

## **The information needs of women newly diagnosed with breast cancer**

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Nurses can play a key role in patient education, including providing patients with useful and appropriate information. Rather than focusing on the process of education or information giving by nurses, this study places emphasis on the content of that information by taking the patients' perspective and asking the patients themselves what particular types of information are perceived as important at a specific point in time. The aim of the study was to explore what particular types of information were important to women newly diagnosed with breast cancer, to enable nurses and other health care professionals to utilize their time as effectively as possible and provide a high-quality service to individuals in their care. Women with breast cancer (a mean of 2.5 weeks from diagnosis) were interviewed and asked to compare items of information. The items of information were presented in pairs and the women stated a preference for one item in that pair. Thirty-six pairs were presented in total. The analysis involved the use of a Thurstone scaling model, which allowed rank orderings, or profiles of information needs, to be developed, reflecting the perceived importance of each item. Information about the likelihood of cure, the spread of the disease and treatment options were perceived as the most important items of information at the time of diagnosis. Other information needs, in order of descending priority, included information about the risk to family, side-effects

of treatments, impact on family, self-care, effect on social life and sexual attractiveness. Profiles of information needs were produced to take account of differences in age, level of education and social class. The use of the profile as a clinical reference guide to assist nurses and others to provide targeted information to individuals is discussed.

## INTRODUCTION

Over the last two decades a great deal has been written about the role of the nurse as a patient educator or teacher. For a review of the literature see Luker & Caress (1989) and Redman (1993). The emphasis on patient teaching in the nursing literature has focused on the process of education, rather than on the content. The assumption has been that nurses know what patients need to know, and have the necessary information to impart. Similarly, little attention has been given to what patients and individuals want to know and what their priority information needs are. It is the case, owing to reduced lengths of stay, that less time is available while a patient is in the hospital for information giving or education in its broadest sense. There is a need to find out more about patients' own concerns and priorities for information, so that the short time in hospital is used to the patients' best advantage. This paper sets out the policy context for focusing on the service user. The study reported may be seen as redressing the imbalance in the literature by focusing on the information needs of one patient group, namely women newly diagnosed with breast cancer.

## BACKGROUND

Increasing emphasis is being placed on promoting effective communication between health care professionals and service users. Empowering people, encouraging active participation in decision making and promoting autonomy have been embodied in the National Health Service and Community Care Act (Department of Health 1990), the *Patients Charter* (Department of Health 1991b) and the *Health of the Nation* consultative document (Department of Health 1991a). Service users' rights are now a more tangible issue and nurses have a key role to play in empowerment and information giving.

Information giving is an essential element in making lay participation effective. In order for people to feel comfortable participating in decisions about health care, it is important that they are adequately informed. Hence, the type of information an individual has access to may be the key to the process of empowerment. Health care professionals arguably have a responsibility to provide individuals with the specific type of information necessary for informed decision making to take place.

Receiving the right amount and type of information is

particularly important for people with cancer. A cancer diagnosis is still regarded with more fear than other diagnoses, instilling feelings of shock, grief, uncertainty and loss of control (Northouse & Northouse 1987, Parry 1990, Schain 1990). Fear and apprehension often mean that individuals are reluctant to ask for specific information, believing that they will be told all they need to know. The subject of cancer is an emotionally loaded area and nurses often feel limited in their ability to communicate effectively (Wilkinson 1991, Suominen 1993). For doctors there is the concern that they will upset the person or dispel hopes for a cure (Slevin 1987) and death is still a taboo subject that some doctors feel ill prepared to discuss (Katz 1984).

In the context of cancer there has been a shift from not informing people of their diagnosis to fully informing them (Novack *et al.* 1979). However, it still appears that people are not receiving as much information as they would wish and on the areas that they perceive to be important (Siminoff 1989, Siminoff *et al.* 1989, Simpson *et al.* 1991, Hack *et al.* 1992).

Providing adequate information to women with breast cancer is of particular importance since a choice of treatment may exist for many. Treating breast cancer with mastectomy, compared to treatment with more conservative surgery followed by radiotherapy, has no demonstrable difference in terms of long-term survival (Fisher *et al.* 1985). Providing women with a choice of treatment has been found to be of benefit in terms of long-term adjustment to the disease (Leinster *et al.* 1989). To facilitate the decision-making process adequate information must be provided or women may feel ill-prepared to take on the role of decision maker.

It has been suggested that younger, more highly educated individuals with a diagnosis of cancer have a greater need for information and want to be more actively involved in the decision-making process (Cassileth *et al.* 1980, Amir 1987). Results from these studies need to be examined in detail as there are many diseases, for example breast cancer, where incidence increases with age and information needs may well vary for different age groups.

### Decision-making process

It should be noted that although information is an important aid to decision making, it should not be assumed that non-participation in decision making relates to a wish for less information. Information may still be required to

function autonomously even if that information is not used to make decisions (Sutherland *et al* 1989)

Obtaining the appropriate information may be a particular problem for older people. Evidence suggests that older women believe in more myths about breast cancer than do younger women and have more negative attitudes to the disease (Rimer *et al* 1983). There is also evidence to suggest that older women have less knowledge of breast cancer risk factors and believe they are less susceptible to breast cancer, as well as having more negative attitudes to screening (Mah & Bryant 1992). There is also the stereotype image that older women will not mind losing a breast, an image dispelled by Fallowfield *et al* (1990). Older women, then, may have particular problems in getting the information they need. Hence, an understanding of the types of information needed by different age groups may usefully facilitate information giving.

Following a review of over 200 papers, spanning 20 years, relating to communication with cancer patients, Northouse & Northouse (1987) concluded that seeking information was one of the major areas of importance for individuals with cancer. However, few studies reviewed concentrated on the type of information required, and evidence suggests that the focus of attention has been on the quantity of information required, rather than on the type of information or the way in which information is given (Tuckett & Williams 1984).

Assumptions are made that health care professionals are aware of the information needs of individuals with cancer. Empirical evidence suggests that there is a difference in perception of what the person wants to know and what the health care professional thinks the person wants to know (Lauer *et al* 1982, GIVIO 1986), with information often being perceived by people as unhelpful rather than constructive and supportive (Thorne 1988). The service user's perspective is therefore of paramount importance if we are to provide adequate information to facilitate informed decision making. If we want to involve people with cancer in the communication process, then we need to find out from them what it is that they need to know (Reynolds *et al* 1981).

### Assessing information needs

Imparting the right type of information is obviously of great importance, but it should be noted that there have been many problems in assessing information needs since people tend to say that they want as much information as possible about all aspects of their care and treatment. This presents particular problems for nurses and other health care professionals, as time is often limited in the hospital environment due to decreased lengths of hospital stay and competing demands on health care professionals' time. Attention and recall have been shown to be severely limited in life-threatening situations (Cumprich 1993), hence

it would be prudent to examine the priority information needs at key points in the illness trajectory to prevent overloading people with information that they will not be able to recall at a later date.

An extensive review of the literature carried out in Canada identified items of information that were important to people with cancer generally and, more particularly, with breast cancer (Degner *et al* 1989). The literature revealed nine major areas of importance for women with breast cancer. These areas included physical, psychological and social aspects of care and treatment, and included information on the spread of disease, likelihood of cure, impact on social life, effect on family and friends, self-care, sexual attractiveness, treatment options, risk to family of getting the same disease, and treatment side-effects.

Time is a valuable resource for nurses, and all health care professionals, and to use the limited time available to the increased benefit of service users would enhance communication through an increased awareness of what the individual considers to be important in terms of information.

In summary, it is important for nurses as patient educators to provide useful and appropriate information to the patients in their care. This applies equally to other health care professionals, and a multi-disciplinary approach to health care, in the context of cancer, should be encouraged. The provision of information can be complicated in the hospital environment by limitations on time available for imparting information. A knowledge of what the patient really wants to know, that is the content of the information, can only make information giving a more effective and worthwhile process.

### THE STUDY

The present study aimed to establish the priority information needs of a sample of women newly diagnosed with breast cancer, and to assess if information need was influenced by variables such as age, level of education and social class.

### Method

A consecutive sample of 150 women newly diagnosed with breast cancer was taken from a consultant's list in a large university teaching hospital. The sample represented 11.6% of the total number of women newly diagnosed with breast cancer in the Mersey Regional Health Authority (MRHA) (Youngson *et al* 1992). A sample of 200 women with benign breast disease was recruited to provide a control group for the study. Ethical approval for carrying out this study was obtained by one of the co-authors. Verbal consent was obtained from all the women involved in the study, confidentiality was assured and each individual

was told that they could withdraw from the study at any time

The newly diagnosed women were interviewed following admission to the hospital ward prior to surgery. The benign control group was interviewed in the out-patient clinic. This sample consisted of women who had presented with a breast symptom but on examination and aspiration cytology were found to have a benign diagnosis. All women were aware of their diagnosis, malignant or benign, at time of interview. Each interview lasted approximately 30 minutes, although time was always available at the end of each interview if women wanted to provide further comments or to ask questions about the study.

A structured interview approach was taken. Details were recorded on several demographic variables, including age, level of education (formal qualifications being used as a proxy for level of education), social class (Office of Population Censuses and Surveys 1990a,b, 1991), marital status and ethnic group.

## Questionnaire

A questionnaire was used to establish information needs based on the paired comparison approach described by Thurstone (1974). To examine preferences for information, nine information needs were presented to the women in pairs. These nine information needs covered physical, psychological and social aspects of care and treatment. They were derived from a literature search of over 200 papers relating to cancer and specifically breast cancer (Degner *et al* 1989). The nine information needs are listed below.

- 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)

Each information need was seen with every other information need. With nine information needs this meant that a possible 36 pairs of information needs existed ( $n(n-1)/2$ ). The pairs were presented in such a way as to avoid any selection bias, as described by Ross (1974). Women were asked to decide which of the two information needs had the greater importance. That is, if they could have information on only one of the two items, which item would be chosen. The procedure was repeated for all 36 pairs. At the end of the questionnaire each woman was asked if there were any other important information needs they felt had been omitted from the measure.

## Analysis

Data were coded using the Data Entry program within the SPSS-PC+ statistical package. A SAS computer program developed in Canada by Sloan *et al* (1994) was used to produce profiles of information needs based on case V of Thurstone's Law of Comparative Judgement (Thurstone 1974).

Thurstone's model assumed that when two stimuli were presented together they could be ranked in terms of some attribute. In the present study that attribute was perceived importance. Thurstone proposed that each item would vary in terms of the attribute under investigation, so that each item will not have a fixed position on the profile at all times and its position will fluctuate. That is, each individual may vary in their judgement of an item from one instance to the next, but overall there will be a most frequently occurring response. Thurstone referred to this most frequently occurring response as the modal discriminational process which, in case V, is assumed to be normally distributed.

Using the computer program a matrix was produced to reflect the number of times that each item was preferred over every other item. From this frequency matrix, a proportions and unit deviate matrix was produced. Scale values were then produced by taking the mean of the normal deviate values for each item of information.

Profiles were produced for the newly diagnosed and benign groups and the pooled variance *t*-test was used to examine if there were any significant differences in rankings between the two profiles. One-way analysis of variance (ANOVA) was used to search for any significant differences in rankings between the profiles for the variables age, level of education and social class.

## Coefficient of agreement

Kendall's coefficient of agreement (Edwards 1974) was used to assess the level of agreement between women in

terms of their judgements. This test would show if there was agreement between the women on what items of information were important and in what order. Kendall's coefficient of consistency assessed how consistent each woman was in her judgement. For example, if item 1 was preferred to item 2 and item 2 was preferred to item 3 then, to be consistent, we would expect item 1 to be preferred to item 3. However, if item 3 is preferred to item 1 then an inconsistency has arisen. This inconsistency is referred to as a circular triad (Edwards 1974).

By using the two tests described by Kendall, we could then assess if each woman in the study was being consistent in her choices and not making arbitrary choices or choosing items at random, and that consistency existed between the women in their choices.

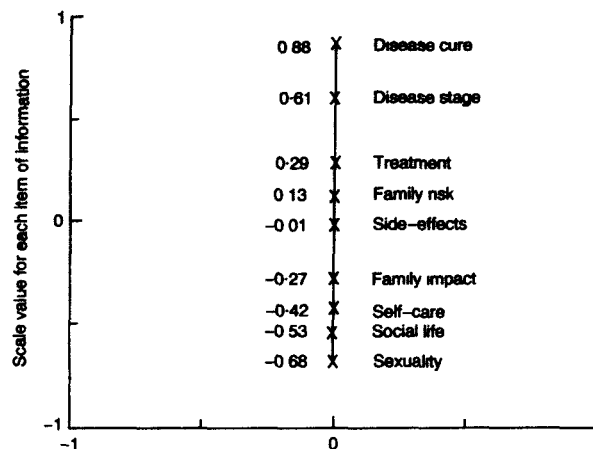
## RESULTS

The newly diagnosed women were an average of 2.5 weeks from diagnosis, with a mean age of 54.8 years (range 32–84 years). The mean age of the benign group was lower than for the experimental group (39.2 years, range 18–70 years). However, there were similarities in many other areas, for example level of education, social class, marital status and ethnicity (Table 1).

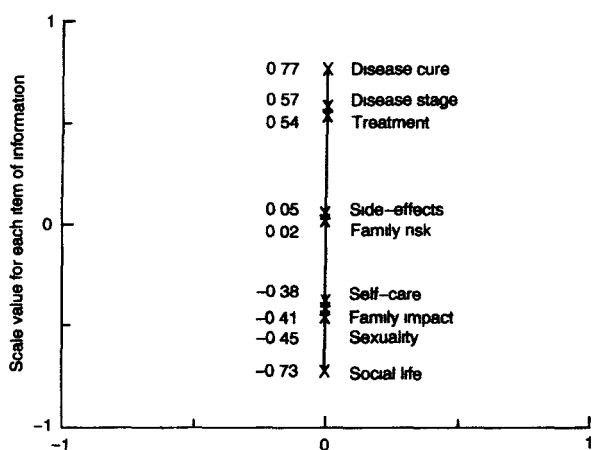
Overall, women ranked information about the likelihood of cure, the spread of disease and treatment options as the priority information needs. Information regarding sexual attractiveness was ranked low in the profile, in fact it was

**Table 1** Characteristics of sociodemographic variables for newly diagnosed and benign groups

	Newly diagnosed (n = 150)	Benign (n = 200)
<b>Age</b>		
< 40 years	7.3% (n = 11)	52.5% (n = 105)
40–60 years	58.7% (n = 88)	42.0% (n = 84)
> 60 years	34.0% (n = 51)	5.5% (n = 11)
<b>Level of education</b>		
No qualifications	64.0% (n = 96)	44.0% (n = 88)
School leaving exams	18.0% (n = 27)	29.5% (n = 56)
Professional/graduate	18.0% (n = 27)	26.5% (n = 53)
<b>Social class</b>		
I and II	31.3% (n = 45)	40.4% (n = 76)
III	49.3% (n = 71)	45.2% (n = 85)
IV and V	19.4% (n = 28)	14.4% (n = 27)
<b>Marital status</b>		
Married/common law	65.1% (n = 97)	62.5% (n = 125)
Widow/divorced/ separated	23.5% (n = 35)	15.0% (n = 30)
Never married	11.4% (n = 17)	22.5% (n = 45)
<b>Ethnic class</b>		
White British	99.3% (n = 149)	98.0% (n = 196)
Other ethnic class	0.7% (n = 1)	2.0% (n = 4)



**Figure 1** Information needs profile newly diagnosed group (n = 150)



**Figure 2** Information needs profile benign group (n = 200)

the lowest item of importance for the newly diagnosed group (Figure 1). Interestingly, no significant differences were found for the ranking of the items between the newly diagnosed and benign groups. The information needs for the newly diagnosed group showed fairly even spacing between the nine information needs, while the profile for the benign group showed much more bunching of items (Figure 2). It may be that having a diagnosis of cancer brings more sharply into focus the information required.

## Ranking

One-way ANOVA revealed significant differences in terms of ranking of items of information for the variable 'age' within the newly diagnosed group. Three age groups were examined (<40 years, n = 11; 40–60 years, n = 88; 60+ years, n = 51). For the newly diagnosed group the women in the age groups <40 years and 40–60 years rated

information pertaining to sexual attractiveness as more important than did women in the 60+ years age group ( $F=3.438$ ,  $P=0.05$ ). Older women rated information pertaining to their social life as more important than did younger women ( $F=4.047$ ,  $P=0.03$ ). No other significant differences were found between the information needs profiles in terms of age. The benign group's information needs profile did not display any significant differences in rankings in terms of age of the women.

No significant differences were found between the ranking of items in terms of level of education or social class. This result applied to both the newly diagnosed and benign groups. That is, more highly educated individuals did not need different information to individuals with lower levels of education. Women from higher social classes did not need different types of information to women from lower social classes.

All women were found to be consistent in their judgments, as shown by Kendall's coefficient of consistency (Kendall's  $\tau=0.979$ ). Kendall's coefficient of agreement showed that there was consistency between women for both newly diagnosed ( $\kappa=0.257$ ) and benign ( $\kappa=0.272$ ) groups.

## DISCUSSION

The study showed that Thurstone (1974) scaling methods could be used to produce rank orderings, or profiles of information needs, for newly diagnosed women with breast cancer that would reflect the priority needs around the time of diagnosis.

The study clearly demonstrated that the priority information needs, at a mean of 2.5 weeks from diagnosis, were information about the likelihood of cure, the spread of disease and the treatment options available. The next most important items in the hierarchy were, in descending order of importance, information about the risk to family of getting the disease, information about the side-effects of treatment, information about the emotional impact on the family, information about self-care, information about the effect on social life and information on sexual attractiveness.

The profiles of information needs (Figures 1 and 2) could be used as a clinical reference guide for nurses and other health care professionals caring for women with breast cancer. In the hospital environment the information needs profile may be particularly important to the clinical nurse specialist in breast care. The guide would have relevance for a large cross section of women, as level of education and social class did not influence the ranking of the information needs. Consideration needs to be taken of the age of the patient, with younger women giving a higher ranking to information on sexual attractiveness. However, the position in the hierarchy for this item remained low regardless of the age of the woman.

It may be important to direct attention, during the hospital admission, towards the items that assumed major importance in terms of rank order. However, this is not to say that an individualized approach to patient care is not warranted. What the study highlights is the important information needs of women, and we suggest that the profiles of information needs (Figures 1 and 2) may be a useful guide in practice in terms of assisting nurses to prioritize teaching and information giving. All health care professionals have limited time available for information giving, and the information needs profile provides a focus of attention on nine important items of information. Presenting this to the patient and asking if any of the items presented are of importance may save time for the nurse and provide the patients with the information they need.

## IMPLICATIONS FOR NURSING PRACTICE

Arguably, the top three information needs found to be of importance to women newly diagnosed with breast cancer, namely likelihood of cure, spread of disease and treatment options, are not within the remit of the average ward nurse as far as information giving is concerned. However, they may fall within the scope of practice of the specialist breast care nurse. An assessment of the information needs that are important to the patient is within the remit of every registered nurse's role, and an awareness of patients' needs is vital for promoting high quality care. If indeed the top three items of information are considered of priority to a patient, then the nurse could act as facilitator, enabling that patient to gain access to that information by, for example, making medical colleagues aware of the patient's information needs. This may, in some cases, lead to the development of protocols or guidelines for information giving.

These findings have further implications for nursing practice. Information giving is often focused on the time of diagnosis and hospital admission and nurses play a lead role. A mastectomy or lumpectomy is a time of crisis, when retention and recall of information may be severely limited (Cimprich 1993). Given that the average length of hospital stay for women with breast cancer is 2–3 days, there is a need to provide information that is perceived as relevant. This study highlighted the importance of survival issues for women at the time of diagnosis, and studies carried out in the USA and Canada have also found survival issues to be a major concern for women with breast cancer (Northouse 1989, Bilodeau 1992). Overwhelming the patient with information that they see as low priority, for example on sexual attractiveness and body image, may not be prudent at this time. It is clearly important to understand when a woman's information needs may change, distance from diagnosis is probably an important variable and further work is underway in this area.

## Clinical reference tool

As a clinical reference tool, the information needs profile could be employed in everyday nursing practice. For example, it could be presented to women either in the outpatient department at the time of diagnosis or perhaps, more appropriately, at the time of admission to the ward for surgery. By using this structured approach it would be possible to provide the women with the information that they consider to be important during their hospital admission. While using a structured format, it would be possible to present the information in a way that is tailored to individual patient needs. However, there is a need to map information needs over time and to develop imaginative forms of service delivery to meet women's information needs. We consider that nurses have a key role to play in this field.

## CONCLUSION

This study examined women's information needs at one time point, a mean of 2.5 weeks from the diagnosis of breast cancer. The findings have highlighted that women are able to identify their own information needs around the time of diagnosis. It may be that information needs change over time as the women move further from the point of diagnosis.

A longitudinal follow-up study is underway that takes account of the impact of time since diagnosis on information need in women with breast cancer. It is anticipated that further information needs profiles can be developed to meet individual's needs. Nurses currently play a lead role in information provision.

However, in the light of these findings it may be important to consider the role of each member of the multidisciplinary team, enabling women with breast cancer to access the information they need. Women's information needs extend beyond the hospital admission, and in situations where admissions are only 2–3 days it is necessary to explore alternative ways of providing women with breast cancer with sources of information.

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