UP STAGE		
	ACTIVE	SHARE	PASSIVE
ACTIVE	4.76% n=5	6.67% n=7	7.62% n=8
SHARE	1.90% n=2	18.10% n=19	9.52% n=10
PASSIVE	2.86% n=3	13.33% n=14	35.24% n=37

A total of 61 individuals (58.10%) had the same preference at the follow up stage (represented by the numbers between the two triangles). That is, of the 20 women who preferred an active role at the newly diagnosed stage 25.0% of these women (5/20) retained a preference for an active role, of the 31 individuals who preferred a sharing role at the newly diagnosed stage 61.3% (19/31) retained a preference for a sharing role, and of the 54 women who preferred a passive role at the newly diagnosed stage 68.5% (37/54) retained a preference for a passive role.

Table 43 shows that 23.8% (25/105) of the women preferred a more passive role at the follow up stage than at the newly diagnosed stage (top triangle in Table 43). Although 18.1% (19/105) of the women preferred a more active role at the follow up stage (lower triangle in Table 43) only 4.8% (5/105) of the women actually preferred an active role as such. For this subset of women the shift had been from preferring a passive role to preferring a sharing role and although this represents a shift towards the more passive end of the scale the preference is for sharing rather than for an active role. Appendix 11 presents the individual shifts in decision making preferences based on first choice of card in the preference ordering.

POST DECISIONAL REGRET AND DECISION MAKING PREFERENCES IN THE FOLLOW UP GROUP

Out of the total sample of 105 women in the follow up group, seven women had regrets over the decisions that they had made or decisions that they felt the doctor had made for them. When the decision making preference orders of these seven women were examined it was found that four women now preferred a more passive role in decision making than previously, two had remained the same and only one woman now preferred a more active role.

The small number of women who had any regrets about the decisions that were made makes it very difficult to draw any conclusions from this data. However, the fact that only 6.6% (n=7) of the total sample expressed any regret about decisions that had been made either by themselves or the doctor may be interesting in itself. It is also interesting that having regrets over the decision made, either by themselves or by the doctor, did not promote a preference for active participation in the women. The specific regrets expressed by these women are listed in Appendix 12.

Summary

In summary, a majority of women had the same decision making preference at the follow up stage as they had at the newly diagnosed stage, particularly those individuals who had chosen sharing and passive roles. Fewer women wanted an active role at the follow up stage than at the newly diagnosed stage and women who had chosen an active role at the newly diagnosed stage were now more likely to want a sharing or a passive role at the follow up stage.

ACTUAL ROLE

As part of the study women were asked to report the actual role they assumed in decision making at the time of diagnosis. Comparison could then be made between the role which women wanted to play in treatment decision making and the role which they perceived they had played. At the follow up interview women were asked to think back and choose the role they believed they had assumed in decision making.

In making comparisons between preferred and actual role it was acknowledged that choice and decision making rarely entered into the consultation for the benign group. However, for completeness the actual roles that all three study groups perceived they had played in decision making were included in the analysis. Table 44 shows the actual roles for the three study groups.

Table 44. Actual Roles for the Benign, Newly Diagnosed and Follow Up Groups

	ACTIVE	SHARE	PASSIVE
Benign (n=200)	10.5% (n=21)	20.5% (n=41)	69.0% (n=38)
Newly Diagnosed (n=150)	15.3% (n=23)	24.0% (n=36)	60.7% (n=91)
Follow up (n=105)	10.5% (n=11)	17.1% (n=18)	72.3% (n=76)

The benign study group were not, on the whole, involved in any treatment decisions and, as would be expected, the majority perceived that they had played a passive role in treatment decision making. However, the newly diagnosed and follow up groups also perceived that they had played a passive role in decision making. Although the breast specialist consultant perceived that he gave choices to the women in the newly diagnosed group they did not, in the majority of cases, perceive that they had been presented with a choice. This perception was strengthened over time with a higher percentage of women in the follow up group perceiving that they had played a passive role in decision making and fewer women believing that they had played an active role in decision making.

Chi-square analysis showed significant differences between the perceived role played in decision making by the newly diagnosed and benign groups ($\chi^2=12.70$, df=2, $p= <0.01$) with the benign group believing they had played a more passive role than the newly diagnosed group. McNemar's test for related samples showed significant differences between the perceived role played in decision making by the newly diagnosed (n=105) and follow up groups ($\chi^2 = 6.00$, df=1, p=0.01). Although women in the newly diagnosed and follow up groups believed that they had primarily played a passive role in decision making, fewer women at the follow up stage believed that they had played an active role in decision making. These findings should be treated with caution as recall of events may have been limited at the follow up stage. Overall, the main perception of women in the benign, newly diagnosed and follow up groups was that they had played a passive role in treatment decision making.

THE RELATIONSHIP BETWEEN PREFERRED AND ACTUAL ROLE

Table 45 shows the relationship between preferred role and actual role for the benign study group; the numbers in each cell representing the number of women who had a particular preferred and actual role. For the benign group 42.5% (85/200) of the women got what they preferred in terms of decision making preferences, while 48.0% (96/200) got a more passive role than they would have wanted and 9.5% (19/200) got a more active role than they would have wanted. It is perhaps not surprising that such a large percentage of women got a more passive role than they would have wanted in this study group as choices were not, in most cases, relevant to this study group.

Table 45. Relationship Between Preferred and Actual Role for the Benign Group (n=200)

ACTUAL ROLE

		ACTIVE	SHARE	PASSIVE
PREFERRED ROLE	ACTIVE	10	8	29
	SHARE	7	25	59
	PASSIVE	4	8	50

Table 46 shows the relationship between preferred role and actual role for the newly diagnosed study group. For this group 56.0% (84/150) of the women got what they preferred in terms of decision making preferences, while 26.7% (40/150) got a more passive role than they would have wanted and 17.3% (26/150) got a more active role than they would have wanted.

Table 46. Relationship Between Preferred and Actual Role for the Newly Diagnosed Group (n=150)

ACTUAL ROLE

		ACTIVE	SHARE	PASSIVE
PREFERRED ROLE	ACTIVE	12	7	11
	SHARE	6	14	22
	PASSIVE	5	15	58

Table 47 shows the relationship between preferred role and actual role for the follow up study group. For this group 64.8% (68/105) of the women got what they preferred in terms of decision making preferences, while 26.7% (28/105) got a more passive role than they would have wanted and 8.6% (9/105) got a more active role than they would have wanted.

Table 47. Relationship Between Preferred and Actual Role for the Follow Up Group (n=105)

PREFERRED ROLE		ACTUAL ROLE		
		ACTIVE	**SHARE**	**PASSIVE**
	ACTIVE	4	1	5
	SHARE	3	15	22
	PASSIVE	4	2	49

These findings are represented graphically in Figures 13, 14 and 15.

Figure 13. Pye Chart Showing Relationship Between Preferred and Actual Role for Benign Group

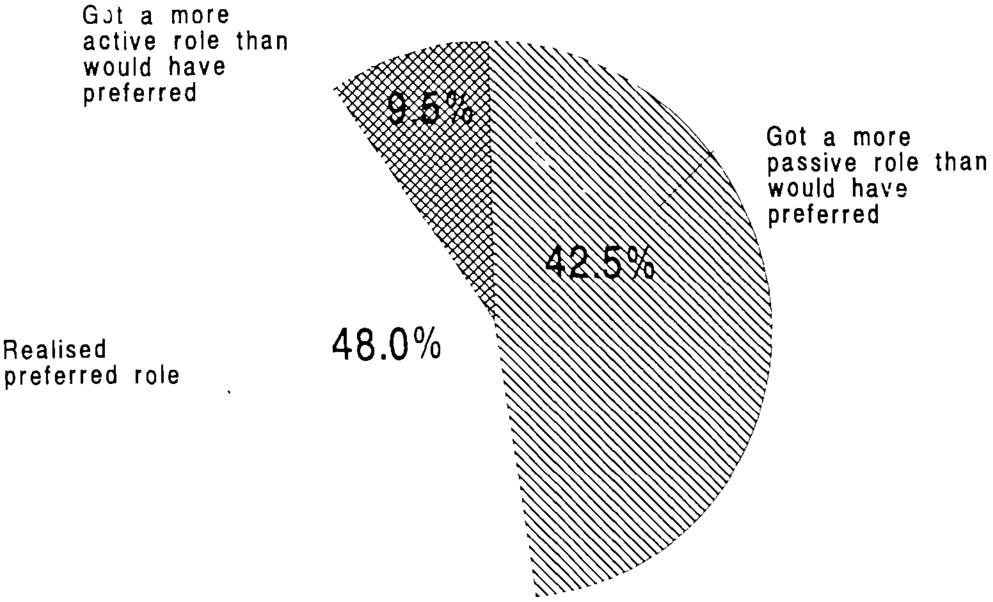


Figure 14. Pye Chart Showing Relationship Between Preferred and Actual Role for Newly Diagnosed Group

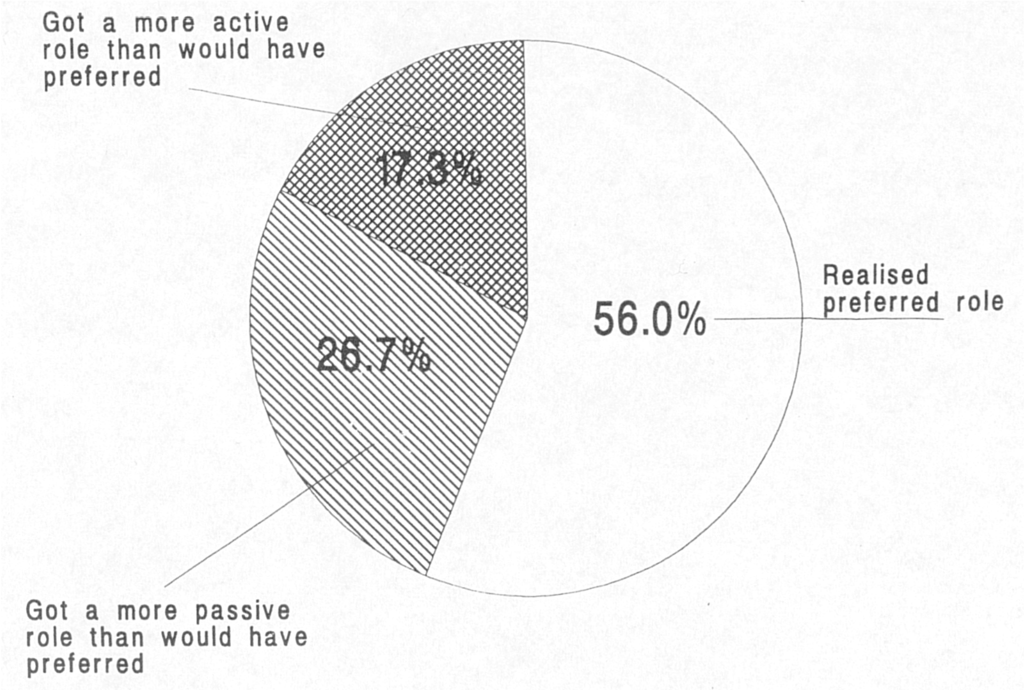
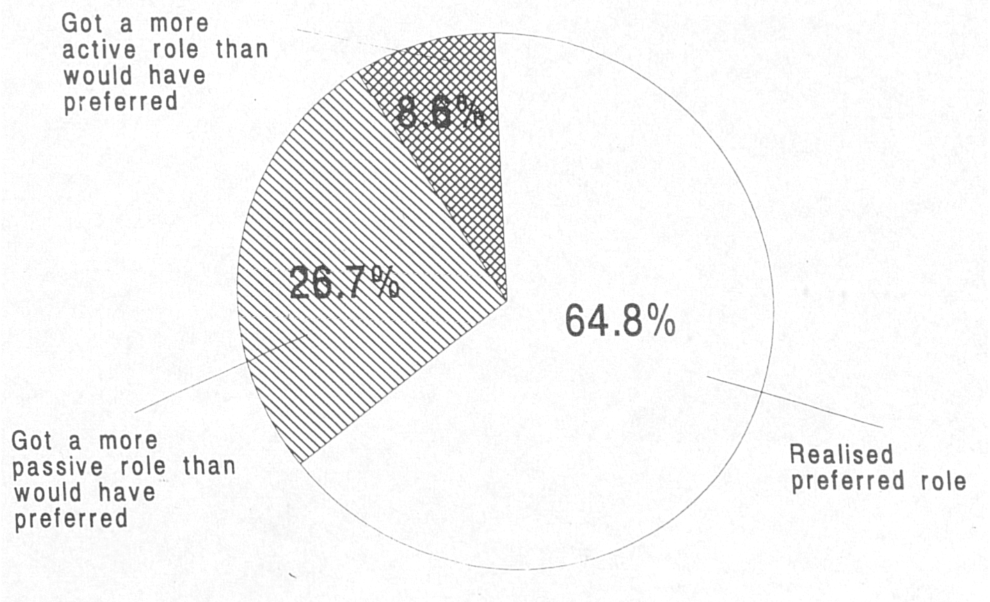


Figure 15. Pye Chart Showing Relationship Between Preferred and Actual Role for Follow-up Group



HOW THE DECISION REGARDING TREATMENT WAS REACHED

In order to gain some qualitative data to enrich the quantitative findings from the card sort technique for establishing decision making preferences, women at the follow up stage were asked to reflect on their experiences and say how the decisions about their treatment had actually come about.

Many comments made by the women reflected the perception that a choice of treatment had not been made available to them and that the doctor had been the decision maker (76.2%, n=80). Expressions such as the "doctor said" or the "doctor advised" were used to emphasise the doctor's role as primary decision maker as can be seen in the examples below.

> *"The doctor said it's cancerous and needs to be removed."*
>
> *(ID:20,002)*

> *"I was recalled from the screening. The doctor said it was cancer and that was that."*
>
> *(ID:20,003)*

> *"They just told me that was the treatment. They gave me a leaflet to explain. My opinion didn't come into it. It was there and it had to go. You go for advice, how can you discuss it?"*
>
> *(ID:20,207)*

> *"He said I had to have a mastectomy. It was a life saving operation. The breast care nurse explained that I could have an implant but I didn't want it, not at my age. They don't really ask you. They just put it to you."*
>
> *(ID:20,347)*

> *"Everyone has their own job. Because I had no choice the implant was given automatically. I don't think they asked me, they just gave it to me."*
>
> *(ID:20,379)*

It may be that women had not expected to be involved in the decision making process as the comments below indicate.

> *"It was my choice (mastectomy). I felt it was safer in the long term and I had small breasts. I didn't want any adjuvant treatment. I hadn't expected to be presented with a choice. It all happened so fast that I wasn't sure what to expect."*
>
> *(ID:20,018)*

> *"I chose a mastectomy at first. I needed the mobility in my arms and the lymph node removal would have made this painful. It was life threatening and so I didn't think there would be a choice. I knew of choices made by other women in the papers and on the TV but not life threatening choices."*
>
> *(ID:20,093)*

> *"You take the doctor's advice. I would have left it all to him. But the breast care nurse told me I had to decide about reconstruction. This was a bit of a surprise but I suppose she was right."*
>
> *(ID:20,092)*

> *"There was no alternative. The lump was below the nipple. I didn't expect to make decisions. I trusted the doctor. Anything medical and you have to leave it to them."*
>
> *(ID:20,015)*

The above comment highlights a common theme found in the women's comments relating to trust in the health care professionals judgments and ability to make decisions for individuals in their care. As the comments below demonstrate this trust is related to a belief that health care professionals have superior knowledge about breast cancer.

> *"The doctors opinion was that only a lumpectomy was necessary. The doctor knows what's best. You put your trust in the doctor. He's more knowledge. I expected to be involved and to make informed decisions. Some people want to know and some don't. The doctor's not a mind reader. If you want to know things you have to ask."*
>
> *(ID:20,057)*

> *"I just listened to him. I put myself in his hands. I can't do anything for myself."*
>
> *(ID:20,068)*

> *"He said 'I think I'll get away with a lumpectomy'. I suppose he would have given a choice if things had been worse. I left it to him. He wouldn't do major surgery if he didn't have to."*
>
> *(ID:20,090)*

> *"He told me what was wrong. He said it was the size of a pea. I wanted to know the truth. As long as I know what to expect I can face it. It's when doctors don't tell the truth I don't like it."*
>
> *(ID:20,299)*

> *"You have that much faith in the doctors."*
>
> *(ID:20,165)*

Although confidence in the health care professional's level of competence may have caused some women to feel more comfortable adopting a passive role in decision making some comments suggested that a lack of full and appropriate information may have limited the women's confidence in making decisions about their treatment.

> *"He explained that it was difficult to remove the cancer. I would need a wire inserting so that they could pinpoint the cancer exactly. I accepted what I was told. They explained about the lymph glands the day before the operation. They hadn't mentioned it before. I found that frightening and it bothered me for a short time but the breast care nurse explained it to me."*
>
> *(ID:20,121)*

> *"The doctor has more knowledge. You can't make decisions if you have no information."*
>
> *(ID:20,102)*

It should not be assumed that receiving full and appropriate information necessarily means that women would want to be involved in the decision making process as the following comment emphasises.

> *" I was apprehensive at first to be involved in decision making. You want to be advised and not have to make decisions. They sent me for a liver and bone scan. I didn't know what they were for. I just got sent along. "*
>
> *(ID:20,141)*

The comments made by some women appeared to indicate a lack of effective communication generally between the women and health care professionals.

> *"The doctor said mastectomy. I didn't ask and they didn't say. I think it was due to the position of the lump. I first realised I was having a mastectomy when I was in the hospital. They weren't in any position to involve me. I didn't know what treatment was planned until I arrived on the ward and saw it up on the board. I wasn't upset by this. The doctors were very busy and they had more knowledge and they would know what to do. "*
>
> *(ID:20,010)*

> *"He just said that was it. They didn't give me the opportunity (to make decisions). I think it was because I didn't have a lump in my breast, it was a mass and they can't cut a mass out can they? They never asked me (about the reconstruction). I wish he had. I would have had that. "*
>
> *(ID:20,138)*

> *"There was a lot of debate over what was the best treatment. They didn't say I was having a mastectomy until the night before the operation. They talked about it but they didn't involve me in that. It makes you lack confidence. They don't discuss it with you properly, they only tell you half the story. You need to fully understand. I didn't realise there were options. "*
>
> *(ID:20,142)*

Making decisions appeared to call for assertive behaviour on the part of some individuals who found that it was only through their insistence that they realised their own preferences for treatment. Comments were also made to the effect that choices were sometimes only acceptable if they conformed to the views of health care professionals and fell within the range of options presented to the women.

> *" The doctor was only happy if I agreed with him."*
>
> (ID:20,142)

> *"It was a very small lump. He said mastectomy or lumpectomy. I chose lumpectomy. He said I had made the right decision."*
>
> (ID:20,326)

> *"I found the lump. The doctor said lumpectomy, it needed removing. I needed a mastectomy 2-3 weeks later. The cancer was still there. They hadn't removed a big enough area. I nearly decided not to have the operation (mastectomy). The breast care nurse went mad. She was really annoyed. She shouldn't have been. It was up to me."*
>
> (ID:20,185)

> *"I'd insisted on a mammogram because my grandmother and aunt had breast cancer. My GP wouldn't agree at first but eventually he said I could have one. And it showed something up."*
>
> (ID:20,359)

> *"The GP sent me away more than once. He put me on evening primrose for 3 months. I insisted he refer me. He told me I was stupid. I was too young to have cancer. Eventually he referred me after I went back 3 times. He didn't refer me urgently. It took months to get an appointment. Then it all happened too fast. I had no time to think. I was rushed along, I felt very vulnerable."*
>
> (ID:20,185)

The feelings expressed in the above comment about vulnerability and being "rushed along" were typical of many comments made about the inability to think clearly at the time of diagnosis due to the perceived life threatening urgency of the situation.

> *"Everybody said I was lucky. If that was lucky I'd hate to be unlucky. At the time it was such a shock. I don't think I seriously had an opinion. If you asked him (breast specialist consultant) he would say he decided. I was too shocked. "*
>
> (ID:20,123)

> *"There was no choice. It all happened so fast. I don't remember what he said I was so shocked. They had it all planned out already. My husband was at the diagnosis so he remembered things I was too shocked to recall. He was only there by chance, he had the day off. Normally I would have gone alone."*
>
> (ID:20,094)

> *"I couldn't take it in at the time. I didn't know what he was talking about. He said he had to take it off. It was such a shock. "*
>
> *(ID:20,222)*

> *"He made up my mind for me. I couldn't decide. He said 'I won't take it off if you don't want me to'. You can't make the decision on the spur of the moment. It's too much of a shock. "*
>
> *(ID:20,327)*

The above selection of comments refer to the "shock" of the diagnosis and the inability to think clearly in that situation. Presenting women with choices when they feel they are in a state of shock may only enhance anxiety as the following comment shows.

> *"The doctor said he would remove the lump and I would have to have chemotherapy and radiotherapy. He asked if I wanted to enter a trial for chemotherapy. I decided not to. I was totally distraught at having to decide about the trial. I was OK until he said the word 'trial'. I didn't know what to decide. I felt awful. There was the guilt and shame if you didn't enter the trial. It's the only way they can learn. If the consultant had just said 'you're in a trial and we're going to do such and such' then I wouldn't have been worried. It was having to make the choice. I was very upset. I couldn't eat or sleep. I had to call the breast care nurse. "*
>
> *(ID:20,107)*

In explaining how the decision about treatment had come about many of the women used medical and technical terminology that had been used during consultations with the breast specialist team. Although some women showed a good understanding of the details of their diagnosis and treatment in some cases it was clear that understanding was limited. Such limitations to understanding could be detrimental in making treatment choices with women making choices based on an inadequate knowledge base. Without checking understanding health care professionals could mistakenly assume that full information had been given and understood.

> *"The needle test had already been done. I had the choice between lumpectomy and mastectomy. There were DCIS (ductal carcinoma in situ) cells around the edge of the tumour so I had a choice between a wider excision and a mastectomy. I chose the mastectomy. I didn't want messing around any longer. I felt like I was going around in circles. I didn't understand properly. You just want to get back to normal."*
>
> *(ID:20,382)*

> *"They thought there might be a choice at one point. The cancer was in situ and they thought tamoxifen would be enough. I had the lumpectomy and after they tested the lump there was no option. It was widespread. I would have liked to have known the full range of options of prostheses."*
>
> *(ID:20,365)*

> *"I had a mammogram and they found a shadow. They couldn't find out what it was. They took off fluid and fibres. It took 2 weeks before they found out there were cancer cells in the milk ducts. He just said they didn't know much about how the cancer spreads in milk ducts so he advised me to have it (breast) removed."*
>
> *(ID:20,184)*

> *"After the lumpectomy they said it was one of those tumours that live on breast tissue so it would have to come off."*
>
> *(ID:20,380)*

> *"When he told me it was cancer I thought he's made a mistake. I thought it must be an abscess. I didn't think cancer could be painful. He suggested because of the size of the lump I should have a lumpectomy. It was a 3.5 by 4cm tumour against the breast wall. It was the most virulent growing cancer, whatever that means. It was cell cancer 3. I had the number 3 which was fast growing. I had radiotherapy but they thought it could get into the bloodstream without going into the glands so they offered chemotherapy"*
>
> *(ID:20,376)*

> *"They looked at 27 lymph glands and only 3 of them had cancer in them so I'm OK."*
>
> *(ID:20,318)*

Conflicting information from different health care professionals led to confusion in women trying to make decisions based on this information.

> *"There was no choice over the surgery. The printed literature said they would be in touch after 3 weeks for the radiotherapy. I rang the breast care nurse after 4 weeks and she got in touch with Dr A. He said I would hear in 2 weeks. But in the meantime I got another letter to see Dr B. Dr A wanted to do 20 plus 3 sessions but Dr B wanted to do an operation and put in wires. They both think their own way is best. I had the choice. How could I choose? I rang the GP. He said one way was no better than the other. So I chose not to have the operation. Dr A said I didn't need such severe treatment. Dr B frightened me. He said the lump was near the lung."*
>
> *(ID:20,349)*

Although many comments were made to the effect that the doctor had been the primary decision maker a smaller number of women felt that they had made the decisions regarding their treatment (19%, n=20) or that some form of shared decision making had taken place (4.8%, n=5). In some cases this seemed to be a fully informed choice and the way in which they described the decision making process showed that they had carefully weighed the advantages and disadvantages of various treatment options.

> *"He could remove the breast: I said I couldn't handle that. Or they could do a lumpectomy. A week after the operation (lumpectomy) they said I had pre cancerous cells. They said I could have a mastectomy or radiotherapy but the radiotherapy could cause the cells to grow. There was a 50% chance. I had the radiotherapy. "*
>
> *(ID:20,196)*

However, in other cases the decision about treatment appeared to be based on an insufficient knowledge base and a lack of understanding of the options available.

> *"I had a mammogram at 60. They sent for me and I went. They did a needle test. Two days later they said there were cancer lumps. He mentioned therapy (radiotherapy) but I said I don't want therapy, I*

> *want it off. I had my mind made up. The breast care nurse said it would suddenly hit me but it didn't. She was amazed I was so down to earth. When he said that word 'therapy' I thought I'm not having that. You're sick and your hair falls out and the cancer can spread somewhere else anyway."*
>
> *(ID:20,110)*

The qualitative data on decision making preferences supported the quantitative data obtained on perceived decision making role. The majority of women in both cases perceived that the doctor had been the primary decision maker. The comments outlined above demonstrate how the women felt the decisions about their treatment had come about. Considering that the breast specialist consultant and breast care nurses at the study site believed that they had presented all individuals with treatment options, it was interesting to note the disparity between the health care professionals' perception of the decision making process and the service user's perception.

SUMMARY OF FINDINGS RELATED TO DECISION MAKING PREFERENCES

The study had six null hypotheses of no differences (H_0). The first null hypothesis was:

> H_0: There are no differences between the treatment decision making preferences of women newly diagnosed with breast cancer and women with benign breast disease.

The study showed that the treatment decision making preferences of women with benign disease were different to the treatment decision making preferences of women newly diagnosed with breast cancer. Women with benign breast disease were more likely to prefer a sharing role in treatment decision making while women newly diagnosed with breast cancer were more likely to prefer a passive role in treatment decision making. Therefore, the null hypothesis was rejected.

The second null hypothesis for the study stated that:

> H_0: There are no differences between the decision making preferences of women newly diagnosed with breast cancer and the same women at a point further from diagnosis.

No significant differences were apparent between the treatment decision making preferences of women newly diagnosed with breast cancer and the same women at a point further from diagnosis. The main preference for the newly diagnosed and follow up groups was for a passive role. The null hypothesis was, therefore, accepted.

Coombs' unfolding theory provided support for the notion that women with breast cancer had systematic preferences about the degree of control they wanted over treatment decision making. The unidimensional model of keep, share, give away control over decision making was supported by the data for women newly diagnosed with breast cancer and women further from diagnosis. The women with breast cancer, on the whole, had a preference for a passive role in decision making. For the women with benign breast disease the preferences were not so clearly defined on the keep, share or give away dimension and a subscale of the main dimension appeared to exist.

A number of socio-demographic and disease/treatment variables were examined to investigate their impact on decision making preferences. Overall, their impact appears to have been minimal. A summary of the rank order correlation coefficients for the variables investigated in this study are presented in Table 48.

Table 48. A Summary of the Rank Order Correlation Coefficients Obtained for Socio-Demographic and Disease/treatment Variables in Relation to Decision Making Preferences

Variable	**r**	**p**
Age	0.27	<0.01
Level of education	-0.22	<0.01
Social class	0.20	<0.01
Marital status	0.01	0.92
Relative with breast cancer	0.02	0.73
Know someone with breast cancer	-0.06	0.23
Type of surgery	0.00	1.00
Stage of disease	0.01	0.91

CHAPTER 8

FINDINGS RELATING TO INFORMATION NEEDS

INTRODUCTION

The findings concerning information needs relate to the second and third aims of the study, that is:

To construct profiles of information needs for women newly diagnosed with breast cancer, and for a comparison group of women with benign breast disease, reflecting priority information needs, and to investigate how these profiles changed over time for women with breast cancer.

To explore the relationship between treatment decision making and information need. That is, to investigate if decision making preferences influenced the type of information needed for women with breast cancer and women with benign breast disease.

THE INFORMATION NEEDS PROFILES FOR THE BENIGN, NEWLY DIAGNOSED AND FOLLOW UP GROUPS

Thurstone scaling methods were applied to the data and profiles of information needs were produced for the three study groups (Figures 16, 17 and 18). In the benign group one individual omitted one of the thirty six information needs pairs while in the newly diagnosed group five individuals each omitted one information needs pair. In terms of data analysis this missing data was considered to be minimal and Thurstone scaling analysis could still be carried out on the data sets containing missing values. A total of 200 data sets were available for the benign study group, 150 for the newly diagnosed group and 105 for the follow up group.

For the benign group of women the top three priority information needs were information about the likelihood of cure from the disease, information about how advanced the disease was and how far it had spread, and information about different types of treatment (Figure 16). Information about social life and sexual attractiveness were ranked last. The profile for the benign group showed some "clumping" of items with some items having very similar scale values. This could indicate that this group did not have a clear view as to what they thought would be their priority information needs.

For the newly diagnosed women the top three priority information needs were also information about the likelihood of cure from the disease, information about how advanced the disease was and how far it had spread, and information about different types of treatment (Figure 17). Lowest on the hierarchy was the item relating to sexual attractiveness. Fairly even spacing existed between all nine information needs which could indicate that the newly diagnosed women had a clear opinion of what their information needs were at the time of diagnosis. It may be that having a diagnosis of cancer brings more clearly into focus the rank ordering between needs.

For the follow up group the top three priority information needs were information about the likelihood of cure, information about the risk to the family of developing breast cancer and information about the stage of disease (Figure 18). The item of information concerning sexual attractiveness was ranked last. Fairly even spacing existed between the items on the profile for the follow up group indicating that these women may have had a clear opinion of what information needs were important and in what order.

Figure 16. The Information Needs Profile for the Benign Group (n=200)

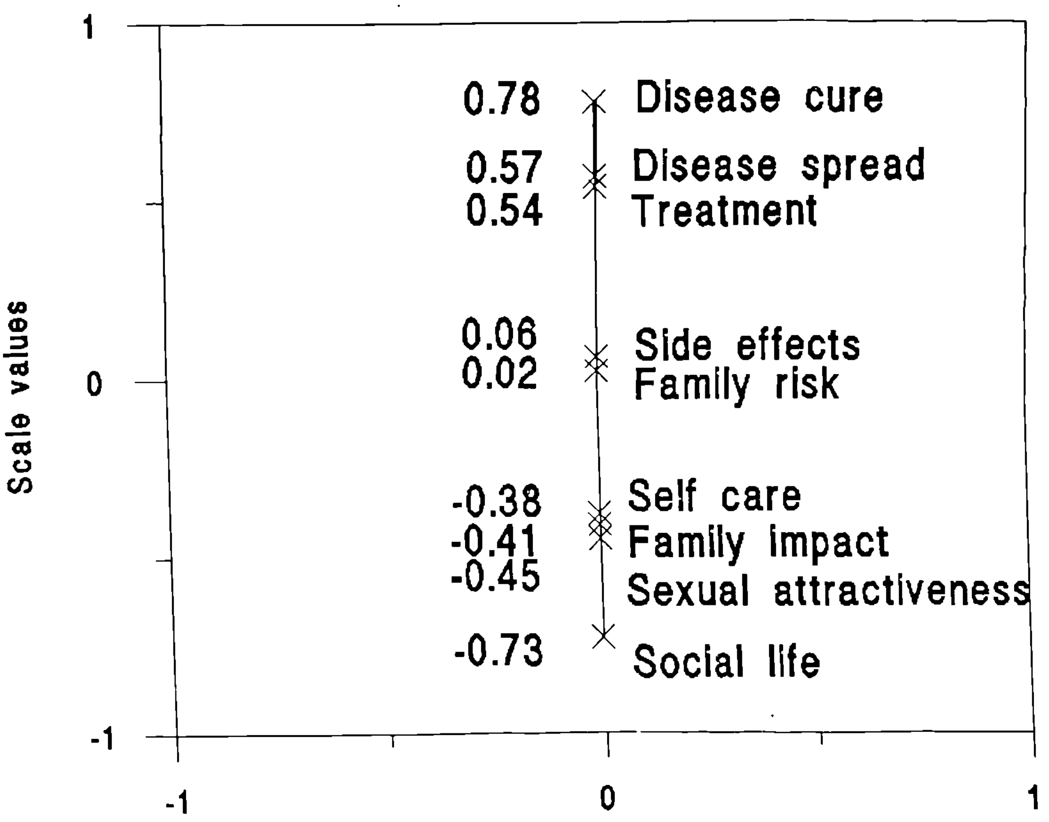


Figure 17. The Information Needs Profile for the Newly Diagnosed Group (n=150)

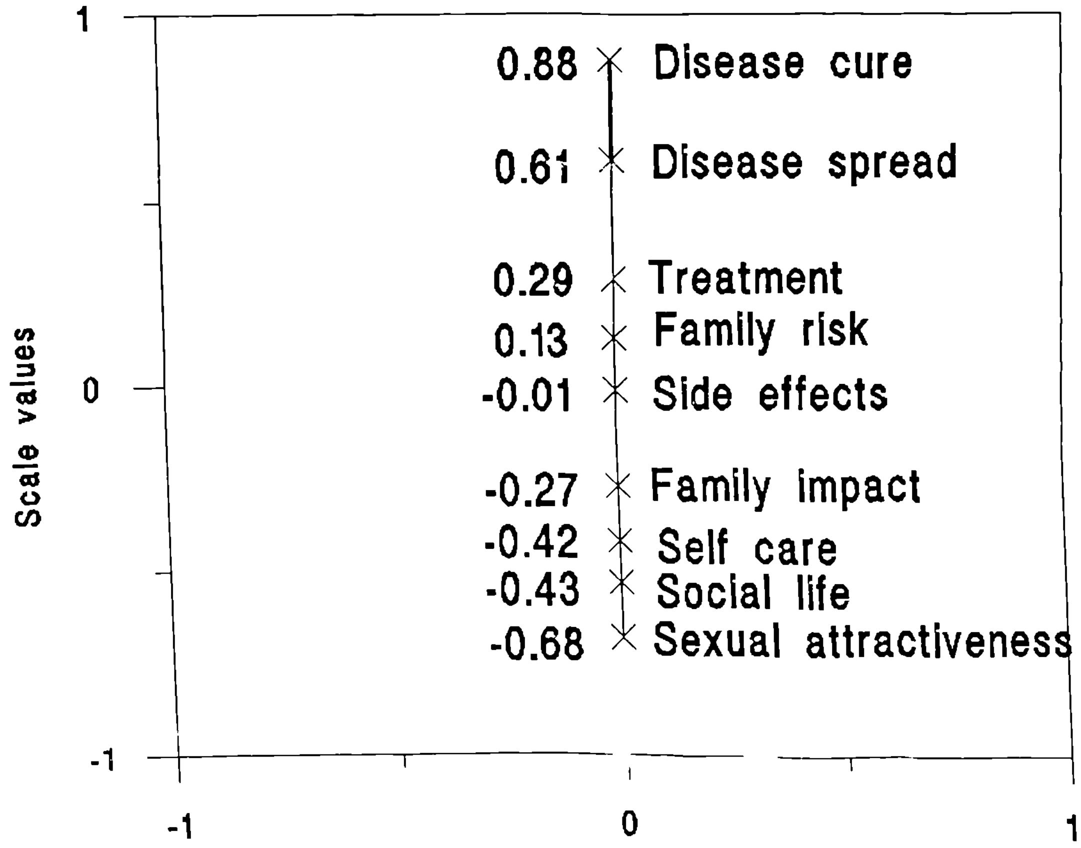
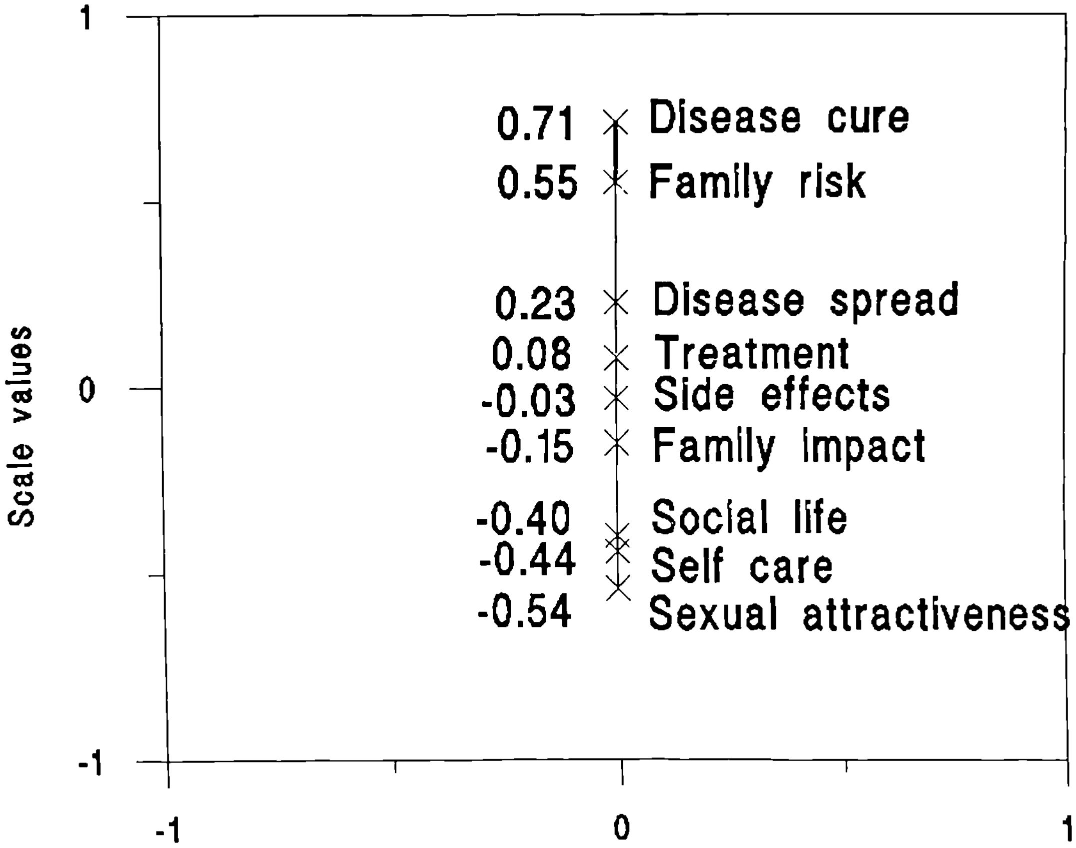


Figure 18. The Information Needs Profile for the Follow Up Group (n=105)



DIFFERENCES BETWEEN THE INFORMATION NEEDS PROFILES FOR THE STUDY GROUPS

As the follow up group were a subset of the newly diagnosed group it was not possible to consider the three study groups as independent samples for comparative analysis. Therefore, the benign and newly diagnosed groups were compared to look for significant differences between the two profiles, using the pooled variance t-test, and the newly diagnosed and follow up groups were compared in a separate analysis for related samples.

In comparing the newly diagnosed and follow up groups a related t-test was used to compare the scale values of 105 women in each of the two groups. This involved 45 women being excluded from the analysis who had been part of the newly diagnosed group but who had not gone on to become part of the follow up group. The scale values of the 105 women in the follow up group are displayed in Figure 18. The scale values of the 105 women at the newly diagnosed stage who went on to become part of the follow up group are shown in Table 49.

Table 49. Scale Values for 105 Women at the Newly Diagnosed Stage

Item of information	Scale value
Disease cure	0.86
Disease spread	0.60
Treatment	0.37
Family risk	0.10
Side effects	-0.01
Family impact	-0.28
Self care	-0.44
Social life	-0.52
Sexual attractiveness	-0.67

No significant differences were found between the profiles of information needs for the benign and newly diagnosed groups (Appendix 13). However, there was one significant difference between the information needs profiles of the newly diagnosed and follow up groups that concerned the item of information relating to family risk. This item was significantly more important to women in the follow up group (t=-2.36, p=0.03) (Appendix 13).

INTERNAL CONSISTENCY

To show that each woman had been consistent in her judgements, and was not simply making random choices about which items of information were important, Kendall's coefficients of agreement and consistence were employed (Edwards, 1974; Dunn-Rankin, 1983, Sloan et al 1994). In this way evidence could be provided to support that there was consistency between the women in the study in terms of their choices and agreement within each individual's choices.

Kendall's Coefficient of Agreement

The coefficient of agreement has values ranging from minus one to plus one and any value in the positive range is considered to show agreement. Table 50 shows the values for the coefficient of agreement (Kendall's u) for the three study groups and indicates agreement between individuals in their judgments for all three study groups, that is choices were not made at random.

Table 50. Kendall's Coefficient of Agreement (u) for the Three Study Groups

Group	u	χ^2	p
Benign	0.27	2003.42	<0.001
Newly diagnosed	0.26	1435.03	<0.001
Follow up	0.20	810.18	<0.001

Kendall's Coefficient of Consistence

The coefficient of consistence, zeta, had values that ranged from 0 to 1. A value of 0 would indicate that an individual was totally inconsistent in her judgments whereas a value of 1 would indicate total consistency. All women in the three study groups were found to be consistent in their judgements (Table 51). Table 51 also displays the mean number of circular triads made by each study group. A large number of circular triads would have to be made before individuals were considered inconsistent by the Kendall zeta statistic (30 triads in this study) and a descriptive analysis of the circular triads that occurred for the three study groups provided additional information on the inconsistencies that occurred for the three study groups.

Table 51. Kendall's Coefficient of Consistency (zeta) for the Three Study Groups

Group	**Zeta (mean)**	**SD**	**Circular triads (mean)**	**SD**
Benign	0.97	0.11	5.48	5.82
Newly diagnosed	0.98	0.08	5.04	5.23
Follow up	0.99	0.03	4.34	4.39

CIRCULAR TRIADS

For nine items the maximum number of circular triads that could be made by each individual was 84. On this basis an individual who made 84 triads would be classed as totally inconsistent in her judgements. A maximum of 30 triads were "allowed" before an individual was judged to be inconsistent. Appendix 14 shows a detailed breakdown of the number of triads made by each of the study groups.

For the benign group, 63% (126/200) of the women made only five triads or less with 19% (38/200) making no triads. The maximum number of triads made by any one individual was 26 triads. No individuals in this group made more than 30 triads and so all women in the benign group were considered consistent in their judgements.

For the newly diagnosed group no individual recorded 30 or more triads and so all women in this group were also deemed to be consistent in their judgements with 67% (100/150) of the women making less than five triads and 16% (24/150) making no triads whatsoever. The maximum number of triads made by any one person was 22.5, the 0.5 occurring because of missing values in the data.

In the follow up group no individual made more than 30 triads and so all women in this group were deemed consistent in their judgements. A majority of women made 5 triads or less (68%, 71/105) while 22% (23/105) made no triads whatsoever. The maximum number of triads made by one individual was 19.

In looking at where the triads occurred for the benign group the most commonly arising inconsistency was between items 1, 7 and 9 which accounted for 21 circular triads:

1. Information about how advanced the disease is and how far it has spread.
7. Information about different types of treatment.
9. Information about possible unpleasant side effects of treatment.

All three items related to physical aspects of care. Items 1 and 7 were in close proximity on the information needs profile, both items being in the top three priority needs, and it may have been this factor that was causing confusion. Items 7 and 9 may have caused confusion as to which came first in the sequence of importance as both concerned aspects of treatment.

Another commonly occurring inconsistency, accounting for 21 triads, was between items 4, 5 and 8:

4. Information about how my family and close friends may be affected by the disease.
5. Information about caring for myself at home.
8. Information about whether my children or other members of the family are at risk of getting breast cancer.

All three items relate to psychosocial needs. Items 4 and 5 were extremely close on the information needs profile with women in the benign group finding it difficult to prioritise these items. Items 4 and 8 both related to the family which may have led to inconsistencies.

The triad occurring between items 3, 5 and 9 also accounted for 21 triads:

3. Information about how the treatment may affect my ability to carry on my usual social activities.
5. Information about caring for myself at home.
9. Information about possible unpleasant side effects of treatment.

All three items were fairly evenly spaced on the information needs profile and providing an explanation for the inconsistency that arose between these items can only be speculative. The underlying factor here may have been a social issue. Concerns about looking after oneself at home and resuming a normal social life may well be affected by the severity of side effects suffered.

In looking in more detail at where the triads occurred for the newly diagnosed group the most commonly occurring triad was between items 3,7 and 9, accounting for 19 triads:

3. Information about how the treatment may affect my ability to carry on my usual social activities.
7. Information about different types of treatment.
9. Information about possible unpleasant side effects of treatment.

All three information needs contained the word "treatment" and it may have been this factor that confused some individuals. Item 7 related directly to treatment while items 3 and 9 refer to the effects of treatment. From anecdotal evidence items 7 and 9 seemed to represent a "chicken and egg" situation with women wanting to know about both items but having difficulty in deciding which of the two items represented the primary need.

The next most commonly occurring triad was between items 7, 8 and 9, accounting for 16 triads:

7. Information about different types of treatment.
8. Information about whether my children or other members of the family are at risk of getting breast cancer.
9. Information about possible unpleasant side effects of treatment.

Inconsistency again occurred with items 7 and 9 but on this occasion an item concerning the family was also involved. Anecdotal evidence suggested that many women claimed to be selfish in their responses and so would choose an item concerning the family on occasion so as to be seen as more considerate of others.

This theory was supported by the next most frequently occurring triad between items 4, 7 and 9, accounting for 15 triads:

4. Information about how my family and close friends may be affected by the disease.
7. Information about different types of treatment.
9. Information about possible unpleasant side effects of treatment.

The nine information needs contained two references to the family, in items 4 and 8, and both these items were causing inconsistencies. It may be that women were being torn between a need to consider self and a need to consider the family. Although the need to consider self was a priority, inherent in the three priority needs, the need to consider family was causing some inconsistencies and feelings of guilt.

For the follow up group the most commonly occurring inconsistency, accounting for 14 triads, was between items 1, 2 and 7:

1. Information about how advanced the disease is and how far it has spread.
2. Information about the likelihood of cure from the disease.
7. Information about different types of treatment.

At the newly diagnosed stage these three items were the highest priority items and it may be that inconsistencies arose at the follow up stage for individuals who still saw these items as high priority and found it difficult to place them in order.

The next most commonly occurring inconsistency was between items 1, 2 and 9, accounting for 12 triads:

1. Information about how advanced the disease is and how far it has spread.
2. Information about the likelihood of cure from the disease.
9. Information about possible unpleasant side effects of treatment.

Items 1 and 2 may again have caused inconsistencies as they were the high priority items at the newly diagnosed stage and were in close proximity on the information needs profile. Item 9 had been involved in inconsistencies with item 7 regarding treatment options at the newly diagnosed stage. In this case item 9 may have been "substituted' for item 7 in the above triad for individuals who found it hard to distinguish between items 7 and 9.

SUMMARY

The information needs profiles for the newly diagnosed and benign study groups were similar with the top three priority items being information about the likelihood of cure from breast cancer, information about the spread of disease and information about treatment options. The only significant difference between the information needs profile at the follow up stage concerned the item on family risk. Information about family risk was significantly more important to the follow up group. Individuals were found to be consistent in their judgements and few triads had been made in completing the Information Needs Questionnaire.

SOCIO-DEMOGRAPHIC FACTORS AND INFORMATION NEED

A number of socio-demographic and disease/treatment factors were investigated to assess their impact on information need.

Age and Information Need

Information needs profiles were constructed for two age groups:

1. Less than 50 years of age.
2. Fifty years or greater.

The pooled variance t-test was used to establish if there were any significant differences in terms of age and information need for the benign, newly diagnosed and follow up groups (Appendix 15a). For women in the benign group the scale values for each item of information showed no significant differences across the two age groups.

The scale values for the newly diagnosed group also showed similar preferences for information regardless of the age of the women. The pooled variance t-test showed that there were no significant differences in the rankings of items by younger and older women, although the ranking of the item on sexual attractiveness did approach a significant level ($t=2.00$, $p=0.06$). This item had a tendency to be considered more important by younger women in the newly diagnosed group (Appendix 15a).

The scale values for the follow up group also showed similar preferences for information regardless of the age of the women. The pooled variance t-test showed that there were no significant differences in the rankings of items by younger and older women although, as with the newly diagnosed group, the ranking of the item on sexual attractiveness did approach a significant level ($t=2.04$, $p=0.06$). This item had a tendency to be considered more important by younger women in the follow up group (Appendix 15a).

Level of Education and Information Need

Information needs profiles were constructed for two levels of education, those who had formal qualifications and those who did not.

The scale values indicated similar preferences for information regardless of the level of education of the women in the benign group, the newly diagnosed group and the follow up group. The pooled variance t-test showed that there were no significant differences in information need in terms of level of education for all three study groups (Appendix 15b).

Social Class and Information Need

Social class was considered in three groups:

1. Social classes I and II.
2. Social class III.
3. Social classes IV and V.

The scale values indicated similar preferences for information regardless of the social class of the women in the benign group, the newly diagnosed group and the follow up group. ANOVA showed that there were no significant differences in information need in terms of social class for all three study groups (Appendix 15c).

Marital Status and Information Need

Marital status was considered in terms of women who had a partner and women who did not. The scale values indicated similar preferences for information regardless of marital status for women in the benign group and the newly diagnosed group (Appendix 15d). However, for women in the follow up group the item of information relating to social life was rated significantly more important to women who did not have a partner ($t=-2.08$, $p=0.05$). While neither women with or without a partner rated the item as a priority issue it was more important to women who did not have a partner.

Having a Relative with Breast Cancer and Information Need

Women were divided into two groups to ascertain if having a relative with breast cancer affected information need; those women who were aware that a family member had breast cancer and those who did not have knowledge of any family member with breast cancer.

The scale values indicated similar preferences for information regardless of whether the women had a family history of breast cancer or not for the benign group, the newly diagnosed group and the follow up group. The pooled variance t-test showed no significant differences between the scale values for women who had a relative with breast cancer and women who did not have a relative with breast cancer (Appendix 15e).

Knowing Someone with Breast Cancer and Information Need

Women were divided into two groups to examine the influence of knowing someone with breast cancer on information need; those women who had personal knowledge of an individual with breast cancer and those who had no personal knowledge of any other person with breast cancer.

The scale values indicated similar preferences for information regardless of whether the women knew someone with breast cancer or not for the benign group, the newly diagnosed group and the follow up group. Pooled variance t-tests showed no significant differences in information need for women who knew someone with breast cancer and women who did not (Appendix 15f).

Type of Surgery and Information Need

Women in the follow up group were divided into two categories to examine the influence of the type of surgery on information need; those women who had mastectomy as their primary surgery and those women who had conservative surgery, for example lumpectomy, as their primary treatment.

The scale values indicated similar preferences for information regardless of whether the women had mastectomy or lumpectomy as their primary surgery. The pooled variance t-test showed that there were no significant differences between the information needs profiles of women who underwent mastectomy and women who underwent lumpectomy for the follow up group (Appendix 15g).

Stage of Disease and Information Need

Women in the follow up group were divided into two categories to examine the influence of stage of disease on information need; those women considered to be Stage 1 according to the TNM classification and those women considered to be Stage II. Any other classifications such as Pagets disease were included in the Stage II category, although this only involved two individuals.

The scale values indicated similar preferences for information regardless of the stage of disease and the pooled variance t-test showed that there were no significant differences between the scale values of women who were classified as Stage I and women who were classified as Stage II (Appendix 15h).

Decision Making Preferences and Information Need

Women were divided into three groups to examine the influence of decision making preferences on information need, representing a preference for an active, sharing or passive role in decision making.

The scale values indicated similar preferences for information, regardless of whether the women had preferred an active, sharing or passive role in treatment decision making, for the benign, newly diagnosed and follow up groups. ANOVA showed that there were no significant differences between the scale values of women who preferred different decision making roles for all three study groups (Appendix 15i).

SUMMARY OF FINDINGS RELATED TO THE IMPACT OF OTHER VARIABLES ON THE INFORMATION NEEDS PROFILES

A number of variables were considered that may have influenced decision making preferences for all three study groups including the impact of age, level of education, social class, marital status, having a family member with breast cancer, knowing someone with breast cancer, type of surgery, stage of disease and decision making preference. Overall, these variables had little impact in predicting information needs.

OTHER ITEMS OF INFORMATION CONSIDERED TO BE IMPORTANT

To assess if the measure covered all aspects of information that the women in the three study groups would require all study participants were asked, on completion of the Information Needs Questionnaire, if there were any other information needs they had which were not covered by the nine information needs presented in the questionnaire.

In the benign group three women made comments about information needs that they felt were not covered sufficiently in the Information Needs Questionnaire. One comment related to wanting more information on the anatomy and physiology of the breast. Another comment related to information on how to tell young children that their mother had breast cancer and a third comment related to information on whether the family should be told the diagnosis.

In the newly diagnosed group three women responded that they felt there were items of information that had not been included in the information needs measure. One comment related to how breast cancer would impact on occupation. Another comment related to recovery times and a third comment related to contraceptive advice following treatment.

In the follow up group two women responded that they felt there were other information needs important to them that were not covered in the measure. One woman responded that it would be important to know when follow up appointments would be planned in the future and one woman wanted to know how long she would need to take the tamoxifen, although neither individual felt that these were their most pressing concerns. Although these two items of information were not mentioned specifically in the information needs measure they could be seen to be covered by the item of information concerning treatment options and the advantages and disadvantages of each treatment.

Eight comments were made out of a total of 455 interviews. This indicated that in the majority of cases (98%) the women in the study feel that the Information Needs Questionnaire had given comprehensive coverage of their information needs.

INFORMATION THAT WAS STILL NEEDED AT THE FOLLOW UP STAGE

A majority of the women in the follow up group responded in the affirmative when asked if there was any information they felt was still needed (65.7%, n=69/105). The information requested covered various aspects of care and treatment with the most common information need (mentioned by 25 women) relating to the risk of other family members of getting breast cancer. This result is compatible with the information needs profile for this group of women which demonstrated that further from diagnosis concern about family risk increases in importance. An example of a comment, made in answer to the question "is there any information you still need?", that relates to the inheritance of breast cancer is given below:

> *"Family risk. My daughter's concerned. She's seventeen. How would she know if she had it? I discovered the lump as soon as it appeared and they said it was aggressive."*
>
> *(ID:20,165)*

A large number of women (26.7%, n=28/105) wanted more information on treatment, requesting more information on the side effects of surgery and chemotherapy, information about reconstruction and information about the latest treatments available. One woman made an interesting comment to the effect that if health care professionals were better informed then patients would benefit:

> *"I had runny eyes from the chemotherapy. I didn't know that this was a side effect so I was quite concerned. You need to know the major side effects so that you know what to expect but you don't want to be given a list of all possible side effects, it's too worrying. But if someone knew it was a side effect they could tell you it was normal and you wouldn't worry. Health professionals need to be better informed."*
>
> *(ID:20,141)*

A number of women (15.2%, n=16/105) wanted more information on tamoxifen including information about the side effects of the drug and information about the duration of this hormonal treatment. Comments made relating to the use of tamoxifen included the following:

> *"I'm not clear on the side effects of tamoxifen. I've been getting ear infections and I wonder if this is the cause. Well you've got to ask. Thousands of women take tamoxifen so it must be OK."*
>
> *(ID:20,001)*

> *"How long will I take the tamoxifen for?"*
>
> *(ID:20,216)*

Eleven women (10.5%) wanted information on their progress, wanting to know how they were doing and whether the cancer had in fact gone. Examples of comments made are given below:

> *"Information about how you're progressing. You don't get enough feedback on whether you're OK or not."*
>
> *(ID:20,055)*
>
> *"Am I clear of the cancer after 5 years?"*
>
> *(ID:20,145)*
>
> *"The likelihood of recurrence and how to stop it."*
>
> *(ID:20,244)*

A small number of women (3.8%, n=4/105) asked specifically about the lymph nodes, wanting to know what they were and how they worked. For example:

> *"What do the lymph nodes do?"*
>
> *(ID:20,003)*

> *"I would have liked a leaflet explaining what 'lymph nodes' meant. They assume you know what this means. A diagram or booklet would have been useful. They said the cancer was in one lymph node. I nodded my head at the time. I'd like to know about this."*
>
> *(ID:20,158)*

Three women wanted to know more about their follow up, wanting to know what investigations were planned for the future, and two women wanted information about support groups. Only one woman wanted to know about the cause of breast cancer, asking if it could be caused by trauma.

Two women made interesting comment on the timing of information giving, saying that:

> *"I don't need any now (i.e information). You gain enough knowledge to feel confident that you know what you're talking about and then you don't need to know any more. Six months from diagnosis I needed to know things about social life, caring for myself at home and sex but there was no one there to give you that information."*
>
> *(ID:20,088)*

> *"I don't need information now, just someone to talk to. It would have been nice if someone had phoned. I've got the number of the breast care nurse but I won't ring. I wanted to talk to her before, but my husband told me not to, so I didn't. I let him talk me out of it."*
>
> *(ID:20,094)*

Although the women at the follow up stage were an average of 21 months from diagnosis their information needs had still not been met in many cases. That these women still wanted more information implies that they had not sought out this information from health care professionals even though all the women in this study were followed up in an out patient department.

THE STUDY HYPOTHESES IN RELATION TO INFORMATION NEED

Three null hypotheses related directly to information need. The first of these stated that:

> H_0: There are no differences between the information needs profile for women newly diagnosed with breast cancer and women with benign breast disease.

The study found no significant differences between the profiles of information needs for women with benign breast disease and women newly diagnosed with breast cancer. The top three priority information needs for both groups were information about the likelihood of cure from the disease, information about the spread of the disease and information about treatment options. The null hypothesis was accepted.

The second null hypothesis relating to information need stated that:

> H_0: There are no differences between the information needs profile of women newly diagnosed with breast cancer and the same women at a point further from diagnosis.

The study found significant differences between the information needs profiles at the newly diagnosed and follow up stages for one item of information. Information about the risk to the family of developing breast cancer was placed in a significantly higher position in the profile by the follow up group. The null hypothesis was rejected.

The third null hypothesis relating to information need stated that:

> H_0: There is no relationship between treatment decision making preferences and information need for women newly diagnosed with breast cancer, women with benign breast disease, and women with breast cancer further from diagnosis.

The study found no significant relationship between different decision making preferences and information need. That is, women who preferred a passive role in treatment decision making did not have different information needs to women who preferred an active role in treatment decision making. This finding applied to the benign, newly diagnosed and follow up groups. The null hypothesis was accepted.

CHAPTER 9

FINDINGS RELATING TO SOURCES OF INFORMATION

INTRODUCTION

Women in the follow up group had been asked to say if they had received information from various stated sources and, if so, to say how useful they had found that information at the time of diagnosis and at the time of the second interview. The findings for this part of the study relate to the following study aim:

To examine the professional and non-professional sources of information available to women with breast cancer and to explore the usefulness of these information sources at two different time points in the breast cancer experience.

INFORMATION RECEIVED

Initially the analysis for this part of the study aimed to determine if women had received information from each source around the time of diagnosis and at the follow up stage. Although it was accepted that information may have been received but not considered useful this part of the analysis aimed to establish whether women had received information and not, at this stage, to determine the usefulness of that information.

The various sources of information and whether women received information from these sources, at both the newly diagnosed and follow up stages, are shown in Tables 52 and 53.

Table 52. Information Received at the Newly Diagnosed Stage (n=105)

	Was information received from the specified source?	
Source of information	**Yes**	**No**
Breast consultant	99.1% (n=104)	0.9% (n=1)
Breast care nurses	86.7% (n=91)	13.3% (n= 14)
Ward/clinic nurses	41.0% (n=43)	59.0% (n=62)
GP	36.2% (n=38)	63.8% (n=67)
Leaflets	76.2% (n=80)	23.8% (n=25)
Medical books	13.3% (n=14)	86.7% (n=91)
Women's magazines	38.1% (n= 40)	61.9% (n=65)
Radio/TV	32.4% (n=34)	67.6% (n=71)
Newspapers	33.3% (n=35)	66.7% (n=70)
Friends/family	27.6% (n=29)	72.4% (n=76)
Support groups	7.6% (n=8)	92.4% (n=97)

Table 53. Information Received at the Follow Up Stage (n=105)

	Was information received from the specified source?	
Source of information	**Yes**	**No**
Breast consultant	46.7% (n=49)	53.3% (n=56)
Breast care nurses	17.1% (n=18)	82.9% (n= 87)
Ward/clinic nurses	21.9% (n=23)	78.1% (n=82)
GP	30.5% (n= 32)	69.5% (n=73)
Leaflets	26.7% (n= 28)	73.3% (n=77)
Medical books	13.3% (n=14)	86.7% (n=91)
Women's magazines	57.1% (n= 60)	42.9% (n=45)
Radio/TV	56.2% (n=59)	43.8% (n=46)
Newspapers	47.6% (n=50)	52.4% (n=55)
Friends/family	36.2% (n=38)	63.8% (n=67)
Support groups	6.7% (n=7)	93.3% (n=98)

At the newly diagnosed stage a large majority of women perceived that they had received information from the breast specialist consultant (99.1%, n=104/105), the breast care nurses (86.7%, n=91/105) and the leaflets distributed by the breast care nurses (76.2%,n=80/105). In considering the remaining professional sources of information fewer women perceived that they had received information from ward and clinic nurses (41.0%, n=43/105) or their own GP (36.2%, n=38/105).

Media sources of information in the form of television, radio and women's magazines provided information for a minority of the women as did medical books. Family and friends provided information for only a small percentage of women (27.6%, n=29/105) and very few women perceived that they got information from support groups (7.6%, n=8/105).

At the follow up stage over half of the women were now receiving information from media sources that included women's magazines (57.1%, n=60/105), television and radio (56.2%, n=59/105) and newspapers (47.6%, n=50/105). While the breast specialist consultant was still providing information for some women (46.7%, n=49/105), few women received information from other professional sources such as the GP (30.5%, n=32/105), ward and clinic nurses (21.9%, n=23/105) or the breast care nurses (17.1%, n=18/105). Family and friends continued to provide information for only a small number of the women (36.2%, 38/105) as did support groups (6.7%, n=7/105).

To investigate if there were any significant differences in terms of information received for the newly diagnosed and follow up groups each source of information was taken in turn and McNemar's test for related samples was carried out (Table 54). Table 54 shows the relevant χ^2 and p values as well as the confidence intervals associated with the differences in proportions between sources of information at the newly diagnosed and follow up stages. For example, 99.1% (n=104/105) of women perceived that they received information from the breast specialist consultant at the newly diagnosed stage while 46.7% (49/105) of women perceived that they received information from the breast specialist consultant at the follow up stage. The difference in proportions in this case was 52.4% with a 95% confidence interval of 42.2% to 61.8% (Table 54). All negative values associated with the differences in proportions in Table 54 indicate that more women received information from a particular source at the follow up stage than at the newly diagnosed stage.

Table 54. McNemar's Test for Each Source of Information to Show Differences Between Newly Diagnosed and Follow Up Stages

Source of information	**Diffs. (%)**	**95% confidence intervals**	χ^2	**p**
Breast consultant[5]	52.4	42.2% to 61.8%	55.00	<0.01
Breast care nurses	69.6	60.2% to 70.4%	71.05	<0.01
Ward/clinic nurses	19.1	8.7% to 25.3%	13.33	<0.01
GP	5.7	-4.3% to 14.3%	1.50	0.22
Leaflets	49.5	38.0% to 55.9%	43.61	<0.01
Medical books	0.0	-7.7% to 7.7%	0.00	1.00
Women's magazines	-19.0	-27.4% to -7.4%	11.11	<0.01
Radio/TV	-23.8	-32.7% to -11.4%	14.53	<0.01
Newspapers	-14.3	-23.5% to -4.0%	7.26	<0.01
Friends/family	-8.6	-15.5% to -0.9%	3.86	0.05
Support groups	1.8	-3.4% to -4.3%	0.67	0.41

Diffs = differences in proportions, degrees of freedom = 1

McNemar's tests showed that significantly more women received professional information at the newly diagnosed stage than at the follow up stage from the breast specialist consultant, the breast care nurses, leaflets provided by the breast care nurses, and ward and clinic nurses. No significant differences were apparent for information received at the newly diagnosed and follow up stages from the women's

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[5] At the follow up stage few women actually saw the specialist consultant and tended to be seen by more junior members of the medical team. Therefore, "breast consultant" at the follow up stage included any doctor the women saw on their visit to the hospital out patient department.

own GP. The GP was perceived as providing information in just under a third of cases at both stages.

Significantly more women received information from media sources at the follow up stage with information being received from women's magazines, radio and television, and newspapers. Family and friends were also a more utilised source of information at the follow up stage.

USEFUL SOURCES OF INFORMATION

For women who perceived they had received information from the specified sources consideration was given to how useful that information was. Individuals had been asked to rate the usefulness of the information on a five point scale, a score of 1 indicating that the information was very useful and a score of 5 indicating that the information was not at all useful. For ease of analysis, women who rated the information as very useful or useful (scores of 1 or 2) were considered as one group and women who rated the information as not useful or useless (scores of 4 or 5) were considered as one group. Generally it appeared that if the women perceived that they had received information, from whatever source, then that information tended to be seen as useful. Few women perceived that the information they had received was not of any use (Table 55 and 56). However, it could be the case that individuals' memory and recall of information provided only extended to useful information that could be seen to have some benefit and value.

Table 55 shows the usefulness of information received at the newly diagnosed stage. For example, of the 104 women who perceived that they had received information from the breast specialist consultant, 96.2% (n=100) perceived that this information had been useful to them. A total of 38 women perceived that they had received information from their GP and 68.4% (n=26) of these women found the information to be useful. However, 18.4% (n=7) of the women who perceived that they had received information from their GP did not perceive that the information had been useful to them.

Table 55. The Usefulness of the Information Received at the Newly Diagnosed Stage

Source of information	**Useful**	**Don't know**	**Not useful**
Breast consultant	96.2% (n=100)	3.9% (n=4)	0.0% (n=0)
Breast care nurses	93.4% (n=85)	5.5% (n=5)	1.1% (n=1)
Ward/clinic nurses	90.7% (n=39)	7.0% (n=3)	2.3% (n=1)
GP	68.4% (n=26)	13.2% (n=5)	18.4% (n=7)
Leaflets	91.3% (n=73)	5.0% (n=4)	3.8% (n=3)
Medical books	71.4% (n=10)	28.6% (n=4)	0.0% (n=0)
Women's magazines	65.0% (n=26)	27.5% (n=11)	7.5% (n=3)
Radio/TV	58.8% (n=20)	32.4% (n=11)	8.8% (n=3)
Newspapers	51.4% (n=18)	31.4% (n=11)	17.1% (n=6)
Friends/family	82.8% (n=24)	13.8% (n=4)	3.4% (n=1)
Support groups	87.5% (n=7)	12.5% (n=1)	0.0% (n=0)

Table 56 shows the usefulness of information received at the follow up stage. For example, only 14 women perceived that they were now receiving any information from the breast care nurse but for the 14 women who were receiving information all of the women found that information to be useful. A large number of women were receiving information from women's magazines (n=60/105) and 78.3% (n=48/60) found this information to be useful.

Table 56. The Usefulness of the Information Received at the Follow Up Stage

Source of information	**Useful**	**Don't know**	**Not useful**
Breast consultant	89.8% (n=44)	6.1% (n=3)	4.1% (n=2)
Breast care nurses	100.0% (n=18)	0.0% (n=0)	0.0% (n=0)
Ward/clinic nurses	78.3% (n=18)	13.0% (n=3)	8.7% (n=2)
GP	90.6% (n=29)	3.1% (n=1)	6.3% (n=2)
Leaflets	92.9% (n=26)	7.1% (n=2)	0.0% (n=0)
Medical books	78.6% (n=11)	14.3% (n=2)	7.1% (n=1)
Women's magazines	78.3% (n=47)	16.7% (n=10)	5.0% (n=3)
Radio/TV	74.6% (n=44)	18.6% (n=11)	6.8% (n=4)
Newspapers	60.0% (n=30)	28.0% (n=14)	12.0% (n=6)
Friends/family	76.3% (n=29)	18.4% (n=7)	5.3% (n=2)
Support groups	85.7% (n=6)	14.3% (n=1)	0.0% (n=0)

The number of women who felt that the information they had received from the specified sources, at both the newly diagnosed and follow stages, was very useful or useful are displayed in Figures 19 and 20. For example, 95% (n–100/105) of women perceived that they had received useful information from the breast specialist consultant.

Figure 19. Sources of Information Considered to be Useful at the Newly Diagnosed Stage (n=105)

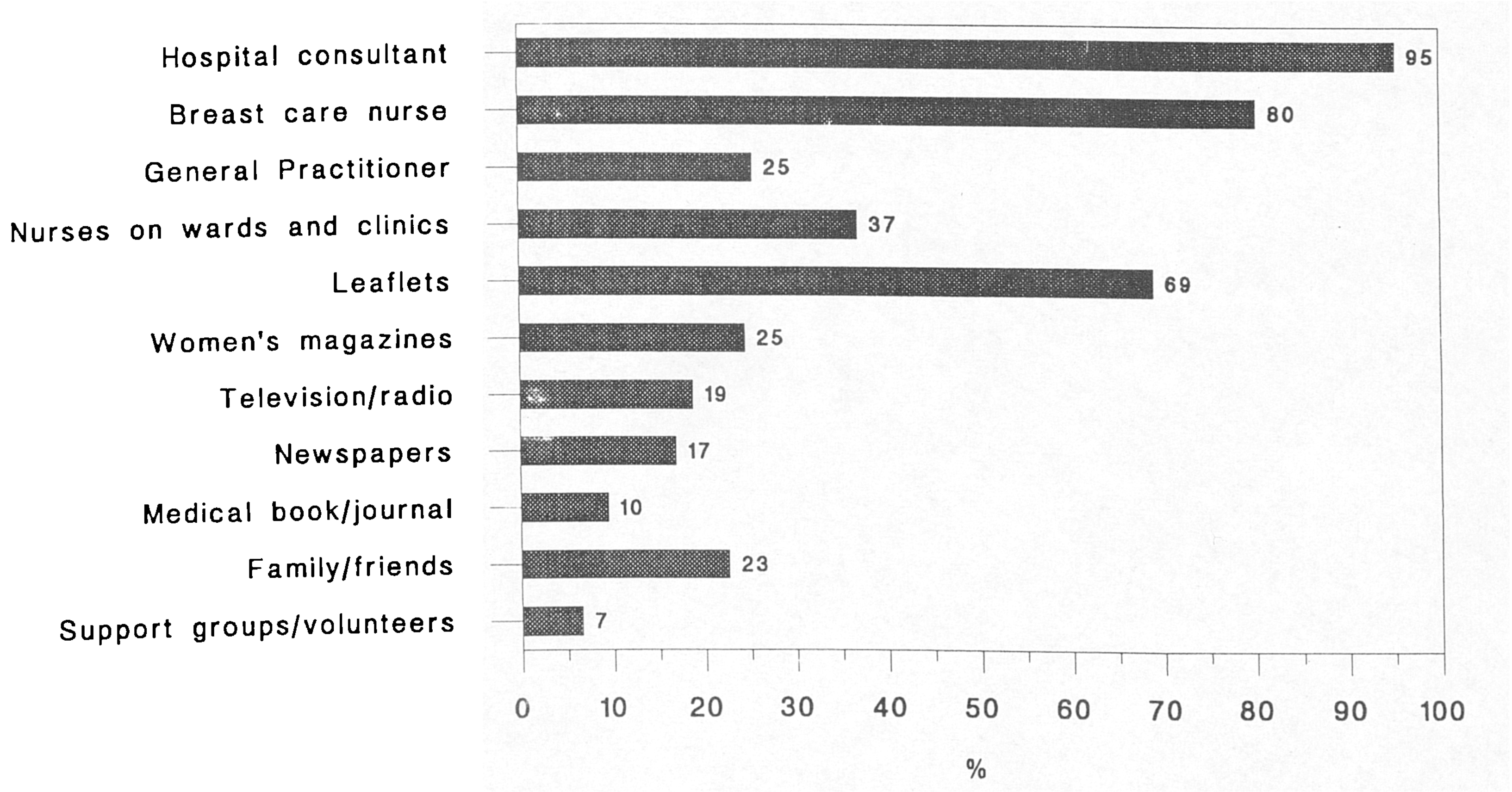
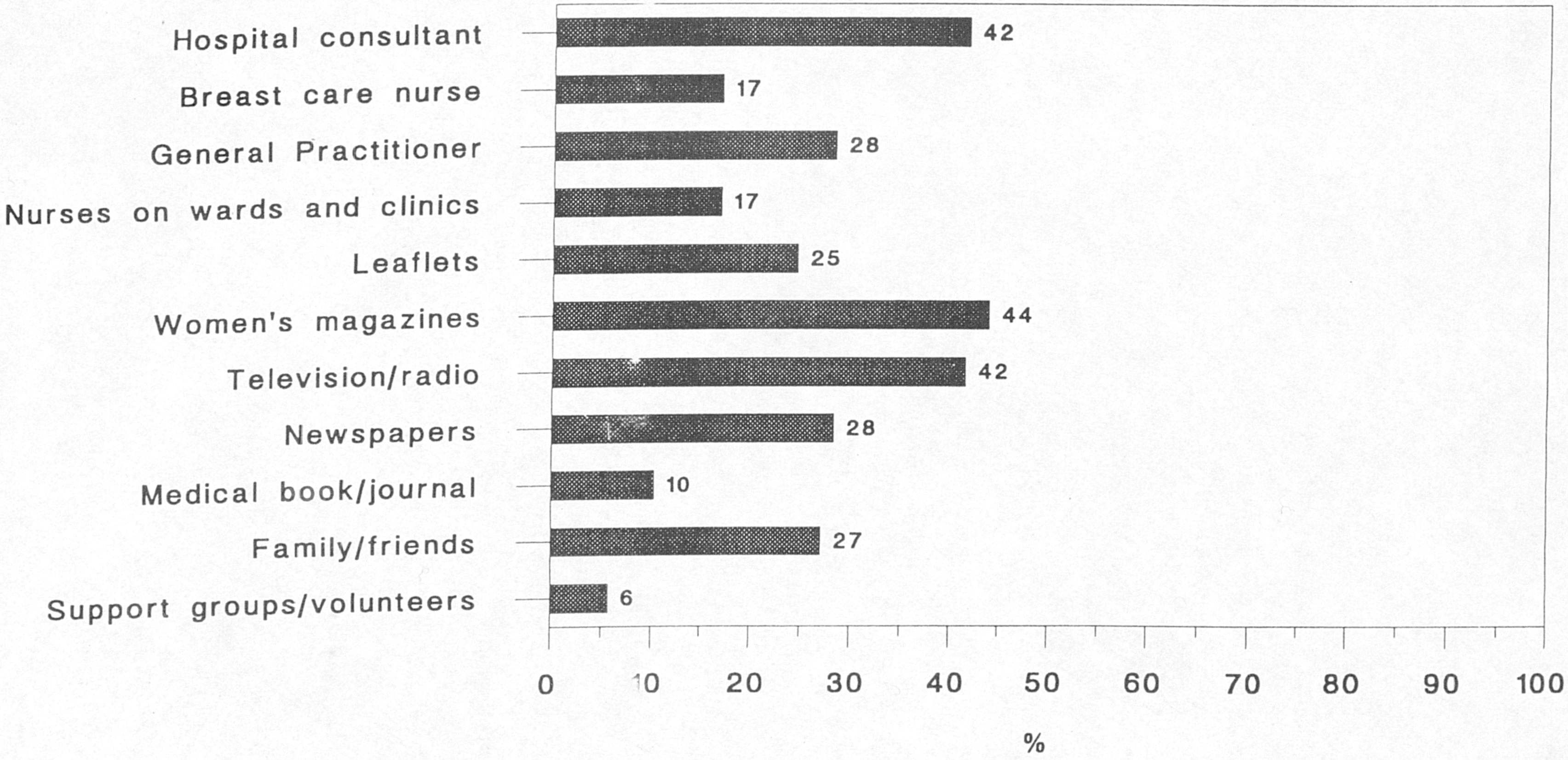


Figure 20. Sources of Information Considered to be Useful at the Follow Up Stage (n=105)



SUMMARY

At the time of diagnosis the sources of information that were considered most useful were the breast specialist consultant, the breast care nurse and the written information provided by the breast care nurse (leaflets). A smaller number of women felt that they had received useful information from their general practitioner (GP), nurses on the wards and in the clinics, or the voluntary sector.

At the follow up stage the sources of information that were considered the most useful were women's magazines, the television and radio, and the breast specialist consultant. At this stage few women were receiving useful information from professional sources such as the breast care nurse, the GP, and nurses on the wards and in the clinics.

The following null hypothesis related to this section of the study:

H_0: There are no differences between the usefulness of different sources of information for women with breast cancer at either the newly diagnosed stage or at a time point further from diagnosis.

Based on the findings related to sources of information for women with breast cancer the null hypothesis was rejected.

THE IMPACT OF BREAST CANCER ON FAMILY AND FRIENDS

Although family and friends were not considered to be a major source of information for women with breast cancer at either the newly diagnosed or follow up stage it was appreciated that family and friends may have been providing some form of emotional support. Two questions had been included in the interview schedule for the follow up group that allowed the women to express how they felt their families and friends had contributed to their recovery (Appendix 6).

How Has Your Partner Coped?

A majority of women interviewed in the follow up group were married or had a partner (66.0%, n=69/105). Overall partners appear to have been supportive towards the women. Fifty women made comments that obviously indicated their partner had played a supportive role, for example:

> *"He's been very good. He was very positive. I was crying a lot at first and he was a help. It might have made us a bit closer."*
>
> *(ID:20,165)*

> *"I'd have been lost without him. He was absolutely marvellous. He stayed with me throughout the chemo when I was being sick. It's made him less of a male chauvinist pig. He realises what goes on in the home now. I value him more than I did before."*
>
> *(ID:20,376)*

> *"He said he wasn't bothered if I had both breasts off. Having a leg off, he said, would be worse. I would still be the same person to him."*
>
> *(ID:20,359)*

Only five women made comments that indicated their partner was unsupportive, for example:

> *"He hasn't coped well, he won't discuss anything. He's very materialistic. If I'm feeling down he suggests a holiday. That's not what I want, I need to be able to talk to somebody but he just won't listen. When the breast care nurse came to see me at home he spoke to her for an hour and he felt great after that, but I never got to speak to her. He's built a big wall around himself and you can't get through. He changes the subject all the time. He thinks that's it, you've had your treatment, you're cured, you're over it, but you still need to talk."*
>
> *(ID:20,094)*

Nine women commented that their relationship had changed since diagnosis in a positive way with the couple becoming closer and more understanding of each other, for example:

> *"We've been strong for each other, we're much closer than we were before"*
>
> *(ID:20,279)*

A number of women (n=10) made comment about their partners practical value in that they were helpful in practical ways, for example:

> *"He's supportive in a practical way, emotionally he was quite dependent. I went away for a week and was glad to get away, but he has nursed me."*
>
> *(ID:20,382)*
>
> *"When I get distraught he always says 'now listen'. He's practical and realistic and always calms me down."*
>
> *(ID:20,107)*

Some women felt that their partners showed more concern than they did themselves about the situation (n=5), for example:

> *"He felt it more than I did, he found it hard to cope as he felt helpless, but he's been supportive."*
>
> *(ID:20,018)*

Overall, few negative comments were made about partners. While many women may not have wanted to imply that their partner was uncaring, and so may not have revealed true personal details about their relationship, comments were overwhelmingly positive about the supportive role of a caring partner.

Family and Friends

Although some family members and friends found it hard to cope with knowing someone with breast cancer, most family members and friends were supportive. A majority of women (60.0%, n=63) made positive comment on the support they had received from their family or friends, for example:

> *"My neighbour was very supportive and so were my work colleagues. Support has been very important"*
>
> *(ID:20,008)*
>
> *"I've a very supportive friend, I find it easier to talk to my friend than my husband."*
>
> *(ID:20,049)*
>
> *"I didn't want to see anyone, I locked myself away, my family live away and my best friend helped most, she pushed me to get it sorted out."*
>
> *(ID:20,185)*

> *"I couldn't have done without them, one friend visits every day even though she has her own problems."*
>
> *(ID:20,279)*

Although the majority of women found their families and friends supportive it seemed that it was often the case that some family members could cope better than others and support was obtained from some, while support was needed by others to cope with the situation, for example:

> *"My youngest daughter ignored me at first, she wouldn't stay in the same room. Two close friends have been the best source of support."*
>
> *(ID:20,076)*

> *"I don't get much support from female family members and this annoyed my husband. Friends have been marvellous, particularly my work mates. My son was 15 years old at the time and going through his 'O' levels. He coped with the surgery, chemotherapy and his 'O' levels. He was fine until it was all over, then he felt really depressed and low for ages after."*
>
> *(ID:20,107)*

> *"I have a very caring family, some relatives I don't bother with, they don't understand."*
>
> *(ID:20,113)*

> *"My son is very supportive. I can talk to him, I don't have the same rapport with my daughter."*
>
> *(ID:20,006)*

> *"Family and friends were terrified, I wanted to talk about it but they avoided it. My sister in law is very helpful but if you've not had the cancer you can't really understand."*
>
> *(ID:20,379)*

A number of women (n=8) talked about the change in their relationship with their family, the breast cancer experience having brought them closer together emotionally, for example:

> *"I'm closer to the children, you get your priorities in order, I'm more affectionate to them."*
>
> *(ID:20,331)*

> *"We do more as a family than we did before, it's made us closer. It makes you appreciate things a lot more, everything, even like watching a video together."*
>
> *(ID:20,175)*

Some family members found it hard to cope and needed reassurance themselves, for example:

> *"My three sons were very upset at first, they were very attentive. Now they've decided to forget about it. One son (aged 25 years) was shocked to hear of a friend of mine who'd died of breast cancer. He said he'd never thought of his mother dying and didn't think he'd know how to cope without me. I want my sons around but feel as though they take me for granted, I wanted a daughter."*
>
> *(ID:20,003)*

> *"I was reassuring to other people, they were more worried than me. My sister doesn't visit me, she said 'what about me?'"*
>
> *(ID:20,128)*

> *"My youngest son was very upset, he imagines his mum is going to die. I have to keep talking to him, he needs a lot of support."*
>
> *(ID:20,069)*

A number of women either didn't want to talk about their experience to their family (n=4) or didn't want to worry their family by talking about breast cancer (n=6), for example:

> *"I didn't want to tell my children, their dad had just died of cancer and I didn't want them to think that I was going to die too. My daughter was really upset but she's coping a lot better now."*
>
> *(ID:20,122)*

> *"I haven't told my family that I've got breast cancer, I don't feel that my brother could cope. He'd pretend he could, he'd run around like a headless chicken. Knowing that he couldn't cope would upset me. I'd like to tell my sister but I know that she wouldn't be confidential about the information, she'd tell everybody. I don't want people feeling sorry for me and asking how I am all the time."*
>
> *(ID:20,057)*

> *"My family have been OK but they don't talk about it, I didn't tell them until the last minute. I don't want to worry them so I keep things to myself."*
>
> *(ID:20,184)*

> *"I have a sister, the rest of the family died pretty young. I don't talk much about it. I try to forget about it. I delayed telling my sister, she gets upset easily. I told my niece about it, she's very positive and practical, I didn't want to end up feeling sorry for myself."*
>
> *(ID:20,090)*

SUMMARY

Although women with breast cancer were generally not receiving much in the way of information from their families and friends the emotional support that the contact with family and friends provided appeared to be very valuable to the women interviewed in this study. Although some of the women felt that they were providing more support than they were receiving the majority felt that they derived valuable support from family and friends.

CHAPTER 10

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

DISCUSSION

This study aimed to investigate how much involvement women with breast cancer preferred to have in the treatment decision making process, what specific types of information they needed, and what sources of information they considered to be useful at two different time points in the breast cancer experience. The aims of the study were guided by two theoretical perspectives: how service users made decisions in life threatening situations (Degner and Beaton, 1987) and how service users may consider some items of information to be more important than others (Derdiarian, 1987).

The discussion section includes a consideration of the relevance of the study findings in relation to the theoretical perspectives. The study findings in relation to the aims of the study are discussed as well as their implications for nursing practice. General limitations of the study as well as limitations of the study design and the measures used are discussed which may have implications for future research.

Findings in Relation to the Theoretical Framework

The Degner and Beaton (1987) model of decision making appeared to be a useful framework from which to understand the way in which women with breast cancer made decisions about their treatment. The provider controlled, patient controlled and joint controlled decision making preferences of the Degner and Beaton model captured the preferences of women with breast cancer on a dimension that ranged from keeping control (active; patient controlled), through collaboration (share; joint controlled) to giving away control (passive; provider controlled) and Coombs' unfolding theory (1964) supported the existence of this dominant dimension.

All the women in the study appeared to be able to clearly recognise the role that they wished to play in treatment decision making. Degner and Beaton (1987) developed their model to be relevant to individuals who were in a life threatening situation and involved in treatment decisions. For women with breast cancer this was pertinent as they were, at the time of diagnosis, presented with treatment decisions having just been presented with a potential life threatening diagnosis. It is not clear if the Degner and Beaton model would be suitable for lower order decisions that were not life threatening or if provider controlled decision making could include health care professionals other than the doctor.

Future research could investigate the preferences of service users if choices other than treatment choices were presented and if health care professionals other than the doctor were incorporated into the model. For example, an investigation could be made of the interaction between the patient and nurse in making nursing care decisions. It may be that individuals feel more able to participate in less life threatening decisions. A desire not to participate in treatment decisions may not mean that individuals do not want to participate in any health care decisions.

The desire to participate in decision making may be related to receiving the right type of information. Derdiarian's (1987) model of a hierarchy of information needs proved to be relevant in establishing the specific types of information important to women with breast cancer at different points in time. Few differences were apparent between the hierarchy of information needs at the newly diagnosed and follow up stages and this may have been as a result of primary needs being unsatisfied. Maslow (1973) believed that primary needs at the top of the hierarchy had to be satisfied before lower level needs could be considered. In this study it may be that priority information needs had not been satisfied at the time of diagnosis and therefore, lower level information needs had not become an issue. Alternatively, some types of information may have been so highly valued at all stages of the disease trajectory that they overshadowed other less important information needs permanently. For example, information about the likelihood of cure may have been such a major issue that, although individuals may have wanted information on other areas of concern, the constant overwhelming concern was about cure.

If a lack of information existed then Derdiarian (1987) believed that individuals would seek out information to satisfy their information need. In this study the women at the follow up stage still had information needs in 65.7% of cases, but utilised few sources of information and were reluctant to seek out information from health care professionals. Derdiarian's model of information seeking may be more relevant to individuals in the USA where service users are familiar with taking a more assertive approach to health care than in the UK where service users have traditionally been passive recipients of health care. It may be interesting to see if government policies that aim to encourage the service user as an active participant in health care will encourage individuals in the UK to become more assertive in seeking information.

Level of Involvement in Decision Making

The unfolding analysis (Coombs, 1964) showed that the women in this study, who had been newly diagnosed with breast cancer, had systematic preferences about the degree of control they wanted over treatment decision making. The findings showed that a majority of these women wanted to play a passive role in treatment decision making (52%, n=78/150). A smaller number (28%, n=42/150) wanted to share in the responsibility for decision making with only 20% (n=30/150) of the newly diagnosed women wanting to assume an active role. At a mean of 21 months from diagnosis this passive preference was sustained, in the same sample of women, and fewer women preferred to play an active role in decision making than when newly diagnosed with breast cancer. For the benign control group the preference was for collaboration (45.5%, n=91/200). These findings support other studies that suggest active involvement in decision making may not be the preferred role for a majority of service users (Degner and Sloan 1992, Ellis and Levanthal 1993, Ende et al 1989, Pickering and Broadley 1995, Sutherland et al 1989).

It is interesting to compare the findings of this study with the findings of a Canadian study that used the same measure of decision making preferences (Degner and Sloan 1992). The Canadian study found that householders, who had never had a diagnosis of cancer, thought that they would want to play an active role in decision making, should they ever develop cancer, while cancer patients preferred a passive role in decision making. The benign group in the present study may be seen as representative of some sort of middle ground between never being diagnosed with cancer and actually having a cancer diagnosis. The benign group could be considered to have had a "near miss" as far as cancer was concerned. It is then interesting to note that a gradient is apparent, as the nearer an individual gets to a diagnosis of cancer the more passive their participation preferences. The householders in the Canadian study preferred an active role, the benign group in the present study preferred a sharing role and the cancer patients in both the Canadian and present study preferred a passive role. It may be that the diagnosis itself is predicting preferences to participate in decision making. The diagnosis may have a disabling effect on the ability to make decisions for some, but not all individuals, as 48% of women with breast cancer in the present study preferred some degree of involvement in the decision making process.

The findings from the present study and the Canadian study (Degner and Sloan 1992) also indicate that it is not useful to ask a person to project themselves into the role of a cancer patient. The cancer experience is clearly unique to each individual and evokes thoughts and feelings that can not easily be imagined by a non sufferer. However, in terms of study design it is useful to have such a comparable group to demonstrate the possible impact of the cancer diagnosis.

If the diagnosis of cancer has a disabling effect on participation preferences, then this effect was sustained at the follow up stage. The preference for a passive role was retained even though the women were a mean of 21 months from diagnosis. They did not gravitate towards the more active end of the scale as they moved further from diagnosis. In fact, fewer women at the follow up stage preferred an active role in decision making than at the newly diagnosed stage. It may be that the fear of cancer was so strong that it permanently disabled individuals from wanting to be involved in the decision making process. Becoming increasingly familiar with the health care system did not incline individuals to prefer more active involvement in the decision making process.

There are alternative suggestions as to why 52% of women newly diagnosed with breast cancer in the present study preferred a passive decision making role. The preference may have been related to problems with retaining and recalling information in a crisis situation. A lack of appropriate information may have limited the ability to make decisions. However, at the follow up stage the crisis situation had presumably passed and yet individuals still retained a passive preference. This may be related to a lack of appropriate information at all stages of the breast cancer experience.

Getting the right amount and type of information, getting information at the appropriate time and in the appropriate format may all be factors that influence the desire to be involved in decision making. Important treatment decisions can not be made effectively without an appropriate knowledge base, and this may explain the reluctance of many individuals to take responsibility for treatment decisions. If knowledge about cancer is an issue in enabling cancer sufferers to play a more active role in decision making then any intervention study aimed at promoting the active role may not be successful. Providing information about the cancer itself may be the first stage in enabling individuals to play a more collaborative or active role. It may be that this is what the women with breast cancer in this study were trying to convey when they indicated that information about the physical aspects of the disease were their priority needs.

For those individuals who did not want any degree of involvement in the decision making process, information can still be considered important as evidence from other studies supports that not wanting to make decisions does not necessarily equate with not wanting information (Bilodeau 1992, Siminoff 1989). Indeed many individuals may not want to make decisions because they do not have the appropriate information, and this could be explored by the nurse when establishing decision making preferences. However, unnecessary anxiety could be avoided for people who wanted to play a passive role in decision making by the doctor taking on the role of primary decision maker. An individual may, of course, prefer someone other than the doctor to make decision for them such as a spouse or other family member.

Having a passive decision making preference may also reflect confidence in the breast specialist team. Many of the women in this study talked about having trust in the doctor stating that the doctor had more knowledge than them and was better placed to make decisions. Only seven women out of the total sample expressed any regrets about the decisions that had been made by them or by their consultant. This may further support the notion that a trusting relationship between the breast specialist team and the women in this study had developed. Alternatively, the implications, in terms of emotional impact, of regretting such an important decision may lead many women to believe that their choice was correct. Admitting regret to oneself about a decision that is likely to be irreversible may cause distress. Far less distressing to accept that the choice was correct in the first instance.

A qualitative study carried out in Canada suggested that the health care relationship evolved over time through different stages (Thorne and Robinson 1988). A stage of 'naive trust' was initially proposed where the patient puts their trust in health care professionals who they believe will act in their best interests. This was followed by a stage of 'disenchantment' where dissatisfaction and frustration may emerge. This was followed by the stage of 'guarded alliance' where trust was re-established as the individual became more informed and knowledgable. Thorne and Robinson (1988) felt that an awareness on the part of nurses of these different stages to the health care relationship would provide greater understanding of the experiences of the patient and would increase nurses abilities to interact with patients in progressing through the three stages.

As the present study only examined two points in time individuals may have passed through these different stages, as proposed by Thorne and Robinson (1988), and come to a position of 'guarded alliance' where a trust in the doctor was evident based on their experiences and the information they had received. At the newly diagnosed stage the women may have been in the stage of 'naive trust' which may have impacted on decision making preferences and explain why so many women preferred to defer decision making responsibility to their doctor. The stage of 'disenchantment' may have occurred in the interim period before the women were interviewed at the follow up stage by which time a period of 'guarded alliance' may have been entered with a passive preference again being most favoured. Further work in this area could indicate the time taken to progress through these proposed stages and to understand how decision making preferences may be influenced by the changing health care relationship.

Another factor which may have influenced decision making preference is the communication of choices to women in this study. When asked what role they perceived they had played in decision making the large majority of women felt that they had played a passive role (60.7% of the newly diagnosed group), that is, they did not perceive that they had been presented with treatment choices. This may say something about the women's expectations and also something about the way in which choices are articulated by health care professionals. Although the breast specialist consultant involved in this study perceived that women were given a choice about surgery, or a choice about reconstruction, the women's perception of choice did not match that of the health care team.

It may be that women did not expect to make choices and so did not perceive that choices were available, this being an alien concept to many women expecting to be the passive recipients of health care. When asked how the decision making process had come about many women used expressions such as 'the doctor stated', 'the doctor suggested' and 'the doctor advised', indicating that they felt they were not equal partners in the decision making process. This may be reflected in that 56% of the newly diagnosed women got what they preferred in terms of decision making preference.

However, 26.7% of the newly diagnosed women (n=40/150) got a more passive role than they would have preferred and it should be noted that, although the main preference was for a passive role, there still remained a substantial number of women in the newly diagnosed group who preferred some form of participation in the decision making process (28% sharing, 20% active). Indeed, if a simple participation versus non-participation dichotomy had been used as in other studies of decision making preference (Cassileth et al 1980, Blanchard et al 1988) then the split would have been almost equal with 48% of women preferring some form of participation and 52% preferring non-participation. This emphasises the limitations of a health care approach that advocates either participation or non-participation as a panacea. Establishing individual preferences to participate is important if service users are to have their preferences realised and their rights as service users respected.

Assessing individual preferences to participate in decision making in the clinical area would allow for an individual assessment of the reasons for non participation. Neufeld, Degner and Dick (1993) aimed to "coach" the patient so that they could become more active in decision making. This type of decisional support, using the Degner and Sloan (1992) card sort technique, may well be appropriate for British women. However, this form of decisional support may only be appropriate for women who want to be more active in the decision making process. Women who choose to play a passive role and feel comfortable with this role may not benefit from this sort of intervention. This could create an ethical dilemma for health care professionals. If studies are showing that choice has certain benefits (Ashcroft, Leinster and Slade 1985, Fallowfield et al 1994, Leinster et al 1989, Morris and Royle 1988) and the health care system is encouraging patient participation (Department of Health, 1991) then it may seem inappropriate to take a non intervention approach with individuals who do not wish to become involved in treatment decision making. Future work to understand the reasons for wanting to assume a passive role may go some way towards resolving this dilemma.

The card sort procedure used in this study to establish decision making preferences could easily be adapted for use in the clinical environment. The procedure could be simplified by asking each individual to choose one card from the five available options. Simplifying the procedure in this way would make for more efficient use of the time available. If used with sensitivity by a trained health care professional it could establish how individuals felt about their level of involvement in the decision making process. Individuals who expressed a desire to participate in treatment decision making could be given some form of decisional support by, for example, a nurse who could assess each individual's knowledge base and make an individual assessment of the information needed at that particular point in time to make an informed decision. Individuals could be encouraged to formulate questions about their care and treatment.

This study did not demonstrate that health care professionals could predict decision making preferences based on socio-demographic or disease/treatment variables. It would be unwise for health care professionals to assume that they know who would want to be involved in the decision making process and who would not. For example, assuming that younger people, with a higher level of education and from a higher social class would prefer to be involved in the decision making process at all stages of the disease trajectory was not borne out by the findings of this study.

This study examined a number of socio-demographic and disease/treatment variables as other studies had reported on the possible impact of these variables in predicting decision making preferences (Ende et al 1989, Cassileth et al 1980). Generally, it appeared that, at the time of diagnosis with breast cancer, variables such as age, level of education and social class had very little impact in predicting decision making preferences. Further from diagnosis, when the acute crisis situation had passed, these variables had slightly more of an impact but there is still little evidence to suggest that these variables could successfully be used as predictor variables. These findings support other work that questions the importance of demographic variables in predicting decision making preferences (Degner and Sloan 1992).

However, an investigation of the decision making preferences of women who had further problems with their breasts (including problems with prostheses and reconstruction as well as surgery) did indicate that these women were more likely to want to play a passive role in decision making than women who had no further breast problems. Women who had experienced no further problems with their breasts did not prefer an active role but had preferences which were more evenly distributed between the sharing and passive roles. It may be that a problem free period following initial treatment leaves women feeling less frightened about the breast cancer experience and enables more of these women to want to take a more collaborative role in decision making. This finding only applied to specific breast problems and more in depth work would be needed in this area to establish if there was a link between the number and severity of problems encountered and decision making preferences. A more in-depth analysis of the data may reveal if women who have undergone more extensive treatment were more unlikely to want to make decisions about their treatment .

Examination, in terms of decision making preferences, was made of women who had further breast problems generally, including health problems that were unrelated to breast cancer. In this case there was no difference between the decision making preferences of women who had problems and those who did not, the main preference was for a passive role. This finding lends supports to the notion that preferences for decision making may be specific to a particular health care team. This study involved individuals with one type of cancer attending one consultant's practice. Future work could establish if different types of cancer lead to different decision making preferences. The choices that women with breast cancer are presented with are clear cut in many situations (mastectomy or lumpectomy followed by radiotherapy) with no difference in outcome. With other types of cancer the decisions may be far more complicated with different decisions having different outcomes. Mortality issues may be more of a pressing concern for individuals with other forms of cancer (for example, lung cancer) than for women with a diagnosis of breast cancer.

Overall it seems that, although exerting some influence, socio-demographic variables were not accounting for the main effects of the study. Thus, nurses and other health care professionals should be cautious in stereotyping patients in terms of demographic details. No simple formula appears to exist for identifying women's preferences to participate in treatment decision making. An assessment of each individuals preferences may be the only way of establishing the preferred role of each individual.

Information Profiles

The priority information needs for women in the benign study group were information about the likelihood of cure, information about the spread of disease and information about treatment options. Although the women were able to articulate what they thought would be their priority information needs if they were diagnosed with breast cancer the profile showed some clumping of items indicating that they may have not been clear on what their priorities would be.

The priority information needs for the women in this study at the time of diagnosis were information about the likelihood of cure, information about the spread of breast cancer and information about treatment options. Survival issues were seen as the priority issues and it is interesting to note that, although the majority of women in this study preferred a passive role in treatment decision making, they still wanted information on the treatments available. This further supports the notion that information may be important even if that information is not used to make treatment decisions. The profile showed a clear distinction between each item indicating that these women had a clear idea of their information needs at this point in time.

The profile of information needs further from diagnosis was similar in most respects to that at the newly diagnosed stage. Information about the likelihood of cure remained the highest priority issue. The one statistically significant difference between the profiles at the newly diagnosed and follow up stages concerned the item on family risk. Information about the risk to the family of getting breast cancer had risen up the hierarchy of nine items and now assumed second position.

Women were concerned about their family members and the genetic transmission of breast cancer. When asked if there was any information that they still needed a large number of women commented that they still needed information about family risk. This finding suggests a lack of knowledge about the genetic transmission of breast cancer and a deficit in information giving. Only approximately 5-10% of all breast cancers show evidence of genetic transmission (this figure rises to 20-25% for early onset cases) (Claus, Risch and Thompson, 1991) and yet this item was ranked in second position in the follow up profile. Also, genetic transmission is less likely in post menopausal breast cancer sufferers and yet women over the age of 50 still ranked information about family risk as a priority issue. Concern was almost always expressed for female family members with women who had sons, and no daughters, believing that genetic transmission could not occur through the male line.

In recent years, there has been a heightened awareness of the genetic component of breast cancer through increased media coverage. Public awareness of this genetic susceptibility has increased fears for many women with a family history of breast cancer with the resultant development of specialist clinics to provide advice about the risks and what to do about them. However, despite the availability of this service, women in this study still wanted information about family risk and did not recall being presented with this information by either the hospital or the primary health care team.

There are few studies that investigate the most effective ways of communicating information about the genetic risk connected with breast cancer or how best to communicate the benefits and limitations of genetic testing (Austoker, 1994). How individuals perceive their own risk is a complex area involving personal attitudes and beliefs as well as societal norms and values (Austoker, 1994). The findings of this study support the notion that public knowledge is limited in this area and services may be overwhelmed in the future by individuals demanding genetic testing. This is a complex area and if not handled sensitively could result in confusion for many individuals and a lack of trust in the health services.

The timing of information giving on family risk appears to be an important factor in this study. This item of information was not considered to be a priority item at the newly diagnosed stage. However, further from diagnosis this item had established itself as a priority issue. Many women in this study still wanted information about this item and did not perceive that they had been given this information. It may be that information was given about family risk but that it was given at an inappropriate time or in an inappropriate format.

At the time of diagnosis the women with breast cancer in this study were concerned about survival. Giving information on other issues at this time may not have been appropriate. Information about family risk was required further from diagnosis and, although the women in this study had a contact number for the breast care nurse, they were reluctant to initiate contact for what they thought would be considered a trivial matter. It is arguable that if contact had been initiated by a member of the hospital or the primary health care team the women would have asked about family risk and would have been given information and advice at an appropriate time point. Alternatively, if the women had been presented with information in a written format to read at a later date this may have been appropriate for many individuals.

Apart from the item on family risk no other significant differences were apparent between the information needs profiles at the newly diagnosed and follow up stages. This is an interesting finding, particularly with regard to the item on sexual attractiveness. Even at a mean of 21 months from diagnosis concern about sexual attractiveness did not appear to be a major issue. This may reflect a satisfaction with the service provided by the centre in the study. Breast reconstruction was available at the time of primary surgery. Many women expressed the view that the breast reconstruction was seen as something positive amongst all the negative feelings surrounding the diagnosis of breast cancer and the majority of women who had breast reconstruction were apparently satisfied with the results.

It could be argued that only two time points had been examined in this study and that problems of a sexual nature may have occurred between, or after these two time points, although anecdotal evidence suggests that this was not the case. However, a study carried out in the UK of 135 mastectomy patients found that 25% had negative views about their body image 4 weeks after surgery (Anderson, 1988). These findings are interesting in that there is much in the nursing literature to support nurses considering their patients' sexuality to be of major significance (Gamel, Davis & Hengeveld 1993, Mock 1993, Smith 1989, Webb 1987). The nursing literature suggests that body image and sexuality should be a concern for nurses and other health professionals in terms of providing information. In a review of the literature on providing teaching and/or counselling on sexuality Gamel, Davis and Hengeveld (1993) stated that nurses had an important role to play in providing information on sexuality and that patients' sexual concerns and problems were a focus for nursing care. However, it has been suggested by Webb (1987) that nurses may need more skills and knowledge to impart information on sexuality. Webb stressed the importance of providing information on sexuality if nurses are to provide a holistic approach to patient care but commented on the problems health professionals have in defining sexuality, emphasising that sexuality involved more than a purely sexual relationship but encompassed a range of both physical and psychological aspects.

The findings from the present study suggest that health care professionals need to be responsive to the priority information needs of each woman with breast cancer rather than assuming that sexual attractiveness is a priority issue for all women with breast cancer at all stages of the disease trajectory. Certainly the findings of this study show that information about sexual attractiveness is a low priority at both the newly diagnosed and follow up stages. However, it should be acknowledged that there are differences in definition and meaning between the terms 'sexuality', 'sexual attractiveness' and 'sexual problems' and while sexual attractiveness may not have been a major issue for women in this study, there may have ben other problems concerning sexuality that were not defined within the Information Needs Questionnaire. There is evidence to suggest that the fear of breast cancer is far greater than the fear of losing a breast (Fallowfield et al 1990). This appears to be substantiated by the present study where loss of breast tissue does not appear to have caused any major problems for the majority of the women in the study in terms of sexual attractiveness. That is not to say that sexual attractiveness is not an issue for women with breast cancer. It should be recalled that all nine items of information in the Information Needs Questionnaire were considered to be important in terms of acquiring information. The issue was one of priority with some items of information representing more pressing concerns than others.

It may have been the case that women did not indicate that information on sexual attractiveness was a priority concern because they did not feel it was within the remit of a health care professional to provide that type of information. Sexual attractiveness is a private and personal area and it may not have been information as such that the women needed. It may have been an area of concern but one which they felt was to be resolved within the confines of their own home environment. Also, the women may not have felt comfortable discussing this sensitive area and may have recalled other information exchanges with health care professionals, for example a consultants ward round with a large entourage of medical students, and this may not have been regarded as an environment conducive to receiving information on such a sensitive subject.

It is not clear why information on sexual attractiveness was not considered to be a priority item of information further from diagnosis. At the time of diagnosis it seems likely that the fear of cancer may have been greater than the fear of losing a breast and survival issues were of paramount importance. Further from diagnosis it may be that lower priority needs could not be addressed as primary needs had yet to be met (Maslow 1973) or other confounding variables may have been involved such as the way in which the item on sexual attractiveness was worded in the Information Needs Questionnaire. Future work in this area could concentrate on the meaning of the terms 'sexuality' and 'sexual attractiveness' for women with breast cancer and how they perceive the role of health care professionals in providing information on this area.

It could be suggested that younger women would consider information about sexual attractiveness as more of a priority than older women and while this was the tendency it was not a significant finding. Women under the age of 50 years placed the item on sexual attractiveness in seventh position while women over the age of 50 years placed this item last out of nine items at both the newly diagnosed and follow up stages (Appendix 15a). Age generally did not have an impact on the information needs profiles for any of the study groups.

A number of other socio-demographic and disease related variables were considered in this study to ascertain if they had any impact on information need including level of education, social class, marital status, type of surgery, stage of disease, knowing someone with breast cancer and family history of breast cancer. The impact of these variables was found to be minimal in defining information need and the information needs profiles were not altered significantly by these variables. This has implications for health care professionals who may be in danger of assuming that older people or people with lower levels of education will not want as much information as a younger person with higher levels of education or that people who have had a mastectomy will want different information to people who have had a lumpectomy.

The use of the information needs profile as a clinical reference tool could certainly be considered for women with breast cancer both at diagnosis and further from diagnosis. Although an individual holistic approach to patient care is the one most often espoused, especially by the nursing profession, the reality of the clinical situation does not always allow for unlimited time to be spent in assessing the needs of service users. As a reference guide the information needs profile would focus attention on what the women with breast cancer consider to be the priority information needs rather than what health care professionals assume individuals want to know. Also, it is not always appropriate to ask individuals what they want to know without any guidance or structure to the consultation; people often say they want to know everything. At the time of diagnosis when recall and retention of information may be limited it may not be appropriate to give large quantities of general information. It may be more appropriate to give high quality information about specific items of information that have been identified as priority issues by the individual, and to give further high quality specific information at the times that it is needed.

Decision Making and Information Need

The role that women wanted to play in treatment decision making did not influence the type of information that they needed either for women in the benign comparison group or for women with breast cancer at both the newly diagnosed and follow up stages. Although attention needs to be paid to individuals' information needs the profile suggests that there are common concerns that are not influenced by socio-demographic and treatment variables or decision making preferences.

While not neglecting individual information needs health care professionals should be aware that there may be a common agenda that women with breast cancer adhere to in terms of wanting information. It should not be assumed that women who want to play a more active role in decision making will need different types of information to women who want to defer decision making responsibility to the doctor. Women who wanted a passive role in decision making were able to indicate the types of information they needed and the priority information included information on treatment details despite the fact that this information would not be used to make decisions.

The nurse, particularly the clinical nurse specialist, appears to be in an excellent position to tailor information giving to individual requirements. While information giving in the form of a leaflet can provide useful general information it is static in that it can not be responsive to specific individual requirements. The information needs profile could enable individuals to focus on areas of importance allowing the nurse to explore these specific areas in greater depth and provide the information that individuals need.

Sources of Information

At the time of diagnosis the women in this study felt that most of the information they received came from the hospital breast specialist team, namely the breast specialist consultant, the breast care nurse and the leaflets distributed by the breast care nurse. A majority of the women in this study perceived that they got no information from either the primary health care team or the voluntary sector at this time of diagnosis. Only about a third of the women perceived that they received any useful information from nurses, either in the wards or in the clinics, at this time, with a majority of the women believing that they had received no information whatsoever from nursing staff.

At the follow up stage the women generally had few sources of information and received little information about breast cancer. The sources that were rated as useful at this time were media sources such as women's magazines, radio and television. While some women still got some information from the breast specialist consultant or more junior doctors (41.6%, n=44/105), this was information gained from an out patient appointment which, for many women, was now every three or six months. Most women no longer saw the consultant and felt that the value of the out patient appointment was in terms of getting reassurance rather than gaining information. A majority of women at the follow up stage received no information from the breast care nurse, the primary health care team or the voluntary sector.

Partners, family and friends were seen as supportive and an essential part of the coping process. Few women, however, saw partners, family and friends as sources of information. Many women, who stated that they did have problems, did not discuss them with health care professionals, preferring instead to share their worries with partners, family and friends. Although essential in terms of support, family and friends could not provide the information these women needed and problems and concerns were not resolved.

A majority of women stated that there was still information they needed (65.7%) but few sources of information were utilised by these women and the majority of women perceived that they were receiving no information at the follow up stage. The findings from this part of the study show a deficit in the information giving process. Information giving is focused on the time of diagnosis. Women certainly need information at this time but, as they have expressed, survival issues are the most important issues, and questions with respect to treatment and prognosis may be best answered by the medical team. Further from diagnosis professional sources of information were noticeably absent. Women did not feel comfortable contacting health care professionals about their concerns. The primary health care team were not seen as a source of information either at the newly diagnosed or follow up stages and information from the voluntary sector was also notable for its absence at both the newly diagnosed and follow up stages. It is arguable that women had negative views about the support they would receive from the voluntary sector due to a lack of knowledge about the services available. These findings have implications for many health care professionals who are not fully meeting the information needs of women with breast cancer.

Clinical nurse specialist

The breast care nurse, by necessity of limited time and resources, tends to focus her attentions on the women newly diagnosed with breast cancer. Once women are discharged from the hospital environment there is often limited opportunity to continue providing support and information unless the women themselves initiate contact. Arguably the women in this study, and their comments support this, felt it was inappropriate to contact the breast care nurse unless they had a specific problem. Seeking information was not viewed as justification for initiating contact and the women perceived that their questions would be seen as trivial when there were other women who needed the services of the breast care nurse more urgently.

The information provided by the breast care nurse at the time of diagnosis was perceived as useful by the majority of women in this study, including both verbal and written information. The service provided to women at the time of diagnosis in terms of support and information giving was rated highly by the women. However, further from diagnosis there seems to be a deficit in professional support and information giving with women getting the support they need from partners, family and friends and the information they need from the media. Although many media sources of information are often both interesting and accurate, some of the women in this study felt that there was an emphasis on the negative experiences of women with breast cancer with television programmes often relating the experiences of young mothers with a poor prognosis.

It is not clear how breast care nurses could respond to this information need further from diagnosis if time and resources are limited. It may be that improved communication between the specialist breast care team and the primary health care team may make information more readily available or it may be that attention should be given to providing written information that can be read at a later date when it is needed. Although written information cannot easily be tailored to meet specific individual requirements it can be responsive to common concerns as expressed by the women in this study.

Hospital nurses

Nurses on the hospital wards and in the out patient clinics were not rated highly as useful sources of information. Comments from the women suggested that they felt the nurses were too busy to provide information but that information would be provided if questions were asked. However, anecdotal evidence suggests that few women saw this lack of information from nurses as a source of complaint. It may be that the women saw nurses more as a source of support than as a source of information as found in other studies (Frank-Stromborg & Wright, 1984). Future work in this area could focus more specifically on how individuals perceive the nurses role in providing information.

Nurses were not interviewed in this study but it would be interesting to know if they believed they did provide information to women with breast cancer at both the newly diagnosed and follow up stages. It may be that the information was given at an inappropriate time or in an inappropriate format. For example, the present study shows that at the time of diagnosis the priority information needs relate to information about the likelihood of cure, the spread of disease and treatment options. These are, arguably, medical matters where information of this nature may not be available to the nurse and is more likely to be discussed by the medical team. Information given about other areas, such as the impact of the surgery on sexual attractiveness, may not be retained by the woman who is in a heightened state of anxiety and primarily concerned with survival issues. Further, there is evidence to suggest that, because nurses are not aware of the information needs of their patients, communication is limited and information given is not helpful to the individual (Thorne, 1988). Providing women with written information that can be referred to at an appropriate point in time, and which reflects the true information needs of the women with breast cancer, may go some way to improving communication between nurses and women with breast cancer. Further work in this area could examine the most appropriate format for presenting information to women with breast cancer. Written material may be of limited value if it is likely to be discarded before it serves any benefit.

While providing information on survival issues may not be within the remit of the hospital nurse an increased awareness of the information needs of service users would improve patient care if the nurse acts as advocate for the patient and ensures that information needs are met. Information is empowering and patients may be empowered if they receive the right information at the right time. Nurses can facilitate this information giving process by assessing individual information needs and liaising with the appropriate health care professional who is able to give the necessary information.

Primary health care team

The findings from this study suggest that the primary health care team are not providing information for women with breast cancer. A majority of women did not perceive that they received any information from their GP at either the newly diagnosed or follow up stage. This is a cause for concern because the study has highlighted the importance of giving the right type of information at the appropriate point in time. The primary health care team are well placed to meet the information needs of women with breast cancer further from the time of diagnosis but the current situation suggests that very little information is provided outside the hospital environment and that women have to look to their families for support and the media for information.

It may be that the primary health care team defer responsibility for information to the specialist hospital breast care team, believing that they will be able to meet the information needs of the women in their care. If this is the case then more information should be provided to members of the primary health care team to increase their own knowledge base on issues relating to breast cancer and to highlight the deficits in information giving which occur so that they can play a significant role in improving the service provided to women with breast cancer.

Increasingly, the primary health care team are being targeted as important service providers for people with cancer. Early in 1995 the government accepted plans for a radical reorganisation of cancer services. This involves a three tier service of specialist centres, cancer units and primary care level treatment (Department of Health, 1995). The cancer units would ideally be part of a large general hospital and would be used for the management of the commoner types of cancer such as breast cancer. These units would have close links with the cancer centres who would specialise in dealing with the rarer forms of cancer. A strong emphasis was placed on primary health care teams who would have a close relationship with both the centres and the units. The primary care team were considered a central and continuing element in cancer care for both the patient and his or her family from primary prevention, pre-symptomatic screening, initial diagnosis, through to care and follow up or, in some cases, death and bereavement (Department of Health, 1995). In this respect the primary health care team will need to have a strong knowledge base from which to function and effective communication channels with specialist cancer services if they are to meet the needs of their patients.

Voluntary sector

Only seven women received any useful information about support services available for women with breast cancer at the newly diagnosed stage and only six women received useful information at the follow up stage. Anecdotal evidence from the study suggested that the women perceived membership of a support group or contact with voluntary support services as a negative experience. Many women commented that they wanted to put the breast cancer experience behind them and get on with their lives, and felt that membership of a support group would involve reliving their own painful experiences and listening to others recalling their own stories of "doom and gloom".

It may be that women with breast cancer do not benefit from this sort of service provision or the findings may reflect a lack of knowledge about the services available. The vast majority of women in the study received no information about support groups and had formed their own negative opinions on what they imagined a support group would be like. It may be that providing women with information about support groups at an appropriate time point would enable women to feel more able to benefit from the services available.

Relevance of Findings to Current Policy

A report by the Expert Advisory Group on Cancer to the Chief Medical Officer of England and Wales and entitled 'A Policy Framework for Commissioning Cancer

Services' stated several principles that should govern the provision of cancer care (Department of Health, 1995). It was stated that all patients should have access to a uniformly high quality of care in the community or hospital wherever they may live and as close to the patient's home as is compatible with high quality, safe and effective treatment. In this respect it has been useful to examine decision making preferences and information need in a sample of women who have had access to a specialist service. If specialist services are available to women with breast cancer throughout the UK in the future then the findings of this study are pertinent and relevant to current health care policy.

The importance of providing clear information to patients, families and their carers was stressed as being essential at all stages of treatment and diagnosis onwards (Department of Health, 1995). The report, therefore, acknowledges the importance of paying attention to individual information needs and to appreciating that information needs may not be constant but may change throughout the disease trajectory. In this respect the findings of this study support the policy document.

The report further stated that cancer services should be patient centred and should take account of patients', families' and carers' views and preferences as well as those of professionals involved in cancer care acknowledging that individuals' perceptions of their needs may differ from those of the professional. The findings of the present study indicate that health care professionals can be in danger of making assumptions about the decision making preferences and information needs of service users that may not be borne out by the reality of the situation.

Good communication between professionals and patients was stated by the Department of Health (1995) as being especially important as well as communication between the different sectors. The findings of the present study suggest that nurses may be in an excellent position to increase awareness of service users preferences by assessing individual preferences for participation in decision making and information needs.

Limitations of the Study Design

The women with benign breast disease were not matched with the women with breast cancer in terms of age or level of education and this meant that the benign study group were younger and had a higher level of education. In this respect the benign group were considered to be a comparison rather than a control group. With larger sample sizes study participants could have been matched in terms of demographic variables but this was not within the financial resources available for this study. However, the samples were similar in many other respects such as social class, marital status, family history of breast cancer, knowing someone with breast cancer and ethnic group.

The vast majority of the three study samples were white British. This does not represent the cultural makeup of the geographical location in which the study was carried out which has many different ethnic groups. There was no attempt to limit the study sample by ethnic group as a consecutive sample of women were interviewed for the duration of data collection. Although there are large differences in the mortality rates from breast cancer between individual countries, when individuals migrate from a country with a low incidence to a country with a high incidence (for example from Japan to the UK) then within one or two generations the mortality rate increases to that of the host country (McPherson, Steel and Dixon 1994) indicating that a lower incidence of breast cancer in different ethnic groups is not a plausible explanation for the predominance of white British women in the study sample. Speculation only can be made as to why the study samples were predominantly white British. It may be that different cultural beliefs dispose to different health practices and women with breast problems seek assistance from within their own culture. Women from different ethnic groups may be more reluctant to engage in breast self examination practices or may delay in seeking advice on a breast problem.

The longitudinal design of the present study was effective at demonstrating changes over time and is generally accepted as a more powerful design of study than a cross sectional design (Menard, 1991). However, the inclusion of only two time points may have been a limitation of the study. The time points were separated by almost two years and many changes will likely have occurred in the women's breast cancer experience over that time. Ideally a design that encompassed data collection at time points of diagnosis, 3 months from diagnosis, 6 months, 12 months, 18 months and 2 years would have been preferable but the resources were not available to adopt this particular design. Future work could examine these different points in time to ascertain if any valuable insights into the decision making preferences and information needs of women with breast cancer occur in this interim period.

Data were collected from one consultants practice at the one centre. This meant that the women in this study had the advantages of a breast specialist centre with specialist staff and a local oncology centre. In effect these women may have felt very cosetted and secure by this situation and may have felt more able to trust their consultant acknowledging that they were receiving the best possible treatment. There is an argument to suggest that decision making preferences may have been very different in a hospital where a number of different general surgeons carried out breast surgery and where a breast specialist nurse was not available.

The decision to sample from one consultant's practice aimed to avoid the potential influence of different treatment regimes and interactional style influencing the women in the study. However, the personality and attitude of the one consultant may have influenced decision making preferences. The consultant in this study demonstrated a strong commitment to ensuring that individuals were provided with information and given time to make choices. Anecdotal evidence suggests that the women in this study held a great deal of confidence in the consultant's level of competence and it may be for this reason that 52% of the women in this study preferred to relinquish control over decision making to this authority.

Carrying out interviews in the hospital environment proved to have practical advantages in that all potential study participants were in similar locations within one building. Some disadvantages were evident in competing for access to the study participants with other health care professionals. A concern in terms of the limitations of the study design may have been that women who were in hospital did not want to influence their care and treatment and may have told the researcher what they thought she wanted to hear. All participants were aware that the researcher was a nurse and was working with the co-operation of the breast specialist consultant. Although it was stressed at the outset of every interview that all comments would be treated as confidential and that the comments made would not influence care there is no certain way of knowing how many participants were making comments based on what they thought the researcher wanted to hear.

Limitations of Measurement Tools

The decision making preference card sort provided a simple and easy to administer measure for establishing decision making preferences that appeared to be readily understood. However, the measure only related to treatment decisions and only involved the doctor and the patient in the decision making process. Future work could modify the measure so that other decisions could be included and other potential decision makers could be involved such as nurses and family members.

Although Coombs' unfolding theory provided a valid means of establishing a dimension of decision making preferences that ranged from active through sharing to passive preferences the analysis would be somewhat unwieldy without the appropriate computer software. Also, Coombs' criteria of 50% plus one of the preference orders having to conform to the dominant dimension to support the existence of a unidimensional model means that a lot of valuable data may be lost from the analysis.

While it is useful to have such stringent criteria in terms of validity, sample sizes need to be large to counteract the potential loss of data.

The Information Needs Questionnaire was quick to complete but appeared daunting to participants at the outset as it ran over seven sides of A4 paper. The questionnaire would not be suitable for a postal survey design as it required explanation on how to complete it at various intervals. Participants became confused on occasion when they realised that they were seeing the same items of information repeated and further explanation was needed to encourage participants to complete all the pairs of information needs.

It may have been useful to establish a base line of knowledge about breast cancer before administering the Information Needs Questionnaire. If information need had already been satisfied in some areas then that information may not have been considered important. It may also have been useful to verify in some way if individuals were considering the item of information to be important or whether they were considering the item to be important only in a positive respect. For example, the item regarding cure may have been perceived as 'how important is it to be cured?' rather than 'how important is it to have information about cure?'. Information about cure may have only been considered important information if the information was positive and the chances of cure were high. The measure did not assess the impact of the information in terms of its positive or negative components.

The Thurstone scaling approach was effective in producing a hierarchy of information needs and avoided the ceiling effect that may have arisen with a Likert type scale where individuals often say they want to know everything about everything. However, the analysis was time consuming without the appropriate computer software.

General Limitations

While the measurement tools used in this study were effective in establishing the role that women with breast cancer wanted to play in treatment decision making and the types of information that these women needed, the tools did not enable the researcher to understand why people had the preferences that they did. Time constraints prevented the researcher from making a more in depth analysis of why so many women preferred to play a passive role in decision making and factors such as existing knowledge, the personality of the consultant, attitudes towards cancer and the way in which choices were communicated could not be investigated to any great degree.

Further research could investigate how individuals prefer to get their information and why they feel reluctant to establish contact with health care professionals. If individuals are reluctant to establish contact with health care professionals when they need information it may be useful to evaluate the effectiveness of a named health care professional establishing contact with the individual for the purposes of providing information, for example a member of the primary health care team.

A further limitation of the study is that it did not seek to examine psychological morbidity and did not include, for example, measures of anxiety and depression. Psychological factors may be an important component in the breast cancer experience and these factors may well have had an impact on the ability to process and receive information and on the ability and desire to participate in decision making. Further work in this area could examine the contribution of psychological factors in this context.

CONCLUSIONS

This study makes an important contribution to nursing knowledge in highlighting the importance of assessing individual decision making preferences and information need and being responsive to changes in preferences over time. This study arose as a replication study of work that was being carried out in Canada that focused on decision making preferences and information need in women with breast cancer at the time of diagnosis. This replication and international collaboration has been valuable in terms of sharing knowledge and determining if there are aspects of the breast cancer experience that are important despite cultural differences. However, this study is original in taking a longitudinal approach to examining treatment decision making and information need in a British population of women with breast cancer and moving the focus of the study into the community setting. It has emphasised the importance of assessing individual preferences but has acknowledged the confines of a clinical reality where time and resources are limited. The findings of this study can be applied in the clinical environment by all nurses (caring for people in the hospital or community) to improve the quality of patient care.

The study also highlighted the potential for further work to understand more clearly the reasons service users have the preferences they articulated. In examining the preferences of service users the study indicates that nurses and other health care professionals should examine more closely their role in providing information and presenting choices. Intrinsically nurses focus on individual needs but they may be making assumptions about these needs in terms of decision making preferences and information need.

Health care professionals are encouraged to promote active patient participation in decisions about care and treatment and yet this study has highlighted that there can be a conflict between what health care professionals want for individuals in their care and what those individuals want for themselves. Health care professionals in this context want to encourage active patient participation because they believe, and there is evidence to support, that participation is beneficial to service users. However, service users may not want to participate and active participation may be an alien concept to many individuals.

Advocating active participation for all may be no more appropriate than the traditional medical model of the doctor as decision maker and the patient as passive recipient of care. This is not to say that consumers should be seen as passive recipients of care and should not be involved in any way with the decisions surrounding their care and treatment. The results of this study showed that 52% of women newly diagnosed with breast cancer preferred to defer the decision making responsibility to their hospital consultant. There still remained a large number of individuals who wanted some degree of involvement in the decision making process, although not necessarily being left to make decisions unaided.

While the presentation of treatment options is more within the remit of the medical profession, nurses are in a unique position to assess individual preferences for involvement and in this way act as patient advocate. An appreciation of the empowering nature of information and that information may not necessarily be used to aid decision making would enable nurses to liaise more effectively with patients and other health care professionals to improve the quality of the information that is given to patients and to ensure that the rights of individuals are respected.

The findings from this study indicate that information giving should be an ongoing process and not limited to the initial period of diagnosis but clinical reality often prevents this. Recent government publications emphasise that the primary health care team will have an important role to play in the provision of information (Department of Health 1995). This will call for improved communication between hospitals and primary health care teams. This study highlights that information giving cannot be an ongoing dynamic process if few sources of information are available to women once they have been discharged from hospital. There appears to be a deficit in information giving with information only being provided if it is specifically asked for. Being truly responsive to information need means giving information when it is needed and nurses may need to be more pro-active in initiating contact with women with breast cancer and asking what information is needed as well as reassuring women that their concerns will not be perceived as trivial. While this may indicate that more resources will be needed in the short term (for example, a named nurse initiating contact with a woman with breast cancer following discharge from hospital) it may save on resources in the long term where a simple need for information will have been prevented from developing into an acute psychological problem that will need the skills of a number of different health care professionals.

The findings of this UK study confirm the findings from Canada (Bilodeau 1992, Degner and Sloan 1992) regarding preferences for treatment decision making and information need. This may indicate that there are aspects of the breast cancer experience that cut across culture and are common to all women diagnosed with breast cancer. Similar work is currently being undertaken in Turkey and Sweden and the findings of these studies are awaited with interest.

RECOMMENDATIONS

The following recommendations are based on the findings of this study.

- Treatment decision making preferences should be assessed on an individual basis. Those individuals wishing to defer decisional responsibility to their doctor or nurse should have their wishes respected. Those individuals who want to have some involvement in the decision making process should be offered appropriate decisional support.

- Attention should be paid to the information needs of women with breast cancer at different points in time. Survival issues are important to the majority of women at the time of diagnosis. The information needs profile could be used as a reference guide to focus attention on what the women with breast cancer consider to be their priority information needs.

- The giving of information should be seen as an ongoing process and not limited to the period of diagnosis and treatment. The involvement of the primary health care team in the providing of information at an appropriate time point should be encouraged and information about voluntary support services needs to be provided to prevent the formation of negative opinions founded on a poor knowledge base.

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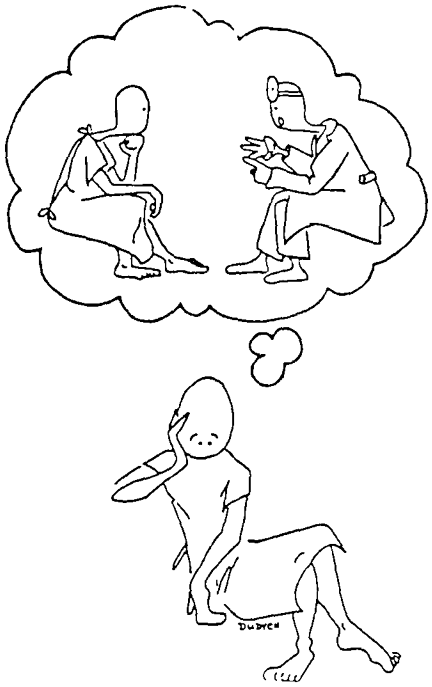
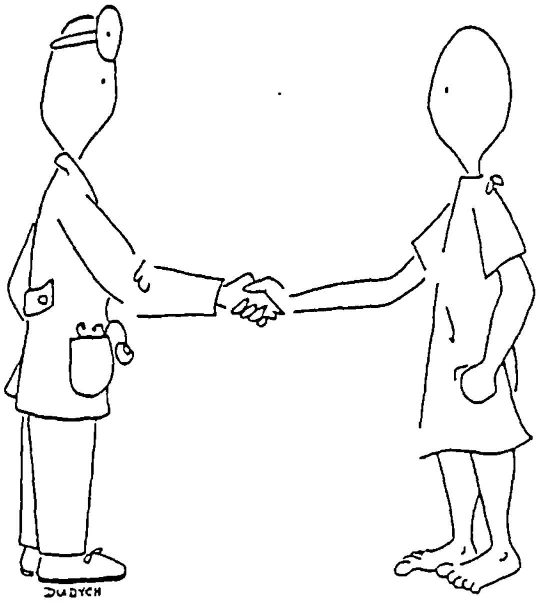
APPENDIX 1: THE FIVE DECISION MAKING CARDS

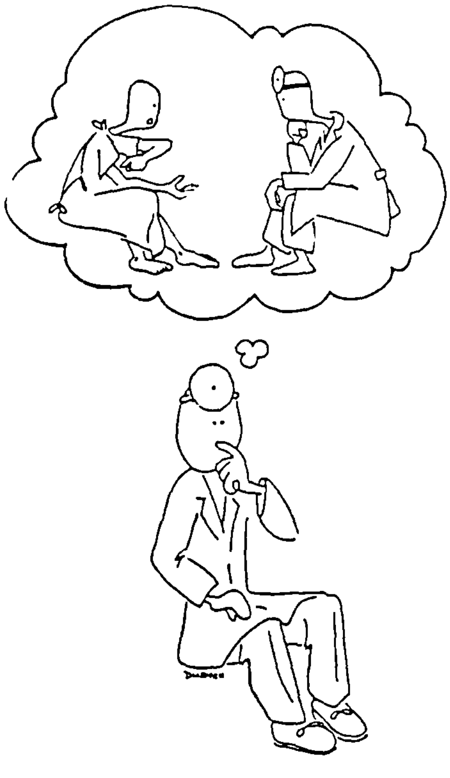
I PREFER TO MAKE THE FINAL SELECTION ABOUT WHICH TREATMENT I WILL RECEIVE.



I PREFER TO MAKE THE FINAL SELECTION OF MY TREATMENT AFTER SERIOUSLY CONSIDERING MY DOCTOR'S OPINION.



I PREFER THAT MY DOCTOR AND I SHARE RESPONSIBILITY FOR DECIDING WHICH TREATMENT IS BEST FOR ME.



I PREFER THAT MY DOCTOR MAKES THE FINAL DECISION ABOUT WHICH TREATMENT WILL BE USED, BUT SERIOUSLY CONSIDERS MY OPINION.

I PREFER TO LEAVE ALL DECISIONS REGARDING MY TREATMENT TO MY DOCTOR.

APPENDIX 2: THE INTERVIEW SCHEDULE FOR THE NEWLY DIAGNOSED AND BENIGN STUDY GROUPS

ID Number: __________
Group: ND Benign

Socio-demographic and Disease/Treatment Information

Date of Interview Day _____ Month _______ Year ______

Where tested/approached:
Inpatient Unit __________
Clinic __________
Other (specify) __________

Age at last birthday __________

Highest Education:
1) No Qualifications __________
2) O levels __________
3) A levels __________
4) Qualifications since age 18 __________
____
____

Marital status:
1) Married __________
2) Common law/co-habiting __________
3) Widowed __________
4) Divorced __________
5) Separated __________
6) Never married __________

Occupation: ______________________________________
Partner's occupation: ______________________________________

Ethnic Group:
1) African __________
2) Arabic __________
3) Black British __________
4) Caribbean
(or Indo-Caribbean) __________
5) Chinese __________
6) Indian __________
7) Irish __________
8) Japanese __________
9) Pakistani __________
10) Somali __________
11) South American __________
12) White British __________
13) White European __________
14) Other __________
(please describe)

Stage of disease: __________

When did the doctor tell her she had breast cancer:
(how long ago in weeks) ________________________

How was your cancer found:
1) You had a breast symptom __________
2) screening programme __________
3) Well woman clinic/GP __________
4) other (specify) __________

How long prior to the date of diagnosis had it been since the woman first mentioned the symptom to a health professional (in weeks)? __________

Who was that health professional?
1) Doctor __________
2) Nurse __________
3) Other (specify) __________

Has any other member of the woman's family had breast cancer?
1) Yes __________
2) No __________

Who was it? ________________

Have you known anyone with breast cancer?
1) Yes __________
2) No __________

If so, who was it? ________________

Date of first treatment: Day _____ Month _____ Year _____

Preference Order __________
Actual Role __________

Information Needs Questionnaire.

From each of the following pairs, circle the one that is more important for you to know **at the present time.**

1. Information about how advanced the disease is and how far it has spread.
2. Information about the likelihood of cure from the disease.

68. ☐

3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, hobbies etc.).
9. Information about possible unpleasant side effects of treatment (for example nausea, pain, change in physical appearance).

69. ☐

4. Information about how my family and close friends may be affected by the disease.
8. Information about whether my children or other members of the family are at risk of getting breast cancer.

70. ☐

5. Information about caring for myself at home (for example, diet, support groups, help at home, social worker, counsellor).
7. Information about different types of treatment (surgical, chemotherapy, radiotherapy) and the advantages and disadvantages of each treatment.

71. ☐

6. Information about how the treatment may affect my feelings about my body and my sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).
1. Information about how far advanced the disease is and how far it has spread.

72 ☐

2\. Information about the likelihood of cure from the disease.
3\. Information about how the treatment may affect my ability to carry on my usual social activities (sports, hobbies etc.). 73.☐

9\. Information about possible unpleasant side effects of treatment (for example nausea, pain, change in physical appearance).
4\. Information about how my family and close friends may be affected by the disease. 74.☐

8\. Information about whether my children or other members of the family are at risk of getting breast cancer.
5\. Information about caring for myself at home (for example, diet, support groups, help at home, social worker, counsellor). 75.☐

7\. Information about different types of treatment (surgical, chemotherapy, radiotherapy) and the advantages and disadvantages of each treatment.
6\. Information about how the treatment may affect my feelings about my body and my sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery). 76.☐

1\.Information about how far advanced the disease is and how far it has spread
3\. Information about how the treatment may affect my ability to carry on my usual social activities (sports, hobbies etc.). 77.☐

4\. Information about how my family and close friends may be affected by the disease.
2\. Information about the likelihood of cure from the disease. 78.☐

5. Information about caring for myself at home (for example, diet, support groups, help at home, social worker, counsellor).
9. Information about possible unpleasant side effects of treatment (for example nausea, pain, change in physical appearance). 79. ☐

6. Information about how the treatment may affect my feelings about my body and my sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).
8. Information about whether my children or other members of the family are at risk of getting breast cancer. 80. ☐

7. Information about different types of treatment (surgical, chemotherapy, radiotherapy) and the advantages and disadvantages of each treatment.
1. Information about how far advanced the disease is and how far it has spread. 81. ☐

3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, hobbies etc.).
4. Information about how my family and close friends may be affected by the disease. 82. ☐

2. Information about the likelihood of cure from the disease.
5. Information about caring for myself at home (for example, diet, support groups, help at home, social worker, counsellor). 83. ☐

9. Information about possible unpleasant side effects of treatment (for example nausea, pain, change in physical appearance).
6. Information about how the treatment may affect my feelings about my body and my sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery). 84. ☐

8. Information about whether my children or other members of the family are at risk of getting breast cancer.

7. Information about different types of treatment (surgical, chemotherapy, radiotherapy) and the advantages and disadvantages of each treatment.

85. ☐

1.Information about how far advanced the disease is and how far it has spread.

4. Information about how my family and close friends may be affected by the disease.

86. ☐

5. Information about caring for myself at home (for example, diet, support groups, help at home, social worker, counsellor).

3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, hobbies etc.).

87. ☐

6. Information about how the treatment may affect my feelings about my body and my sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).

2. Information about the likelihood of cure from the disease.

88. ☐

7. Information about different types of treatment (surgical, chemotherapy, radiotherapy) and the advantages and disadvantages of each treatment.

9. Information about possible unpleasant side effects of treatment (for example nausea, pain, change in physical appearance).

89. ☐

8. Information about whether my children or other members of the family are at risk of getting breast cancer.

1.Information about how far advanced the disease is and how far it has spread.

90. ☐

4. Information about how my family and close friends may be affected by the disease.
5. Information about caring for myself at home (for example, diet, support groups, help at home, social worker, counsellor).

91. ☐

3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, hobbies etc.).
6. Information about how the treatment may affect my feelings about my body and my sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).

92. ☐

2. Information about the likelihood of cure from the disease.
7. Information about different types of treatment (surgical, chemotherapy, radiotherapy) and the advantages and disadvantages of each treatment.

93. ☐

9. Information about possible unpleasant side effects of treatment (for example nausea, pain, change in physical appearance).
8. Information about whether my children or other members of the family are at risk of getting breast cancer.

94. ☐

1. Information about how far advanced the disease is and how far it has spread.
5. Information about caring for myself at home (for example, diet, support groups, help at home, social worker, counsellor).

95. ☐

6. Information about how the treatment may affect my feelings about my body and my sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).
4. Information about how my family and close friends may be affected by the disease.

96. ☐

7. Information about different types of treatment (surgical, chemotherapy, radiotherapy) and the advantages and disadvantages of each treatment.
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, hobbies etc.).

97. ☐

8. Information about whether my children or other members of the family are at risk of getting breast cancer.
2. Information about the likelihood of cure from the disease.

98. ☐

9. Information about possible unpleasant side effects of treatment (for example nausea, pain, change in physical appearance).
1. Information about how far advanced the disease is and how far it has spread.

99. ☐

5. Information about caring for myself at home (for example, diet, support groups, help at home, social worker, counsellor).
6. Information about how the treatment may affect my feelings about my body and my sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).

100 ☐

4. Information about how my family and close friends may be affected by the disease.
7. Information about different types of treatment (surgical, chemotherapy, radiotherapy) and the advantages and disadvantages of each treatment.

101 ☐

3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, hobbies etc.).
8. Information about whether my children or other members of the family are at risk of getting breast cancer.

102. ☐

2. Information about the likelihood of cure from the disease.

9. Information about possible unpleasant side effects of treatment (for example nausea, pain, change in physical appearance).

103. ☐

Are there any other information needs you have **at the present time** ?

____

____

____

104. ☐

APPENDIX 3: THE TUMOUR SIZE-NODE-METASTASIS (TNM) CLASSIFICATION

The staging was based on the Tumour size-Node-Metastasis classification (TNM) (Spiessl et al 1992) as shown in Table 57. This form of staging is generally referred to as clinical rather than pathological staging. However, the information gained from the TNM classification was being used as a reference guide for a second interview with the newly diagnosed group and accurate pathological staging was not considered to be critical to the outcome of the study. The TNM classification was used to categorise each individual into one of the four generally accepted stages for breast cancer (Table 58).

The staging of the histology reports was carried out by regular meetings between the breast specialist consultant and the researcher where each report was scrutinised and individually staged to the satisfaction of the consultant.

Table 57. Tumour Size-Node-Metastasis Classification (TNM)

Tumour size	
T_0	No evidence of discrete tumour.
T_1	<2cm
T_2	2-5cm
T_3	>5cm
Node	
N_0	No regional node metastasis
N_1	Mobile nodes
N_2	Fixed nodes
Metastasis	
M_0	No evidence of distant metastases
M_1	Distant metastases

Adapted from Dixon & Sainsbury (1993).

Table 58. Four Stages Derived from TNM Classification

Stage 1. T_1, N_0, M_0	**Stage II.** T_1, N_1, M_0 T_2, $N_{0\text{-}1}$, M_0
Stage III. Any T, N_2, M_0 T_3, N_1, M_0	**Stage IV.** Any T, Any N, M_1

Adapted from Dixon & Sainsbury (1993).

APPENDIX 4: SAMPLE SIZE ESTIMATION USING THE ARCUS™ STATISTICAL PACKAGE

The ARCUS™ statistical package was used to estimate sample sizes for the newly diagnosed and benign study groups. The calculation was based on information gained from the Degner and Sloan (1992) study which showed that 41% of a sample of 436 newly diagnosed cancer patients wanted to have some involvement in the treatment decision making process. Comparison was made to a sample of individuals from the general public where it was found that 91% of individuals wanted some degree of involvement in the treatment decision making process (active and sharing roles).

In the present study it could be hypothesised that the number of women in the benign comparison group would want a degree of involvement in the decision making process that would fall between the findings for the newly diagnosed cancer patients and householders in the Degner and Sloan (1992) study. In this case it was estimated that approximately 66% of the benign group may want to have some degree of involvement in the decision making process.

In the estimation of sample size the study design was entered as an "unpaired case-control" and the following questions were answered in obtaining the estimation:

Enter a best estimate of the rate at which the characteristic under investigation occurs in your control group. 66%

Estimate the study rate which you wish to distinguish from the population rate. 41%

How confident must you be that you can detect a difference as small as 25%?
95%

How confident must you be that any difference detected has not arisen by chance?
95%

Enter the number of controls you wish to use for each case.
1

Looking for a Study Rate Difference of at Least 25%.

Control group rate	66%
power	95%
confidence level	95%
controls/case	1

For a Two Tailed Study

Uncorrected:	a minimum of 100 cases and 100 controls
With Fleiss correction:	a minimum of 108 cases and 108 controls

APPENDIX 5: LETTERS SENT TO THE FOLLOW UP STUDY GROUP

THE UNIVERSITY
of LIVERPOOL

Professor Karen A Luker
PhD, BNurs, RGN, RHV, NDN Cert.
Director

Research and Development
Unit
Department of Nursing

Faculty of Medicine

The Whelan Building
Liverpool L69 3BX

Telephone: 0151 794 5906
Facsimile: 0151 794 5678
Email: lukerka@liv.ac.uk

7th June 1994

Dear Ms -----------

I am a research nurse working with Professor -------- at the Royal Liverpool Hospital. You may remember that I spoke to you in May 1992 when you were a patient on ward ----.

You were very kind in helping with our work at that time and we wondered if you could spare the time to speak to me again. I would take up about an hour of your time. I would like to ask you very similar questions to what I asked you previously to see what has been happening to you since we last met and to see if you have been satisfied with your care and treatment. Your opinions would be very valuable to us and would be treated as confidential.

I could come and visit you at home on any day and at any time that is convenient for you. I would really appreciate it if you could get in touch with me on (051) 794 5677. If there is no reply on this number please ring (051) 794 2316 and leave a message. You could write to me if you prefer at the Department of Nursing, The Whelan Building. PO Box 147, University of Liverpool, Liverpool L69 3BX. If you enclose your phone number I could call you back.

I will gladly reimburse you for any money you spend on postage or telephone calls.

I look forward to hearing from you.

Yours sincerely

Ms Kinta Beaver
(Research Nurse)

University switchboard
Telephone: 0151 794 2000
Facsimile: 0151 708 6502

THE UNIVERSITY
of LIVERPOOL

Professor Karen A Luker
PhD, BNurs, RGN, RHV, NDN Cert.
Director

Research and Development
Unit
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Liverpool L69 3BX

Telephone: 0151 794 5906
Facsimile: 0151 794 5678
Email: lukerka@liv.ac.uk

27th June 1994

Dear Ms --------

You may remember that I wrote to you a while ago asking if you would mind if I asked you some questions about your care and treatment while you were a patient of Professor --------. I am so sorry to bother you again but some of the women I have spoken to had difficulty in reaching me on the numbers I gave.

If you have tried to contact me unsuccessfully I do apologise (I can be reached on 051 794 5677 or 051 794 5916 to leave a message).

If you have the time I would appreciate it if you could fill in the enclosed slip of paper and return it to me in the envelope provided. That way I will know if you do not wish to be contacted in which case I apologise for troubling you.

Thank you.

Yours sincerely

Ms Kinta Beaver
(Research Nurse)

University switchboard
Telephone: 0151 794 2000
Facsimile: 0151 708 6502

To: K.Beaver

Please tick the appropriatc box.

☐ I do NOT wish to be contacted again.

☐ I have tried to contact you unsuccessfully.

If you have tried to contact me please try again on 051 794 5677 or 051 794 5916 (to leave a message).

If you are on the telephone please let me know your number and I will contact you directly.

Telephone number ----------

From: -------------------------

THE UNIVERSITY
of LIVERPOOL

Professor Karen A Luker
PhD, BNurs, RGN, RHV, NDN Cert.
Director

Research and Development
Unit
Department of Nursing

Faculty of Medicine

The Whelan Building
Liverpool L69 3BX

Telephone: 0151 794 5906
Facsimile: 0151 794 5678
Email: lukerka@liv.ac.uk

18th July 1994

Dear Ms ----------

Thank you very much for helping with our research yet again. Your opinions are very important to us and we really appreciate your contribution to our work. I have enclosed a short letter explaining our study in case you are asked about it in the future.

Thank you again.

Yours sincerely

Kinta Beaver
(Research Nurse)

University switchboard
Telephone: 0151 794 2000
Facsimile: 0151 708 6502

Treatment decision making and information need.

You have been taking part in a study that examines how involved women with breast cancer would like to be in making decisions about their treatment. We have also been investigating the different types of information that are important.

We found that most of the women interviewed did not want to make decisions about their treatment and would feel happier leaving the decision making to their hospital consultant. However, this would obviously not suit all women and we think it is important to ask each individual patient what their preference is.

We also found that the information that was important to women when they were first diagnosed with breast cancer was information about the spread of the disease, cure, and different types of treatment.

We are now repeating our interviews to see what has changed over time and to see what different types of information are important at this later date.

We are also interested to know how satisfied you have been with your care and treatment. We hope that our work will be of benefit to women diagnosed with breast cancer in the future and we thank you for your contributions to our work which we consider to be extremely valuable.

All the answers you gave to the questions will be treated with complete confidentiality. The only person who is aware of your identity is the research nurse who carried out your interview. No other member of the project team has access to that information.

Thank you.

Yours sincerely

Kinta Beaver.

APPENDIX 6: THE INTERVIEW SCHEDULE FOR THE FOLLOW UP STUDY GROUP[6]

---

[6] The Information Needs Questionnaire (INQ) is not included in the interview schedule for the follow up group to avoid repetition. Please refer to Appendix 2 for INQ.

1.ID Number____________________

1. ☐☐☐☐☐

Interview Schedule.

All questions in boxes may be completed prior to or following interview by the interviewer.

A. Socio-Demographic Information.

2. Date of 1st interview. ☐☐☐☐☐☐ 2. ☐☐☐☐☐☐

3. Date of 2nd interview. ☐☐☐☐☐☐ 3. ☐☐☐☐☐☐

4. Time from diagnosis. ☐☐ months. 4. ☐☐

5. Age at 2nd interview. ☐☐ years. 5. ☐☐

6. Education: no qualifications. ☐
school leaving exams ☐
higher qualifications ☐ 6. ☐

7. Marital status (please tick appropriate box).

i. Married ☐
ii. Common law / co-habiting ☐
iii. Divorced ☐
iv. Widowed ☐
v. Separated ☐
vi. Never married ☐ 7. ☐

8. Do you have any children ?

YES ☐ NO ☐

8. ☐

If no, please go to question 13.

9. How many children do you have ? ☐☐

10. How many female children do you have? ☐☐

11. How many male children do you have ? ☐☐

9. ☐☐
10. ☐☐
11. ☐☐

12. Do you have any children of school age or younger?

YES ☐ NO ☐

12. ☐

13. Are you currently employed ?

YES ☐ NO ☐

13. ☐

13a. What is your current or most previous occupation ?

____

13b.What is your partner's occupation ?

____

(if you have no partner at the present time please go to question 16)

14. SEG (socioeconomic group) ☐☐.☐ 14 ☐☐.☐

15. SC (social class) ☐ 15. ☐

16. Ethnic group (please tick appropriate box)

i. White British ☐
ii. Other (please state) ☐

____

16. ☐

17. Do you have a relative/relatives with breast cancer ?

YES ☐ NO ☐

17. ☐

18. If yes, how many relatives ? ☐☐

18. ☐☐

19. If you answered yes to question 17 could you please say from which of the following groups that relative belongs (if you have more than one relative with breast cancer please answer this question based on the **closest relative** to you).

i. Same generation as yourself ☐
ii. Older generation ☐
iii. Younger generation ☐

19. ☐

20. Have you known anyone with breast cancer ?

YES ☐ NO ☐

20. ☐

21. Who have you known with breast cancer ? (please tick appropriate box or boxes).

i. Family member (blood relative)	☐	21. ☐
ii. Family member (non blood relative)	☐	22. ☐
iii. Friend	☐	23. ☐
iv. colleague	☐	24. ☐
v. patient/client	☐	25. ☐
vi. acquaintance	☐	26. ☐

B. Treatment.

1. What type of surgery did you have ? (please tick appropriate box).

a. Mastectomy ☐
b. Lumpectomy/local excision ☐
c. Wire guided/biopsy ☐
d. None ☐

27.☐

2. How much of that decision was: (please tick)

a. Your choice ☐
b. Your doctor's choice ☐
c. Someone other than yourself or the doctor
(please say who that person was) ☐

____

d. undecided ☐

28. ☐

3. How was this decision arrived at ?

____

____

____

____

29.☐☐

4. Did you have any of the following after your surgery ?

a. wound infection	☐	30. ☐
b. prolonged pain	☐	31. ☐
c. swollen arm	☐	32. ☐
d. other (please state)	☐	33. ☐

____

5. Did you have reconstructive surgery ?

YES ☐ NO ☐ 34. ☐

If no, please got to question 8.

6. When was this performed ?

_______________________________ 35. ☐

7. Looking back, are you glad you had the reconstruction ?

YES ☐ NO ☐ 36. ☐

8. What other kinds of treatment did you have ?

a. Radiotherapy	☐	37. ☐
b. Chemotherapy	☐	38. ☐
c. Hormonal eg Tamoxifen	☐	39. ☐
d. None	☐	40. ☐

9. If you had radiotherapy did you have any side effects ?

YES ☐　　　NO ☐

41. ☐

10. If yes, please describe the side effects and their duration.

____

____

____

42. ☐☐
43. ☐☐

11. If you had chemotherapy, did you have any side effects ?

YES ☐　　　NO ☐

44. ☐

12. If yes, please describe the side effects and their duration.

____

____

____

45. ☐☐
46. ☐☐

13. Have you had any other problems with your breasts ?

YES ☐　　　NO ☐

47. ☐

14. If yes, could you please say what sort of problems you had.

____

____

____

48. ☐☐

15. Have you had any other problems at all ?

YES ☐ NO ☐

49. ☐

16. If yes, could you please say a little more about these problems.

____

____

____

50. ☐☐

C. Decision Making Preferences.

1. Previous preference order. ☐☐☐☐☐ 51. ☐☐☐☐☐
2. Current preference order. ☐☐☐☐☐ 52. ☐☐☐☐☐

3.Based on the subject's first choice of card place a circle around the previous and current response.

3a. Previous A B C D E 53. ☐

3b. Current A B C D E 54. ☐

4. Based on subject's first choice of card please state if current preference order is:

Same as previous ☐

More active ☐

More passive ☐ 55. ☐

5. Please choose the one card that best describes what actually happened to you.

A	B	C	D	E
☐	☐	☐	☐	☐

56. ☐

6. Previous perception of actual role. ☐

7. Did you make any decisions concerning your treatment ?

YES ☐ NO ☐

8. If yes, what decisions did you make ?

If No, please go to question 11.

____

____

____

9. Looking back would you have made the same decision again ?

YES ☐ NO ☐

10. If no, what decision would you have made and why ?

____

____

____

57. ☐

58. ☐

59. ☐☐

60. ☐

61. ☐☐

11. Are you having any medical treatment at the present time ?

YES ☐ NO ☐

62. ☐

12. If yes, could you please say what that treatment is ?

If no, please go to question 15.

____

____

____

63. ☐☐

13. Which doctor is providing that treatment ?

____

64. ☐

14. Who is making the decisions about your current treatment ?

____

65. ☐

15. Are you on any medications at the present time ?

YES ☐ NO ☐

66. ☐

16. If yes, please list medications.

____

____

____

____

____

67. ☐☐

D. Information Needs.

Information Needs Questionnaire (see Appendix 2)

1. Please refer to the list of nine information needs (see separate sheet) and tick the number below that corresponds to the **one** that you think is most important to you **at the present time**.

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
☐	☐	☐	☐	☐	☐	☐	☐	☐	105.☐

2. Do you have enough information on the item you have picked in question 1 ?

YES	NO	
☐	☐	106.☐

3. Some women reported problems with sexual activity. Has this been a problem for you ?

YES	NO	
☐	☐	107.☐

4. If yes, could you say what those problems are ?

____

____

____ 108.☐☐

5. Do you have any other problems or worries ?

YES ☐ NO ☐

109. ☐

6. If yes, could you say what those problems or worries are ?
If no, please go to section E.

____

____

____

110. ☐☐

7. Is there someone that you can share these problems with ?

YES ☐ NO ☐

111. ☐

8. If yes, who is that person ?

____

112. ☐

9. Have you discussed these problems with a health care professional (eg. doctor, nurse) or support group?

YES ☐ NO ☐

113. ☐

10. If yes, please say who that professional or group was.

____

114. ☐

E. Impact on family and friends.

1. How do you feel your partner has coped ?
(please ignore this question if you have no partner at the present time).

117. ☐

2. What has been the reaction of family and friends ?

118. ☐

F. Sources of Information.

1 .Please look at the list below and rate the sources of information that were most useful **at the time of your diagnosis.** Please indicate on a scale of one to five how useful you found each of the sources listed below.

1. Very useful.
2. Useful
3. Neither useful /not useful
4. Not useful
5. Useless

Please circle the word ‘None’ if you did not receive any information from this source.

For example, although you may have read a lot of magazine articles on breast cancer they may not have been particularly useful **to you** so you may wish to record that source of information as 4 (not useful). On the other hand you may have found that information useful in which case you would give a score of 2.

Women’s magazines	1.	2.	3.	4.	5.	None.	119.	☐
Friends/relatives	1.	2.	3.	4.	5.	None.	120.	☐
General Practitioner (GP)	1.	2.	3.	4.	5.	None.	121.	☐
Hospital Consultant	1.	2.	3.	4.	5.	None.	122.	☐
Medical journal/book	1.	2.	3.	4.	5.	None.	123.	☐
TV/radio	1.	2.	3.	4.	5.	None.	124.	☐
Newspaper	1.	2.	3.	4.	5.	None.	125.	☐
Leaflets	1.	2.	3.	4.	5.	None.	126.	☐
Nurses on wards/clinics	1.	2.	3.	4.	5.	None.	127.	☐
Breast care nurse	1.	2.	3.	4.	5.	None.	128.	☐
Support groups/volunteers	1.	2.	3.	4.	5.	None.	129.	☐

2 .Please look at the list below and rate the sources of information that are most useful **at the present time.** Please indicate on a scale of one to five how useful you found each of the sources listed below.

1. Very useful.
2. Useful
3. Neither useful / not useful
4. Not useful
5. Useless

Please circle the word 'None' if you did not receive any information from this source.

Women's magazines	1.	2.	3.	4.	5.	None.	130. ☐
Friends/relatives	1.	2.	3.	4.	5.	None.	131. ☐
General Practitioner (GP)	1.	2.	3.	4.	5.	None.	132. ☐
Hospital Consultant	1.	2.	3.	4.	5.	None.	133. ☐
Medical journal/book	1.	2.	3.	4.	5.	None.	134. ☐
TV/radio	1.	2.	3.	4.	5.	None.	135. ☐
Newspaper	1.	2.	3.	4.	5.	None.	136. ☐
Leaflets	1.	2.	3.	4.	5.	None.	137. ☐
Nurses on wards/clinics	1.	2.	3.	4.	5.	None.	138. ☐
Breast care nurse	1.	2.	3.	4.	5.	None.	139. ☐
Support groups/volunteers	1.	2.	3.	4.	5.	None.	140. ☐

3. How satisfied were you with the information you received from the following people? Please rate your answer on a scale of one to five.

1. Very satisfied
2. Satisfied
3. Neither satisfied or unsatisfied
4. Unsatisfied
5. Very unsatisfied

Your Hospital Consultant	1.	2.	3.	4.	5.	141. ☐
Other doctors	1.	2.	3.	4.	5.	142. ☐
Breast care nurse	1.	2.	3.	4.	5.	143. ☐
Nurses on wards	1.	2.	3.	4.	5.	144. ☐
Nurses in clinics	1.	2.	3.	4.	5.	145. ☐

4. What information do you still need?

____

____

146. ☐☐

5. Do you have any other comments on your satisfaction with the care you received?

____

____

147. ☐☐

APPENDIX 7: AN EXAMPLE OF THE FREQUENCY, PROPORTIONS AND UNIT DEVIATE MATRICES

To carry out the Thurstone scaling procedure a frequency matrix is first produced that reflects the number of times that each item is preferred to every other item (Matrix 1). In Matrix 1 the numbers 1 to 9 represent the nine information needs. From this frequency matrix a proportions matrix is produced that reflects the percentage of times that each item is preferred over every other item (Matrix 2). A unit deviate matrix is then produced where each percentage value is converted to a z score (Matrix 3). Finally, the scale value for each item is derived by summing the z scores for each item of information and taking a mean value for each item (Table 59).

Matrix 1. The frequency matrix for the follow up group (n=105)

	1	2	3	4	5	6	7	8	9
1	.	78	30	36	19	34	42	66	33
2	27	.	13	21	14	13	23	52	22
3	75	92	.	72	48	44	72	81	77
4	69	84	33	.	38	28	67	89	60
5	86	91	57	67	.	40	68	90	72
6	71	92	61	77	65	.	81	86	73
7	63	82	33	38	37	24	.	68	46
8	39	53	24	16	15	19	37	.	31
9	72	83	28	45	33	32	59	74	.

Matrix 2. The proportions matrix for the follow up group (n=105).

	1	2	3	4	5	6	7	8	9
1	.	74.3	28.6	34.3	18.1	32.4	40.0	62.9	31.4
2	25.7	.	12.4	20.0	13.3	12.4	21.9	49.5	21.0
3	71.4	87.6	.	68.6	45.7	41.9	68.6	77.1	73.3
4	65.7	80.0	31.4	.	36.2	26.7	63.8	84 8	57.1
5	81.9	86.7	54.3	63.8	.	38.1	64.8	85.7	68.6
6	67.6	87.6	58.1	73.3	61.9	.	77.1	81.9	69.5
7	60.0	78.1	31.4	36.2	35.2	22.9	.	64.8	43.8
8	37.1	50.5	22.9	15.2	14.3	18.1	35.2	.	29.5
9	68.6	79.0	26.7	42.9	31.4	30.5	56.2	70.5	.

Matrix 3. The unit deviate matrix for the follow up group (n=105).

	1	2	3	4	5	6	7	8	9
1	0.00	0.63	-0.55	-0.39	-0.91	-0.46	-0.26	0.34	-0.49
2	-0.63	0.00	-1.12	-0.85	-1.07	-1.12	-0.78	-0.01	-0.81
3	0.55	1.12	0.00	0.46	-0.12	-0.21	0.48	0.74	0.60
4	0.39	0.85	-0.46	0.00	-0.35	-0.62	0.35	1.00	0.16
5	0.91	1.07	0.12	0.35	0.00	-0.30	0.36	1.03	0.46
6	0.46	1.12	0.21	0.62	0.30	0.00	0.75	0.92	0.52
7	0.26	0.78	-0.48	-0.35	-0.36	-0.75	0.00	0.36	-0.14
8	-0.34	0.01	-0.74	-1.0	-1.03	-0.92	-0.36	0.00	-0.54
9	0.49	0.81	-0.60	-0.16	-0.46	-0.52	0.14	0.54	0.00

Table 59. Producing Scale Values for the Follow Up Group (n=105)

Item	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
Sum	2.09	6.39	-3.62	-1.32	-4.00	-4.90	0.68	4.92	-0.24
Scale value	0.23	0.71	-0.40	-0.15	-0.44	-0.54	0.08	0.55	-0.03

A profile of information needs can then be constructed from the scale values to reflect the position in the hierarchy of each item of information. For the follow up group this profile would be as follows:

Scale Value	Item of information	
0.71	Disease Cure	(Item 1)
0.55	Family Risk	(Item 8)
0.23	Disease Spread	(Item 1)
0.08	Treatment	(Item 7)
-0.03	Side Effects	(Item 9)
-0.15	Family Impact	(Item 4)
-0.40	Social Life	(Item 3)
-0.44	Self Care	(Item 5)
-0.54	Sexuality	(Item 6)

APPENDIX 8: SELECTION BIAS

Forty five women in the newly diagnosed group had not been included in Stage 2 of the study. To investigate if any selection bias may have arisen this sample of women were compared to the 105 women in the follow up group to determine if there were any differences in terms of age, level of education, social class, marital status, having a relative with breast cancer, knowing someone with breast cancer, type of surgery and stage of disease. The analysis of these variables using the Chi-square test for independent samples.

Tables for each of these variables and subsequent results for the Chi-square analysis associated with each variable are shown below.

Table 60. A Comparison of Age Distributions in Women Included and Not Included in the Follow Up Sample

Age	Excluded (n=45)	Follow up (n=105)
<50 years	31.1% (n=14)	24.8% (n=26)
≥50 years	68.9% (n=31)	75.2% (n=79)

$\chi^2=0.65$, df=1, p=0.42

Table 61. A Comparison of Level of Education in Women Included and Not Included in the Follow Up Sample

Education	**Excluded (n=45)**	**Follow up (n=105)**
No qualifications	73.3% (n=33)	64.8% (n=68)
Qualifications	26.7% (n=12)	35.2% (n=37)

$\chi^2=1.05$, df=1,p=0.31

Table 62. A Comparison of Social Classes for Women Included and Not Included in the Follow Up Sample

Social class	Excluded (n=45)	Follow up (n=105)
I &II	57.8% (n=26)	32.4% (n=34)
III	31.1% (n=14)	50.5% (n=53)
IV & V	0.0% (n=0)	17.1% (n=18)
Missing values	11.1% (n=5)	0.0% (n=0)

$\chi^2=15.81$, df=2,p=<0.01

Table 63. A Comparison of Marital Status for Women Included and Not Included in the Follow Up Sample

Marital Status	**Excluded (n=45)**	**Follow up (n=105)**
Partner	64.4% (n=29)	65.7% (n=69)
No partner	33.3% (n=15)	34.3% (n=36)
Missing values	2.2% (n=1)	0.0% (n=0)

χ^2=0.001, df=1,p=0.98

Table 64. Comparisons for Having Family Members with Breast Cancer for Women Included and Not Included in the Follow Up Sample

Relative with breast cancer	**Excluded (n=45)**	**Follow up (n=105)**
Yes	22.2% (n=10)	21.9% (n=23)
No	77.8% (n=35)	78.1% (n=82)

χ^2=0.02, df=1,p=0.97

Table 65. Comparisons for Knowing Someone with Breast Cancer for Women Included and Not Included in the Follow Up Sample

Know someone with breast cancer	**Excluded (n=45)**	**Follow up (n=105)**
Yes	64.4% (n=29)	77.1% (n=81)
No	35.6% (n=16)	22.9% (n=24)

χ^2=2.60, df=1,p=0.11

Table 66. A Comparison of Type of Surgery for Women Included and Not Included in the Follow Up Sample

Type of surgery	**Excluded (n=45)**	**Follow up (n=105)**
Mastectomy	35.5% (n=16)	31.4% (n=33)
Lumpectomy	62.2% (n=28)	65.7% (n=69)
Other	2.2% (n=1)	2.9% (n=3)

$\chi^2=0.22$, df=1,p=0.64

nb. The category 'other' was not included in the chi-square analysis

Table 67. A Comparison of Stage of Disease for Women Included and Not Included in the Follow Up Sample

Stage of disease	**Excluded (n=45)**	**Follow up (n=105)**
Stage I	62.2% (n=28)	66.7% (n=70)
Stage II	31.1% (n=14)	30.5% (n=33)
Other	6.7% (n=3)	2.9% (n=2)

$\chi^2=0.05$, df=1,p=0.82

nb. The category 'other' was not included in the chi-square analysis.

APPENDIX 9: THE REPORTING OF TOTAL DISTRIBUTIONS

For the women who were not consistent with the dominant ABCDE dimension, a categorical value was given to their preference orders depending on their first choice of card in the order. The distribution of preference orders for women were consistent with the ABCDE dimension were then compared to the distribution of preferences for the total sample, that is all preferences regardless of whether they were consistent with the dominant ABCDE dimension or not. Chi-Square analysis revealed no significant differences for the benign group ($\chi^2=1.67$, df=2, p=0.43), the newly diagnosed group ($\chi^2=0.47$, df=2, p=0.79) or the follow up group ($\chi^2=0.89$, df=2, p=0.64) (Tables 68, 69 and 70).

As the results for those women who were consistent with the dominant ABCDE dimension were very similar to the results for the total sample the distributions for the total sample were reported in the study.

Table 68. Reporting of Total Samples for the Benign Group

	ACTIVE	SHARE	PASSIVE
Consistent with ABCDE metric (n=98)	28.6% (n=28)	46.9% (n=49)	24.5% (n=25)
Total sample (n=200)	23.5% (n=47)	45.5% (n=91)	31.0% (n=62)

Table 69. Reporting of Total Samples for the Newly Diagnosed Group

	ACTIVE	SHARE	PASSIVE
Consistent with ABCDE metric (n=87)	18.4% (n=16)	32.2% (n=28)	49.4% (n=43)
Total sample (n=150)	20.0% (n=30)	28.0% (n=42)	52.0% (n=78)

Table 70. Reporting of Total Samples for the Follow Up Group

	ACTIVE	SHARE	PASSIVE
Consistent with ABCDE metric (n=73)	10.8% (n=8)	43.2% (n=32)	44.6% (n=33)
Total sample (n=105)	9.5% (n=10)	38.1% (n=40)	52.4% (n=55)

APPENDIX 10: FURTHER BREAST PROBLEMS

A number of women reported further problems with their breasts following initial treatment (n=46). The definition of "further breast problems" was left to each woman's perception of her condition. Following the transcribing of the women's comments related to these problems a number of categories were devised to included the descriptions of breast problems. These categories and the number of women in each category are shown in Table 71. Two women had more than one further problem and this is reflected in the total number of further problems.

Table 71. Further Breast Problems

Problem	**Frequency**
Further surgery for incomplete excision	12
Pain	11
Recurence of breast cancer	7
Problems with reconstruction	7
Problems with wound	5
Benign breast lumps	4
Problems with prosthesis	2
Total	48

APPENDIX 11: CHANGE IN DECISION MAKING PREFERENCE OVER TIME

The summary below shows how decision making preference changed between the newly diagnosed and follow up stages.

FIRST CHOICE OF CARD AT THE NEWLY DIAGNOSED STAGE:A
CURRENT PREFERENCE:
A: 1
B: 1
C: 2
D: 3
E: 1

FIRST CHOICE OF CARD AT THE NEWLY DIAGNOSED STAGE:B
CURRENT PREFERENCE:
A: 0
B: 3
C: 5
D: 4
E: 0

FIRST CHOICE OF CARD AT THE NEWLY DIAGNOSED STAGE:C
CURRENT PREFERENCE:
A: 1
B: 1
C: 19
D: 6
E: 4

FIRST CHOICE OF CARD AT THE NEWLY DIAGNOSED STAGE:D
CURRENT PREFERENCE:
A: 0
B: 2
C: 12
D: 16
E: 6

FIRST CHOICE OF CARD AT THE NEWLY DIAGNOSED STAGE:E
CURRENT PREFERENCE:
A: 0
B: 1
C: 2
D: 4
E: 11

Sixty four women (61%) did not change their role preference from the newly diagnosed to the follow up stages. For example, a change from D to E or A to B does not represent a change in role, although a change from A to C would represent a change from an active to a sharing role. Tables 72, 73 and 74 give information on the number of individuals who changed role between the newly diagnosed and follow up stages as well as information on the previous and current roles and the number of places moved in the scale. For example, a change in preference from C to E would involve a move of two places along the scale.

Table 72. Move to an Active Role (n=5)

Shift from:	**Shift to:**	**Number of individuals**	**Number of places**
C	A	1	2
C	B	1	1
D	B	2	2
E	B	1	3

Table 73. Move to a Sharing Role (n=19)

Shift from:	**Shift to:**	**Number of individuals**	**Number of places**
A	C	2	2
B	C	5	1
D	C	10	1
E	C	2	2

Table 74. Move to a Passive Role (n=17)

Shift from:	Shift to:	Number of individuals	Number of places
A	D	3	3
A	E	1	4
B	D	4	2
C	D	5	1
C	E	4	2

APPENDIX 12: POST DECISIONAL REGRET AND DECISION MAKING PREFERENCES IN THE FOLLOW UP GROUP

Out of the total sample of 105 women, seven women had regrets over the decisions that they had made or decisions that they felt the doctor had made for them. When the decision making preference orders of these seven women were examined it was found that four women now preferred a more passive role in decision making than previously, two had remained the same and only one woman now preferred a more active role. The specific regrets expressed by these women are listed below. The decision making preference order at the newly diagnosed and follow up stages respectively are expressed below each case.

Case 1. A 71 year old woman with regrets about reconstructive surgery.
This woman felt that she had been influenced by another patient who was having this treatment. She felt that she had not fully understood the procedure and if she had realised that it would have taken weeks to inflate the expander and that another operation was inevitable then she would not have decided against the reconstruction. She also commented that she felt she was too old to undertake this treatment.
(From EDCBA to ECDBA): retained a preference for a passive role.

Case 2. A 58 year old woman with regrets about the decision to have a lumpectomy. This woman had a lumpectomy carried out, followed by a mastectomy for incomplete excision of the breast cancer. Regret was expressed at having to have two operations and she stated that if she had known she was going to need further surgery then she would have had a mastectomy in the first instance.

(From BCAED to CBADE): from an active to a sharing role.

Case 3. A 51 year old woman with regrets about the surgery performed. This woman perceived that she was not given a choice over treatment and a lumpectomy was carried out. Although no further problems had developed this woman would have preferred to have had a mastectomy carried out rather than a lumpectomy.

(From ABCDE to DCBAE): from an active to a passive role.

Case 4. A 62 year old woman who chose to have a lumpectomy rather than a mastectomy. She now says that she wishes she had been given more information because she would have preferred a mastectomy to have been carried out. A recurrence of the breast cancer had occurred in a lymph node in the neck.

(From CDBEA to DCBAE): from a sharing to a passive role.

Case 5. A 53 year old woman who perceived that the doctor decided on her treatment. A lumpectomy had been carried out followed by a mastectomy for incomplete excision of the breast cancer. She says she would have preferred to have had a mastectomy carried out in the first instance.

(From CDEBA to EDCBA): from a sharing to a passive role.

Case 6. A 36 year old woman who perceived that her doctor had decided on her treatment. A lumpectomy had been carried out followed by a mastectomy with reconstruction for incomplete excision of the breast cancer. This woman states that she would have preferred to have had both breasts removed and no reconstructive surgery performed.

(From CBADE to ABCDE): from a sharing to an active role.

Case 7. A 50 year old woman who has regrets over her decision to have reconstructive surgery. Problems had ensued with the reconstruction in matching the reconstructed breast to the real breast.

(From CBADE to CBADE): retained a preference for a sharing role.

APPENDIX 13: DIFFERENCES BETWEEN THE INFORMATION NEEDS PROFILES

Table 75. T-test for Differences Between the Profiles of the Benign (n=200) and Newly Diagnosed (n=150) Groups

Item of information	t	p
Disease spread	-0.03	0.98
Disease cure	-0.42	0.68
Social life	-0.92	0.37
Effect on family	-0.58	0.57
Self care	0.15	0.88
Sexual attractiveness	0.94	0.36
Treatment options	0.91	0.38
Risk to family	-0.50	0.62
Side effects	0.20	0.84

Table 76. T-tests for Differences Between the Profiles of the Newly Diagnosed (n=105) and Follow Up (n=105) Groups

Item of information	t	p
Disease spread	1.61	0.13
Disease cure	0.66	0.52
Social life	-0.53	0.60
Effect on family	-0.53	0.60
Self care	0.03	0.98
Sexual attractiveness	-0.64	0.53
Treatment options	1.08	0.30
Risk to family	-2.36	**0.03**
Side effects	0.06	0.95

APPENDIX 14: THE NUMBER OF CIRCULAR TRIADS MADE BY THE STUDY GROUPS

Table 77. Number of Circular Triads Made by the Benign Group

Number of triads	Frequency	Percentage
0	38	19.0
1	19	9.5
2	28	14.0
3	17	8.5
4	12	6.0
5	12	6.0
6	11	5.5
7	9	4.5
8	10	5.0
9	5	2.5
10	3	1.5
11	2	1.0
12	5	2.5
13	5	2.5
13.5	1	0.5
14	1	0.5
15	2	1.0
16	6	3.0
17	4	2.0
18	2	1.0
19	2	1.0
20	1	0.5
22	3	1.5
24	1	0.5
26	1	0.5

Table 78. Number of Circular Triads Made by the Newly Diagnosed Group

Number of triads	**Frequency**	**Percentage**
0	24	16.0
1	21	14.0
2	21	14.0
3	10	6.7
4	12	8.0
5	12	8.0
6	8	5.3
7	6	4.0
8	4	2.7
8.5	1	0.7
9	4	2.7
10	2	1.3
10.5	1	0.7
11	3	2.0
12	2	1.3
13	6	4.0
13.5	1	0.7
14	3	2.0
14.5	1	0.7
15	1	0.7
16	1	0.7
17	1	0.7
18	1	0.7
21	1	0.7
22	2	1.3
22.5	1	0.7

Table 79. Number of Circular Triads Made by the Follow Up Group

Number of triads	Frequency	Percentage
0	23	21.9
1	8	7.6
2	18	17.1
3	7	6.7
4	10	9.5
5	5	4.8
6	9	8.6
7	5	4.8
8	2	1.9
9	4	3.8
10	3	2.9
11	1	1.0
12	1	1.0
13	4	3.8
14	1	1.0
15	2	1.9
17	1	1.0
19	1	1.0

APPENDIX 15A: T-TESTS FOR AGE AND INFORMATION NEED

The mean values given for each age group are the scale values relating to each item of information. Degrees of freedom = 16.

Table 80. T-Tests for Age and Information Need: Benign Group

Item of information	**Age <50yrs (Mean)**	**Age ≥50yrs (Mean)**	**T**	**p**
Disease spread	0.58	0.56	0.09	0.93
Disease cure	0.80	0.67	0.54	0.60
Social life	-0.72	-0.78	0.29	0.77
Effect on family	-0.44	-0.27	-0.71	0.49
Self care	-0.42	-0.15	-0.84	0.41
Sexual attractiveness	-0.41	-0.71	1.01	0.33
Treatment options	0.57	0.42	0.53	0.61
Risk to family	-0.01	0.19	-0.92	0.37
Side effects	0.05	0.08	-0.09	0.93

Table 81. T-Tests for Age and Information Need: Newly Diagnosed Group

Item of information	Age <50yrs (Mean)	Age ≥50yrs (Mean)	T	p
Disease spread	0.82	0.52	1.21	0.24
Disease cure	0.80	0.94	-0.50	0.63
Social life	-0.72	-0.45	-1.01	0.33
Effect on family	-0.22	-0.29	0.24	0.81
Self care	-0.54	-0.37	-0.55	0.59
Sexual attractiveness	-0.39	-0.85	2.00	0.06
Treatment options	0.46	0.23	0.70	0.50
Risk to family	-0.01	0.20	-1.02	0.32
Side effects	-0.20	-0.07	-0.82	0.42

Table 82. T-Tests for Age and Information Need: Follow Up Group

Item of information	Age <50yrs (Mean)	Age ≥50yrs (Mean)	T	p
Disease spread	0.20	0.25	-0.19	0.85
Disease cure	0.68	0.74	-0.30	0.77
Social life	-0.37	-0.43	0.33	0.75
Effect on family	-0.13	-0.15	0.09	0.93
Self care	-0.37	-0.49	0.50	0.62
Sexual attractiveness	-0.29	-0.64	2.04	0.06
Treatment options	0.14	0.06	0.32	0.75
Risk to family	0.41	0.61	-0.96	0.35
Side effects	-0.27	-0.06	-1.39	0.18

APPENDIX 15B: TESTS FOR LEVEL OF EDUCATION AND INFORMATION NEED

The mean values given for each level of education are the scale values relating to each item of information. Degrees of freedom = 16.

Table 83. T Tests for Level of Education and Information Need: Benign Group

Item of information	Quals. (Mean)	No Quals. (Mean)	T	p
Disease spread	0.61	0.53	-0.35	0.73
Disease cure	0.79	0.76	-0.11	0.91
Social life	-0.75	-0.72	0.15	0.88
Effect on family	-0.48	-0.34	0.55	0.59
Self care	-0.37	-0.39	-0.07	0.95
Sexual attractiveness	-0.45	-0.27	0.57	0.58
Treatment options	0.71	0.36	-1.27	0.22
Risk to family	-0.12	0.22	1.38	0.19
Side effects	0.06	0.07	0.04	0.97

Table 84. T-Tests for Level of Education and Information Need: Newly Diagnosed Group

Item of information	Quals. (Mean)	No Quals. (Mean)	T	p
Disease spread	0.74	0.54	-0.85	0.41
Disease cure	0.88	0.89	0.04	0.97
Social life	-0.66	-0.47	0.74	0.47
Effect on family	-0.32	-0.23	0.35	0.73
Self care	-0.55	-0.35	0.66	0.52
Sexual attractiveness	-0.48	-0.81	-1.43	0.17
Treatment options	0.52	0.18	-1.05	0.31
Risk to family	-0.08	0.25	1.52	0.15
Side effects	-0.05	0.01	0.19	0.85

Table 85. T-Tests for Level of Education and Information Need: Follow Up Group

Item of information	Quals. (Mean)	No Quals. (Mean)	T	p
Disease spread	0.27	0.17	0.46	0.65
Disease cure	0.71	0.75	-0.17	0.87
Social life	-0.42	-0.42	0.00	1.00
Effect on family	-0.18	-0.10	-0.27	0.79
Self care	-0.42	-0.54	0.54	0.60
Sexual attractiveness	-0.66	-0.35	-1.71	0.11
Treatment options	0.06	0.12	-0.30	0.77
Risk to family	0.60	0.49	0.56	0.59
Side effects	0.03	-0.11	0.58	0.57

APPENDIX 15C: ANOVA FOR SOCIAL CLASS AND INFORMATION NEED

The mean values given for each category of social class are the scale values relating to each item of information. Degrees of freedom =26.

Table 86. ANOVA for Social Class and Information Need: Benign Group

Item of information	**SC I & II (Mean)**	**SC III (Mean)**	**SC IV & V (Mean)**	**F**	**p**
Disease spread	0.74	0.65	0.67	0.14	0.87
Disease cure	0.68	0.93	0.56	1.91	0.17
Social life	-0.72	-0.84	-0.73	0.18	0.84
Effect on family	-0.10	-0.41	-0.30	0.19	0.83
Self care	-0.35	-0.43	-0.46	0.07	0.94
Sexual attractiveness	-0.45	-0.43	-0.55	0.10	0.90
Treatment options	0.55	0.48	0.43	0.45	0.65
Risk to family	-0.10	0.09	0.27	1.13	0.34
Side effects	0.14	-0.04	0.12	0.14	0.87

SC: Social Class

Table 87. ANOVA for Social Class and Information Need: Newly Diagnosed Group

Item of information	SC I & II (Mean)	SC III (Mean)	SC IV & V (Mean)	F	p
Disease spread	0.60	0.59	0.68	0.07	0.94
Disease cure	0.89	0.89	0.92	0.01	0.99
Social life	-0.48	-0.58	-0.48	0.11	0.90
Effect on family	-0.36	-0.24	-0.21	0.16	0.85
Self care	-0.55	-0.37	-0.45	0.18	0.84
Sexual attractiveness	-0.49	-0.72	-0.86	1.16	0.33
Treatment options	0.39	0.32	0.15	0.34	0.72
Risk to family	-0.03	0.17	0.30	1.10	0.35
Side effects	0.02	-0.06	-0.04	0.06	0.95

Table 88. ANOVA for Social Class and Information Need: Follow Up Group

Item of information	SC I & II (Mean)	SC III (Mean)	SC IV & V (Mean)	F	p
Disease spread	0.20	0.07	0.45	1.09	0.35
Disease cure	0.78	0.68	0.85	0.22	0.81
Social life	-0.30	-0.42	-0.66	1.23	0.31
Effect on family	-0.16	-0.07	-0.39	0.54	0.59
Self care	-0.70	-0.40	-0.23	1.64	0.22
Sexual attractiveness	-0.64	-0.45	-0.73	0.87	0.43
Treatment options	0.19	0.03	0.02	0.28	0.76
Risk to family	0.66	0.54	0.43	0.98	0.39
Side effects	-0.03	0.02	0.27	1.39	0.27

SC: Social Class

APPENDIX 15D: T-TESTS FOR MARITAL STATUS AND INFORMATION NEED

The mean values given for each category of marital status are the scale values relating to each item of information. Degrees of freedom = 16.

Table 89. T-Tests for Marital Status and Information Need: Benign Group

Item of information	Partner (Mean)	No partner (Mean)	T	p
Disease spread	0.53	0.66	-0.51	0.62
Disease cure	0.82	0.72	0.41	0.69
Social life	-0.81	-0.61	-0.98	0.34
Effect on family	-0.41	-0.42	0.05	0.96
Self care	-0.16	-0.47	0.97	0.35
Sexual attractiveness	-0.46	-0.44	-0.10	0.92
Treatment options	0.58	0.49	0.34	0.74
Risk to family	0.04	-0.00	0.16	0.87
Side effects	-0.12	0.08	-0.57	0.58

Table 90. T-Tests for Marital Status and Information Need: Newly Diagnosed Group

Item of information	Partner (Mean)	No partner (Mean)	T	p
Disease spread	0.65	0.53	0.56	0.58
Disease cure	0.95	0.76	0.76	0.46
Social life	-0.61	-0.38	-0.91	0.38
Effect on family	-0.23	-0.35	0.49	0.63
Self care	-0.51	-0.26	-0.83	0.42
Sexual attractiveness	-0.68	-0.70	0.09	0.93
Treatment options	0.26	0.34	-0.29	0.78
Risk to family	0.22	-0.04	1.27	0.22
Side effects	-0.05	0.10	-0.46	0.65

Table 91. T-Tests for Marital Status and Information Need: Follow Up Group

Item of information	Partner (Mean)	No partner (Mean)	T	p
Disease spread	0.31	0.10	0.92	0.37
Disease cure	0.69	0.56	0.60	0.56
Social life	-0.66	-0.22	-2.08	0.05
Effect on family	-0.23	-0.14	-0.35	0.73
Self care	-0.45	-0.37	-0.34	0.74
Sexual attractiveness	-0.55	-0.51	-0.23	0.82
Treatment options	-0.02	-0.10	-0.54	0.60
Risk to family	0.63	0.29	1.70	0.11
Side effects	-0.07	0.20	-1.06	0.31

APPENDIX 15E: T-TESTS FOR HAVING A RELATIVE WITH BREAST CANCER AND INFORMATION NEED

The mean values given for women who have a relative with breast cancer and women who do not are the scale values relating to each item of information. Degrees of freedom = 16.

Table 92. T-Tests for Having a Relative with Breast Cancer and Information Need: Benign Group

Item of information	**Relative (Mean)**	**No relative (Mean)**	**T**	**p**
Disease spread	0.69	0.55	0.60	0.56
Disease cure	0.73	0.80	-0.27	0.79
Social life	-0.64	-0.76	0.58	0.57
Effect on family	-0.50	-0.40	-0.38	0.71
Self care	-0.46	-0.36	-0.35	0.73
Sexual attractiveness	-0.48	-0.45	-0.12	0.91
Treatment options	0.61	0.53	0.29	0.78
Risk to family	-0.01	0.03	-0.16	0.88
Side effects	0.07	0.05	0.05	0.96

Table 93. T-Tests for Having a Relative with Breast Cancer and Information Need: Newly Diagnosed Group

Item of information	**Relative (Mean)**	**No relative (Mean)**	**T**	**p**
Disease spread	0.43	0.66	-1.01	0.33
Disease cure	0.83	0.90	-0.30	0.77
Social life	-0.45	-0.55	0.40	0.69
Effect on family	-0.33	-0.25	-0.35	0.73
Self care	-0.40	-0.43	0.11	0.91
Sexual attractiveness	-0.55	-0.72	0.87	0.40
Treatment options	0.24	0.28	-0.14	0.89
Risk to family	0.12	0.13	-0.06	0.95
Side effects	0.04	-0.02	0.20	0.84

Table 94. T-Tests for Having a Relative with Breast Cancer and Information Need: Follow Up Group

Item of information	**Relative (Mean)**	**No relative (Mean)**	**T**	**p**
Disease spread	0.00	0.29	-1.09	0.29
Disease cure	0.68	0.75	-0.29	0.78
Social life	-0.47	-0.42	-0.24	0.82
Effect on family	0.01	-0.20	0.71	0.49
Self care	-0.48	-0.45	-0.13	0.90
Sexual attractiveness	-0.36	-0.60	1.30	0.21
Treatment options	0.15	0.12	0.13	0.90
Risk to family	0.70	0.50	0.86	0.40
Side effects	0.01	0.01	-0.03	0.98

APPENDIX 15F: T-TESTS FOR KNOWING SOMEONE WITH BREAST CANCER AND INFORMATION NEED

The mean values given for women who knew someone with breast cancer and women who did not are the scale values relating to each item of information. Degrees of freedom = 16.

Table 95. T-Tests for Knowing Someone with Breast Cancer and Information Need: Benign Group

Item of information	**Yes (Mean)**	**No (Mean)**	**T**	**p**
Disease spread	0.55	0.61	-0.25	0.81
Disease cure	0.78	0.79	-0.04	0.97
Social life	-0.73	-0.74	0.05	0.96
Effect on family	-0.41	-0.47	0.25	0.80
Self care	-0.39	-0.36	-0.08	0.93
Sexual attractiveness	-0.46	-0.45	-0.03	0.98
Treatment options	0.55	0.53	0.06	0.95
Risk to family	0.03	0.00	0.15	0.88
Side effects	0.06	0.09	-0.06	0.95

Yes: know someone with breast cancer, No: no contact with anyone with breast cancer

Table 96. T-Tests for Knowing Someone with Breast Cancer and Information Need: Newly Diagnosed Group

Item of information	**Yes (Mean)**	**No (Mean)**	**T**	**p**
Disease spread	0.57	0.67	-0.42	0.68
Disease cure	0.86	0.91	-0.19	0.86
Social life	-0.47	-0.64	0.70	0.49
Effect on family	-0.28	-0.25	-0.10	0.92
Self care	-0.45	-0.37	-0.26	0.80
Sexual attractiveness	-0.63	-0.75	0.52	0.61
Treatment options	0.23	0.40	-0.54	0.60
Risk to family	0.18	0.05	0.59	0.56
Side effects	-0.02	0.01	-0.07	0.94

Table 97. T-Tests for Knowing Someone with Breast Cancer and Information Need: Follow Up Group

Item of information	**Yes (Mean)**	**No (Mean)**	**T**	**p**
Disease spread	0.20	0.35	-0.67	0.51
Disease cure	0.72	0.77	-0.23	0.82
Social life	-0.37	-0.58	0.95	0.36
Effect on family	-0.10	-0.34	0.88	0.39
Self care	-0.47	-0.42	-0.20	0.84
Sexual attractiveness	-0.54	-0.57	0.19	0.85
Treatment options	0.04	0.23	-0.78	0.45
Risk to family	0.59	0.43	0.69	0.50
Side effects	-0.06	0.15	-0.84	0.42

Yes: know someone with breast cancer, No: no contact with anyone with breast cancer

APPENDIX 15G: T-TESTS FOR TYPE OF SURGERY AND INFORMATION NEED

The mean values given for each type of surgery are the scale values relating to each item of information. Degrees of freedom = 16.

Table 98. T-Tests for Type of Surgery and Information Need: Follow Up Group

Item of information	**Mast. (Mean)**	**Cons. (Mean)**	**T**	**p**
Disease spread	0.13	0.28	-0.64	0.53
Disease cure	0.70	0.74	-0.19	0.85
Social life	-0.41	-0.43	0.08	0.94
Effect on family	0.08	-0.26	1.27	0.22
Self care	-0.50	-0.44	-0.23	0.82
Sexual attractiveness	-0.45	-0.60	0.74	0.47
Treatment options	-0.01	0.12	-0.59	0.57
Risk to family	0.74	0.48	1.26	0.23
Side effects	-0.27	0.10	-1.55	0.14

Mast: mastectomy as primary surgery. Cons: conservative surgery as primary treatment, eg. lumpectomy.

APPENDIX 15H: T-TESTS FOR STAGE OF DISEASE AND INFORMATION NEED

The mean values given for each stage of disease are the scale values relating to each item of information. Degrees of freedom = 16.

Table 99. T-Tests for stage of disease and information need: Follow up group

Item of information	Stage I (Mean)	Stage II (Mean)	T	p
Disease spread	0.25	0.22	0.10	0.92
Disease cure	0.72	0.73	-0.05	0.96
Social life	-0.46	-0.35	-0.48	0.64
Effect on family	-0.20	-0.06	-0.50	0.62
Self care	-0.40	-0.59	0.78	0.45
Sexual attractiveness	-0.55	-0.55	0.04	0.97
Treatment options	0.06	0.12	-0.28	0.78
Risk to family	0.49	0.69	-0.94	0.36
Side effects	0.07	-0.21	1.14	0.25

Yes: know someone with breast cancer, No: no contact with anyone with breast cancer

APPENDIX 15I: ANOVA FOR DECISION MAKING PREFERENCES AND INFORMATION NEED

The mean values given for each decision making role are the scale values relating to each item of information. Degrees of freedom = 26.

Table 100. ANOVA for Decision Making Preferences and Information Need: Benign Group

Item of information	Active (Mean)	Share (Mean)	Passive (Mean)	F	p
Disease spread	0.72	0.56	0.49	0.45	0.65
Disease cure	0.78	0.77	0.79	0.00	1.00
Social life	-0.66	-0.70	-0.85	0.07	0.93
Effect on family	-0.50	-0.46	-0.28	0.38	0.69
Self care	-0.41	-0.37	-0.37	0.01	0.99
Sexual attractiveness	-0.42	-0.40	-0.57	0.22	0.81
Treatment options	0.49	0.52	0.63	0.12	0.89
Risk to family	-0.11	0.02	0.13	0.53	0.60
Side effects	0.10	0.05	0.03	0.28	0.76

Table 101. ANOVA for Decision Making Preferences and Information Need: Newly Diagnosed Group

Item of information	Active (Mean)	Share (Mean)	Passive (Mean)	F	p
Disease spread	0.81	0.80	0.47	1.04	0.37
Disease cure	0.89	0.82	0.92	0.08	0.93
Social life	-0.69	-0.61	-0.43	0.58	0.57
Effect on family	-0.34	-0.23	-0.28	0.07	0.93
Self care	-0.52	-0.49	-0.36	0.15	0.87
Sexual attractiveness	-0.71	-0.64	-0.70	0.05	0.95
Treatment options	0.32	0.28	0.28	0.01	0.99
Risk to family	0.12	0.16	0.12	0.03	0.98
Side effects	0.11	-0.09	-0.20	0.19	0.83

Table 102. ANOVA for Decision Making Preferences and Information Need: Follow Up Group

Item of information	Active (Mean)	Share (Mean)	Passive (Mean)	F	p
Disease spread	0.16	0.32	0.20	0.22	0.81
Disease cure	0.61	0.80	0.76	0.56	0.58
Social life	-0.81	-0.47	-0.38	0.68	0.52
Effect on family	-0.07	-0.31	-0.05	0.49	0.62
Self care	-0.38	-0.68	-0.36	0.94	0.41
Sexual attractiveness	-0.35	-0.51	-0.63	1.85	0.18
Treatment options	0.08	0.15	-0.01	0.23	0.80
Risk to family	0.14	0.80	0.47	2.99	0.07
Side effects	0.47	-0.10	0.00	0.98	0.39