Information Needs and Preferences for Participation in Treatment Decisions Among Swedish Breast Cancer Patients

Birgitta Wallberg, Helena Michelson, Marianne Nystedt, Christina Bolund, Lesley F. Degner and Nils Wilking

From the Department of Clinical Oncology, Karolinska Hospital, Stockholm, Sweden (B. Wallberg, H. Michelson, M. Nystedt, C. Bolund, N. Wilking), and the University of Manitoba and St. Boniface General Hospital Research Centre, Winnipeg, Manitoba, Canada (L.F. Degner)

Correspondence to: Dr Birgitta Wallberg, Department of Clinical Oncology, Radiumhemmet, Karolinska Hospital, SE-171 76 Stockholm, Sweden

Acta Oncologica Vol. 39, No. 4, pp. 467–476, 2000

Patient participation in treatment decisions presupposes well-informed patients. The purpose of this study was to determine Swedish breast cancer patients' information needs and their preferences for participation in treatment decisions. Patients (n = 201) were interviewed on nine categories of information and five patient roles, using paired comparisons. Patients gave priority to facts about disease and treatment (chances of cure, stage of disease, treatment options). A collaborative role in treatment decisions was preferred by 87% of the patients. Most patients (56%) preferred a passive form of collaboration: I prefer that my doctor makes the final decision about my treatment but seriously considers my opinion. Younger and better educated patients tended to prefer a more active role. Many patients wanted to be more active (20%) and some more passive (8%) than they actually were. Patients gave priority to disease-specific information, but this reflected needs other than taking control of treatment decisions.

Received 29 December 1999
Accepted 29 January 2000

Modern breast cancer treatment involves difficult choices for patients and physicians. Treatment options and combinations of treatments multiply and an increasing number of patients are offered participation in clinical trials that imply additional uncertainties about benefits and risks as well as putting pressure on the patient to decide on whether to participate or not.

The processes of informing patients and involving them in treatment decisions differ in various parts of the world and are influenced by cultural, legal and economic differencies. In the Western countries there has been a rapid change in recent decades towards more open communication with cancer patients. This means discussing patients' priorities about chances of cure or prolonged life contra risks of treatment and influence on quality of life. This trend raises several questions: what role do patients want to have in treatment decisions? What do patients want to know about diagnosis and prognosis? About possible effects and side effects of treatment?

Research in the new field of decision-making aims at providing the ethical and political debate about patients' rights with facts and arguments. In the US and Canada, research in medical decision-making is established, mainly as a result of the ethical debate about informed consent (1, 2). In Sweden, as well as in most European countries, this type of research is developing. However, the Swedish Health and Medical Services Act from 1982 (3) stipulates that medical care and treatment should be based on respect for the self-determination and integrity of the patient and should as far as possible be performed in cooperation with the patient. The patient does not have the right to demand a certain type of treatment, but the law gives the patient the right to refuse treatment. This implies enough information about diagnosis and prognosis to allow the patient to take a stand. Moreover, in Sweden and many other countries commissions in healthcare are working to find strategies to strengthen patients' rights, to improve patient information and stimulate patient participation in medical decisions.

What role do Swedish patients want to have in treatment decisions?

According to one Swedish study, not even half of the patients (41%) waiting for an operation regarded the deci-

 ISSN 0284-186X

sion to operate as a joint patient–doctor decision (4). However, 73% felt that their involvement in the decision-making process was as much as they wanted. Cancer patients saw it as a joint patient–doctor decision to the same extent as other patients.

Reports from other countries show, however, that patients with cancer generally prefer a more passive role than patients with other diseases. In a British study, breast cancer patients wanted to play a more passive role (52%) than patients with benign breast disease (31%) (5). In two Canadian studies a substantial proportion of patients with prostate cancer (58%) and breast cancer (43%) wanted to play a passive role in treatment decisions (6, 7). However, according to a more recent study, only 34% of patients with breast cancer preferred passive roles, suggesting that breast cancer activism in Canada has shifted women's attitudes (8). When cancer patients were compared with healthy people, the majority (59%) of cancer patients preferred a passive role, whereas the majority (64%) of the general public thought they should be very active and even wanted to select their own treatment if they were to develop cancer (9).

What are the consequences for patients who have real choices in treatment decisions?

Patients with early breast cancer who were encouraged to participate in the decision of breast-conserving therapy versus mastectomy had a lower incidence of anxiety and depression than those whose surgeons made the decision (10). In a follow-up study three years later, half of the patients had positive reactions to the fact that they had had a choice (11). Some patients (24%) considered the decision to be very difficult—13% had not been able to reach a decision but had asked their physicians to decide on their behalf.

Active participation in treatment decisions presupposes that the patient has enough information about the disease and effects and side effects of treatment options. Do cancer patients want as far-reaching information as that? It has actually been suggested that the information given to patients being offered participation in treatment decisions ought to include that participation per se might cause increased distress (12). There is evidence that they do want information (13–17) and that physicians underestimate the information needs of their patients (14, 17, 18). According to a British report from 1995, an overwhelming majority (94%) of cancer patients wanted as much information as possible—good or bad (15). Patients who wanted less information were older and had poorer prognoses.

What kind of information is of importance to breast cancer patients?

The way patients would give priority among different items of information might reflect their wish to be involved in treatment decisions. This issue has been investigated in Canada using a model developed by Degner et al. (6, 7, 19–21). Patients' preferences for involvement in treatment decisions were defined by five potential patient roles, ranging from a very active role, through collaborative roles to a passive role, where the physician makes the decision for the patient (Fig. 1). Patients' preferred roles can then be compared with their actual roles; that is, how involved patients think they have actually been in treatment decisions.

In agreement with Degner et al., we decided to apply their research design and tools on a cohort of breast cancer patients in Stockholm. The aim of the study was fourfold: 1) to determine the information needs of the patients, 2) to determine their preferences for participation in treatment decisions, 3) to determine to what extent they believed they had achieved their preferred degree of participation, and 4) to determine how their information needs were related to their preferred degree of participation.

Our hypothesis was that the patients would have a strong need for disease-related information and would prefer a passive role in treatment decisions, but that younger and better-educated patients would want to be more active. A second hypothesis was that patients would prefer a more active role with increased time from diagnosis.

MATERIAL AND METHODS

Sample

A consecutive sample of 261 Swedish women treated for breast cancer was taken from the attendance lists of the outpatient breast cancer clinic at Radiumhemmet, Karolinska Hospital in Stockholm. Eligible patients were those who had been diagnosed with breast cancer within the latest 18 months; had undergone primary surgery; were

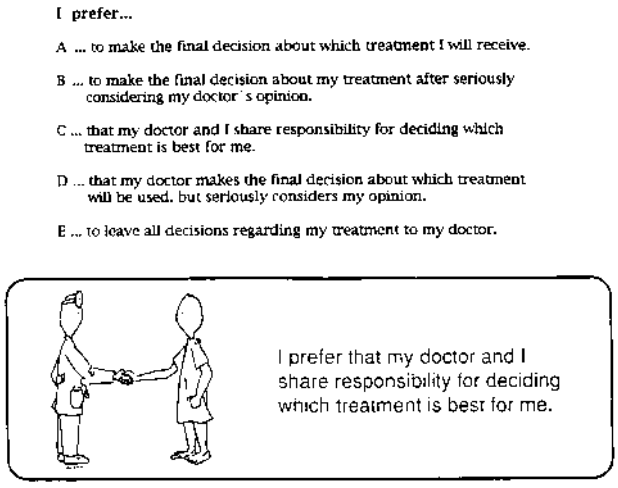

Fig. 1. Five patient roles describing varying degrees of patient participation in treatment decisions. Picture illustrates alternative C—the collaborative role.

less than 75 years of age; showed no sign of mental confusion; had not previously been diagnosed with cancer and were able to speak and read Swedish. In total, 201 patients (77%) agreed to participate in the study and were interviewed between July 1994 and March 1995. Of the 60 patients who declined to participate, we have information about the reasons for 29 of them. Sixteen patients referred to lack of time, 8 were unable to read and speak Swedish well enough and 5 had mental problems. The sample was stratified into two groups: women who were interviewed 1–6 months and 6–18 months, respectively, after diagnosis.

'Education level' was defined as: 1) basic: 8–9 years of schooling, i.e the Swedish 'folkskola/grundskola'; 2) Intermediate: 10–13 years of schooling, i.e. the Swedish 'gymnasium'; 3) High: university.

The study was approved by the Ethics Committee of the Karolinska Hospital.

The patients were informed about the study by phone one or two days prior to a regular appointment with their physicians. On the day of their appointment patients interested in participating received more information, written and verbal, about the aims and procedure of the study. Confidentiality was assured and information given about the right to decline participation and to withdraw from the study at any time.

Written informed consent was not required in Sweden at the time of the study, but the participants gave their verbal approval.

Of the 201 patients willing to participate, 156 were interviewed before seeing their doctor; 45 patients were unable to come to the clinic earlier than planned and were interviewed after seeing their doctors.

Information about the study was given and the interviews were made by two research assistants (one research nurse and one research assistant/former secretary). As the research design and tools were adopted from a Canadian research group, the questionnaires were translated from English to Swedish and then back to English again, according to standard procedures. The translations were undertaken by professionals in cancer care.

The interview dealt with 1) information needs and 2) preferred and actual role in treatment decisions. Sociodemographic data were recorded on age and level of education. Medical data were registered from the medical report of each patient about stage of disease at time of diagnosis and interview, surgical treatment and adjuvant treatment with hormones, chemotherapy and/or radiotherapy. A structured interview method was used. Each interview lasted 30 to 40 min.

1. Information needs

This part aimed at establishing a profile of information needs for women with breast cancer. The patients were to rank 9 categories of information covering medical, psychological and social issues (Table 1). A method of paired comparisons was used so that the patients could rank as many as 9 items and to avoid so-called 'ceiling effects', that is when patients give high priority to 'all items of information'. The 9 items have been identified in a review of the literature by Degner et al. (17). To avoid selection bias, the items were presented in pairs in a specific order according to Ross's method of optimal ordering (22).

Table 1

Information needs about breast cancer

	Nine items of information
1.	Information about the diagnostic stage and the extent of involvement of my disease.
2	Information about the likelihood of cure from my disease.
3.	Information about how the treatment may affect my ability to carry on my usual social activities (sports, hobbies, etc).
4.	Information about how to handle the physical and emotional impact of the disease on my family and significant others.
5.	Information about caring for myself at home (nutrition, support groups, home care, social workers, mental health workers, etc).
6.	Information about how the treatment may affect my usual feelings of physical and sexual attractiveness (breast disfigurement, breast prothesis, reconstructive surgery).
7.	Information about different types of treatments (surgical, chemo-therapy, 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 in developing the disease.
9.	Information about possible unpleasant side effects of treatment (nausea, pain, change in physical appearance).

The items were presented two at a time and the patient had to choose the item in each pair that was of greatest importance to her. Every possible combination of 2 of the 9 items was presented, yielding 36 pairs $= (n(n-1)/2 = (9 \times 8)/2)$. The result was the preference order of all 9 items for each patient. The preference order for all 201 patients formed a profile of information needs for Swedish breast cancer patients. The method with paired comparisons is derived from Thurstone's Law of Comparative Judgement (23).

2. Preferred role in treatment decisions

A card sort procedure (9) was used to determine preferences for participation in treatment decisions. Five cards described, in words and pictures, five potential roles for patients in relation to their physicians when treatment decisions were made: A, B, C, D and E (Fig. 1). The roles changed gradually from the patient selecting her own treatment (A) through a collaborative role (C) to the doctor selecting the treatment without involvement of the patient (E). A method of paired comparisons was used—

the cards were presented to the patient in subsets of two at a time by the research assistant. The patient consistently chose the one that best described her preferred role in treatment decisions. All five roles were combined with one another and in total the patient made 10 choices $n(n-1)/2 = (5 \times 4)/2 = 10$.

The card sort procedure produces a ranking order, the preference order, of the five possible roles for each patient, with the patient's first preference at the beginning. ABCDE represents the preference order of the most active patient and EDCBA the order of the most passive patient. The preference order for all patients is based on the number of times different permutations of ABCDE evolve. Calculations were then made to determine the percentage to which patients' preference orders were consistent with an underlying dominant psychological dimension of keeping-sharing-giving away control, that is ABCDE.

Finally, each patient was asked to select the card with the patient role that best described the role that she actually had in relation to her doctor when treatment decisions were made. This actual role was then compared with the patient's first preferred role according to the card sort procedure. Calculations were made for the percentage of congruence between preferred and actual role.

Analysis

For the statistical analyses, we used SAS computer program developed by Sloan et al. (24, 25).

Information needs. According to Thurstone's model, two stimuli presented together could be ranked in terms of some attribute. In our study that attribute was perceived importance. Thurstone proposed that each item would vary in terms of the attribute under investigation so that each item would not have a fixed position on the profile at all times—its position would fluctuate. This means that each individual may vary in her or his judgement of an item from one instance to the next but there will always be a most frequently occurring response. Thurstone referred to this most frequently occurring response as the modal discriminal process, which is assumed to be normally distributed.

Data were analysed using Thurstone scaling (23). The number of patients who preferred item 1 over item 2, item 1 over item 3, and so on, yielded preference frequencies that were divided by the number of patients responding in order to calculate the percentage of the sample that preferred each item over each other item. These preferred proportions were then translated into standard normal scores and reflected the patients' weightings of the items. The scale score of 0 meant that exactly 50% of the participants supported the item. The larger the value, the more preferred was that item of information. A negative score meant that fewer than 50% of the participants supported the item. Profiles of information needs for subgroups were compared using a test for equality of proportions using a Bonferroni correction (24). The test statistic differed from the traditional Z statisitic for testing equality of proportions in that it incorporated a multiplier of $(k-1)^{-1/2}$, which is a result of the proportions being an average of $k-1$ individual proportions rather than singular proportions themselves.

The *Bonferroni correction* for pairwise tests was also used to correct for multiple comparisons. The *Kendall coefficient of consistency* was used to assess how consistent each participant was in her judgement (26). If not, inconsistencies in the form of circular triads occur. For example, if item 1 is preferred over item 2 by a participant, and item 2 over item 3, then item 1 would be preferred over item 3. If, instead, item 3 is preferred over item 1, a circular triad has occurred. The *Kendall coefficient of agreement* was used to assess the level of agreement among the participants in their judgements (26). This test shows whether there is agreement between what items of information are important and in what ranking order. By using the two Kendall coefficients we could therefore assess if each participant was consistent in her choices—not making arbitrary or random choices—and if consistency existed between participants in their choices.

Preferred role in treatment decisions. Regarding patients' first preference among suggested patient roles, frequency calculations were made for the whole sample and for subgroups.

Regarding the preference order, the analysis was based on a scaling model developed by Coombs, termed the 'unfolding theory' (27). In the present study, the ranking order of preferred roles represented the degree of control that each individual wanted to have over treatment decisions. The aim of the unfolding theory is to establish the existence of an underlying dominant psychological dimension onto which each individual's preference order could be placed. The aim here was to determine the existence/non-existence of an underlying dimension of control ranging from keeping control (active role), to sharing control (collaborative role), to giving away control (passive role). Coombs stated that at least $50\% + 1$ of the preference orders would fall on the dimension to support his theory (27).

RESULTS

Sample

Interviews were conducted with 201 patients, 83 of them 1–6 months after breast cancer diagnosis and 118 patients 6–18 months after diagnosis. Sociodemographic data are presented in Table 2.

Information needs

Information about the possibility of cure was rated highest by the patients, with information about stage of disease and different types of treatment as second and third priorities (Fig. 2). Information was rated much lower

about the social consequences of cancer, self-care, how family and friends may be affected and sexual attractiveness.

The two top priorities (cure, stage of disease) had Thurstone scale scores significantly different from all four items rated lowest (pairwise tests corrected for multiple comparisons by use of the Bonferroni correction, p-value = 0.001). There was also a strong suggestion that the third priority (treatment options) belonged to the group of top ranked information needs (p-value = 0.01).

In fact, three classes of information needs emerged: facts about chance of cure, stage of disease and treatment options as first priority, issues about genetic risks and side effects as second and issues about how cancer affects life as third priority.

How active patients wanted to be in treatment decisions (preferred role) and time from diagnosis did not change patients' ranking of the three items of information on top compared to the whole sample (data not shown). Furthermore, regarding subgroups of patients (age, education), the same three items of information were given priority, with only one exception: Women with intermediate levels of education rated information about treatment options as second and stage of disease as third priority. Young women (≤ 50 years) rated information about sexual attractiveness somewhat higher than older women ($p = 0.005$). Women with the lowest level of education rated information about cure and genetic risk as more important than women with higher education ($p = 0.002$ and $p = 0.000$, respectively) but information about sexual attractiveness as less important ($p = 0.002$). Women with low and intermediate levels of education rated information about genetic risk higher than women with higher education ($p = 0.00002$) (data not shown).

Table 2

Sociodemographic data

Sociodemographic variables	Total No. (%) 201 (100)
Age	
≤50 y	88 (44)
51–65 y	73 (36)
≥66 y	40 (20)
Education	
Basic	85 (42)
Intermediate	52 (26)
High	58 (29)
Information missing	6 (3)
Time from diagnosis	
≤6 months	82 (41)
6–18 months	118 (58)
Information missing	1 (1)

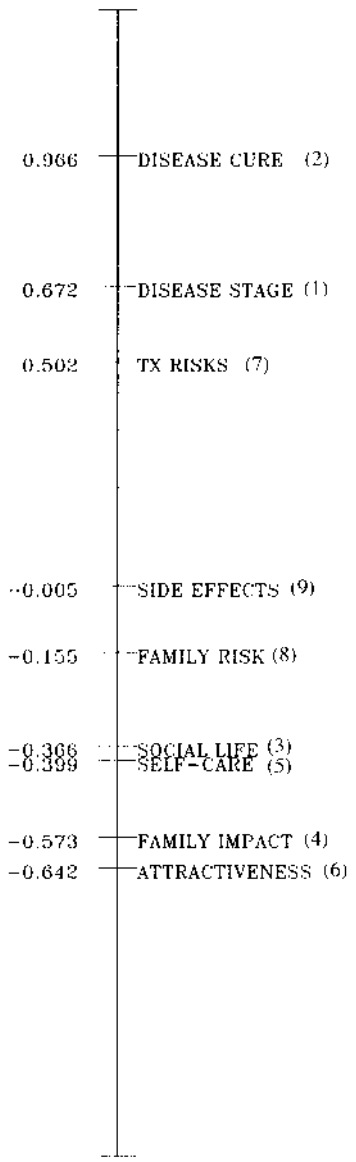

Fig. 2. Profile of information needs for 201 Swedish breast cancer patients—the ranking order of nine items of information. Item number according to Table 1 are presented in brackets.

The Kendall coefficient of consistency showed a mean value of 0.988, indicating very high consistency. Participants in the study generally had few triads and 46 participants had no triad. Maximum number of triads, 20, involved the combination of items 3, 5 and 8 and 17 triads involved the combinations 3, 5 and 7 and 3, 5 and 9, respectively (Table 1). A small group of 11 patients was responsible for a mean of 17 triads, compared to a mean of 3.6 triads for the whole sample. The Kendall coefficient of agreement was 0.299, indicating agreement among all women concerning overall priorities for information. Two different reliability tests were performed: The Gulliksen and the Tukey measures of 0.95 is close to maximal reliability.

Table 3

Preferred role in treatment decisions

Preferred role	Total	Age			Education (information missing = 6)			Time from diagnosis (information missing = 1)	
	No. (%)	≤50 y No. (%)	51–65 y No. (%)	≥66 y No. (%)	Basic no. (%)	Intermed. No. (%)	High No. (%)	≤6 mo. No. (%)	>6 mo. No.(%)
A	5 (3)	2 (2)	2 (3)	1 (2)	1 (1)	1 (2)	3 (5)	1 (1)	4 (3)
B	20 (10)	11 (13)	8 (11)	1 (2)	6 (7)	2 (4)	10 (17)	11 (13)	9 (8)
C	43 (21)	19 (22)	17 (23)	7 (18)	19 (22)	10 (19)	14 (24)	19 (23)	24 (20)
D	113 (56)	54 (61)	37 (51)	22 (55)	43 (51)	35 (67)	31 (54)	48 (59)	64 (54)
E	20 (10)	2 (2)	9 (12)	9 (23)	16 (19)	4 (8)	0 (0)	3 (4)	17 (15)
Total	201	88	73	40	85	52	58	82	118

Preferred and actual role in treatment decisions

Regarding patients' first preference, the most frequently chosen alternative was D (Fig. 1), the most passive of the three collaborative patient roles (B, C, D). D was preferred by 56% of the patients. The majority of patients (87%) preferred to be collaborative in treatment decisions to some degree (B + C + D) (Table 3). In the youngest age group (≤ 50 years), 96% of the patients preferred one of the collaborative roles.

The most active role (A) was preferred by 3% of all patients and 13% preferred to be on the active end of the scale (A + B), whereas 66% preferred to be on the passive end of the scale (D + E). This was most pronounced in the oldest age group (≥ 66 years), where 78% of the patients were on the passive end of the scale (D + E). These patients chose the most passive alternative (E) more frequently (23%) than younger patients (2% and 12%, respectively) (Table 3).

Patients with high level of education preferred a more active role, e.g. 22% preferred a role on the active end of the scale (A + B) compared with patients with intermediate and low education (6% and 8%, respectively) (Table 3). Patients with the lowest education preferred the most passive alternative (E) to a greater extent (19%) than better-educated patients (8% and 0%, respectively).

Considering the two strata of 'time from diagnosis', more patients preferred the most passive alternative (E) later in the process, 15% compared with 4% closer to diagnosis (Table 3).

When asked about the role they actually had in treatment decisions, most of the patients (53%) reported the alternative (D). The oldest patients reported having had the most passive role (E) to a greater extent (35%) than younger patients (9% and 21%, respectively) (data not shown).

Most of the patients played the role that they preferred in treatment decisions, 72% reported agreement with their first preference (Fig. 3). Just above 20% of patients wanted to be more active and 8% wanted to be more passive, whereas among the oldest patients (≥ 66 years) 13% wanted to be more passive. The most passive role (E) was first preference for 10% of the patients but 19% had actually had that role in treatment decisions. Among these patients there were consequently those who would have preferred a more active role. Some patients who were interviewed close to time of diagnosis (≤ 6 months from diagnosis) had been more passive than they preferred—14% had actually had the most passive role (E), while only 4% had (E) as first preference (data not shown).

Unfolding analysis

The aim of the unfolding theory is to investigate the possible existence of an underlying dominant psychological dimension onto which each individual's preference order can be placed. The preferences of the patients in our study did not agree with the proposed underlying psychological

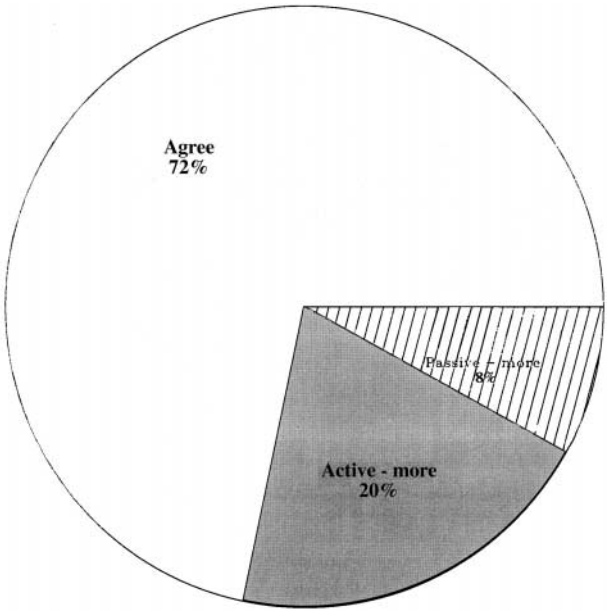

Fig. 3. Congruence between patients' preferred and actual role in treatment decisions.

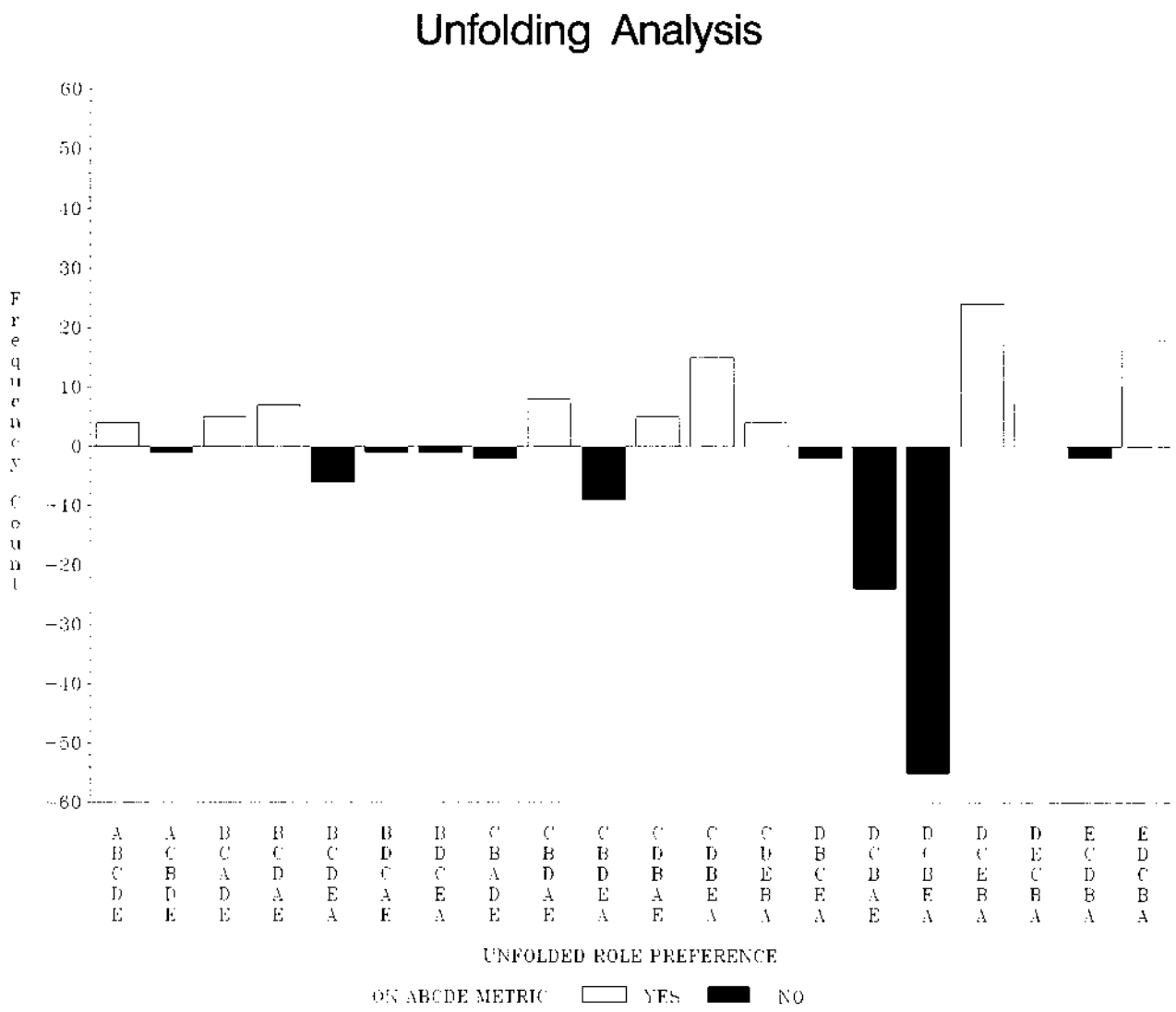

Fig. 4. Frequency of preference orders that fit with an underlying psychological dimension of ABCDE–EDCBA are above the horizontal axis at zero. Preference orders that do not fit are below the axis.

dimension of keeping-sharing-giving away control (ABCDE–EDCBA) according to the criteria postulated by Coombs ($\geq 51\%$) (27). The results are illustrated graphically in Fig. 4. The preference orders that did agree with the model are above the horizontal line (49%) and the ones that did not agree are below the line (51%). To illustrate this graphically, the horizontal line was placed at zero, which means that negative values in reality are positive values.

Analysis of data for subgroups reveals that the preferences of the oldest patients and patients with the lowest education were consistent with the proposed psychological dimension of keeping-sharing-giving away control (65% and 55%, respectively). For patients in the middle age group, the results were just above the limit according to Coombs's criteria $\geq 51\%$ (52%) (data not shown).

As the majority of the preference orders were not consistent with the ABCDE–EDCBA dimension, they were specifically studied. DCBEA, which was the most frequently occurring single preference order (27%), did not fit with the proposed dimension. It starts with the combination DCB, which describes varying degrees of patient–doctor collaboration in treatment decisions. The same can be said about other preference orders that do not fit the model (BCDEA, BDCAE, BDCEA, CBDEA, DBCEA, DCBAE) but also about several that do fit (BCDAE, CBDAE, CDBAE, CDBEA). Together, these 11 preference orders of collaboration represented 66% (133 out of 201) of all preference orders, which constitutes a clear majority of patients' choices.

DISCUSSION

The two most important findings of our study were that Swedish breast cancer patients gave highest priority to

facts about disease and treatment, i.e. information about cure, stage of disease and treatment options, and that they preferred a collaborative role in treatment decisions. The results were essentially consistent when controlling for age, education and time from diagnosis. The same three information categories had the highest priority, regardless of how active patients wanted to be in treatment decisions. Only priorities of the patients preferring the most active role, A, were somewhat different but as they were so few, 5 patients (3%), they will not be discussed separately.

Patients' highest priorities for information about cure, stage of disease and treatment options were consistent with the British and Canadian results (6–8, 28). This does not mean that other information categories are of no importance—they are just of less importance. The method of paired comparison is a useful tool to avoid 'ceiling effects' and to extract a preference order from the patients. Regarding information needs, 'ceiling effects' might however be legitimate—another proof of the importance of considering many aspects of information.

It might seem inconsistent for patients to have a strong preference for disease-related information but to abstain from being active in treatment decisions. However, this was also the conclusion from other studies (6, 7, 16, 18). According to a study of American hypertensive patients, physicians overestimate patients' desire to participate in medical decisions but underestimate their desire for information (18). Patients seem to need to be well informed about their disease for other reasons than to control treatment decisions. There are several potential explanations: information might be used as a coping strategy to gain control and to understand what is happening to body and mind. To leave decisions to the physician might be a reflection of regression and a wish to be taken care of. It might also simply reflect a patient's high and satisfying confidence in the competence of the physician. The findings might also reflect the factual experiences of the patients concerning what information they have been given and what attitude their physicians have demonstrated in treatment decisions. This might even have affected their self-esteem regarding their competence to participate in medical decisions. This interpretation is supported by the tendency to prefer a more passive role when more time has elapsed from diagnosis. Support for this is also implied by the high figure of agreement (72%) between how active patients wanted to be and how active they actually had been in treatment decisions. In a Canadian report there was a striking discrepancy, with only 42% of the patients reporting agreement between their own preferred and realized involvement in treatment decisions (8). Among the discontented Canadian patients, there were more patients wanting to be more active than patients wanting to be more passive. This is assumed to be a reflection of increasing breast cancer activism in North America.

In some previous studies, where patients were reported to prefer an active role, the choice was between only two alternatives, 'I prefer to leave decisions about my medical care and treatment to my doctor' and 'I prefer to participate in decisions about my medical care and treatment' (13, 14). Comparing this with the five options in our study would be to compare preferences for the most passive role (E) with all the others (Fig. 1). An overwhelming majority of patients in our study preferred to participate to some extent in treatment decisions—90%—a considerably higher figure than in the studies using two patient roles (13, 14).

We question the existence of an underlying dominant psychological dimension of keeping-sharing-giving away control for our patients, as their preferences for involvement in treatment decisions did not agree with the unfolding theory. As the majority of our patients had preference orders beginning with any combination of the three roles describing collaboration, we suggest the existence of a new pattern, namely that of collaboration.

However, looking at the passive end of the scale (D + E) the Swedish patients had more 'passive preferences' than English and Canadian patients (5–8). More patients in Sweden preferred D + E (66%) than patients in the UK (52%) and Canada (58%, 43% and 34%, respectively).

Discussions are in progress about an analysis of data concerning breast cancer patients from all three countries.

The card sort procedure along with paired comparisons regarding patient roles is a research methods that allows a theoretical analysis of its results—preference orders. In the clinical situation, however, the method is too complex and time consuming. Patients' first preferred role is more relevant to the clinician than the whole preference order of five patient roles. In future work we therefore intend to use a pick-one method for first preferred role, just as patients in this study picked their 'actual role', a method that has also been successfully used by others (16, 18, 29).

Patients' reluctance to take responsibility in treatment decisions is interesting in the light of the present ethical debate in the Western world, with a shift from paternalism towards increased respect for the autonomy and competence of the patient. Political promises are made about increased patient participation in treatment decisions and improved patient information as a means of strengthening patients' rights.

It is urgent that we learn more about patients' own preferences. Research in medical decision-making is an important tool in evaluating the effects of changes in routines and legislation and in studying possible changes in patient preferences over time. New generations and groups of patients that possibly have other preferences because of changing values or different educational or cultural backgrounds are continuously introduced into the healthcare system. Our results point to such differences where young and well-educated patients have more 'active' preferences

than other patients. Furthermore, on the basis of our results, we suggest that the preference of the 'modern patient' is not to take control over treatment decisions but to communicate with the physician and to demand collaboration. This is also supported by the even more evident results of the Canadian report mentioned earlier (8).

The demand to improve patient information in clinical practice seems to be unquestionable, while the demand for patient activity in medical decisions is less clear. There is evidence that more and better patient information reflects the needs and desires of many patients. Several studies conclude that most patients want a maximum of detailed information, good or bad (13, 15, 30). There is also evidence that physicians underestimate patients' need for information (14, 18). Healthcare givers must respond to these needs and increase their efforts to improve patient information.

The fact that the majority of patients preferred a collaborative role indicates a desire to communicate and puts a demand on doctors to learn effective and sensitive communication skills. Several investigations have shown that many physicians suffer a severe lack of skill in communicating with patients (13, 31–33). There are interesting and promising examples of the positive effect of training physicians in improving their skill in conveying difficult messages (34–36).

Further research is needed to analyse the importance of patients' preferences in decision-making by using simpler methods and to find ways of optimizing the information-giving process. The role of new media, internet and interactive techniques should be investigated. It is important to follow the development towards more open communication and increased patient participation and to be attentive to signs of psychological harm or discontent.

ACKNOWLEDGEMENTS

The study was supported by grants from the Swedish Cancer Society and the Cancer Society of Stockholm.

REFERENCES

1. Lantos J. Informed consent. Cancer 1993; 72: 2811–5.
2. Cassileth B, Zupkis RV, Sutton-Smith K, et al. Informed consent—why are its goals imperfectly realized? N Engl J Med 1980; 302: 896–900.
3. Health and Medical Services Act (Hälso- och sjukvårdslagen). SFS 1982: 763, SFS 1985: 560 (in Swedish).
4. Sätterlund-Larsson U, Svärdsudd K, Wedel H, et al. Patient involvement in decision-making in surgical and orthopaedic practice: the project perioperative risk. Soc Sci Med 1989; 28: 829–35.
5. Beaver K, Luker KA, Owens RG, et al. Treatment decision making in women newly diagnosed with breast cancer. Cancer Nurs 1995; 18: 1–12.
6. Davison BJ, Degner LF, Morgan TR. Information and decision-making preferences of men with prostate cancer. Oncol Nurs Forum 1995; 22: 1401–8.
7. Bilodeau BA, Degner LF. Information needs, sources of information and decisional roles in women with breast cancer. Oncol Nurs Forum 1996; 23: 691–6.
8. Degner LF, Kristjanson LJ, Bowman D, et al. Information needs and decisional preferences in women with breast cancer. JAMA 1997; 277: 1485–92.
9. Degner LF, Sloan JA. Decision making during serious illness: what role do patients really want to play? J Clin Epidemiol 1992; 45: 941–50.
10. Fallowfield LJ, Hall A, Maguire GP, et al. Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. Br Med J 1990; 301: 575–80.
11. Fallowfield LJ, Hall A, Maguire GP, et al. A question of choice: results of a prospective 3-year follow-up study of women with breast cancer. The Breast 1994; 3: 202–8.
12. Richards MA, Ramirez AJ, Degner LF, et al. Offering choice of treatment to patients with cancers. A review based on a symposium held at the 10th annual conference of the British Psychosocial Oncology Group, December 1993. Eur J Cancer 1995; 31A: 112–6.
13. Cassileth BR, Zupkis RV, Sutton-Smith K, et al. Information and participation preferences among cancer patients. Ann Int Med 1980; 92: 832–6.
14. Blanchard CG, Labreque MS, Buckdeschel JC, et al. Information and decision-making preferences of hospitalized adult cancer patients. Soc Sci Med 1988; 27: 1139–45.
15. Fallowfield L, Ford S, Lewis S. No news is not good news: information preferences of patients with cancer. Psychooncology 1995; 4: 197–202.
16. Sutherland HJ, Llewellyn-Thomas HA, Lockwood GA, et al. Cancer patients: their desire for information and participation in treatment decisions. J R Soc Med 1989; 82: 260–3.
17. Degner LF, Farber JM, Hack TF. Communication between cancer patients and health care professionals; an annotated bibliography. Winnipeg, Manitoba: National Cancer Institute of Canada, 1989.
18. Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making? JAMA 1984; 252: 2990–4.
19. Degner LF, Beaton JI. Life–death decisions in health care. New York. NY: Hemisphere Publishing Corp, 1987.
20. Degner LF, Russel CA. Preferences for treatment control among adults with cancer. Res Nurs Health 1988; 11: 367–74.
21. Degner LF, Sloan JA, Venkaresh P. The control preference scale. Can J Nurs Res 1997; 29: 21–43.
22. Ross RT. Optimal orders in the method of paired comparisons. In: Maranell GM, ed. Scaling: A sourcebook for behavioral scientists. Chicago, Ill: Aldine, 1974: 106–9.
23. Thurstone LL. A law of comparative judgement. In: Maranell GM, ed. Scaling: a sourcebook for behavorial scientists. Chicago, Ill: Aldine; 1974: 81–92.
24. Sloan JA, Doig W, Yeung A. A manual to carry out Thurstone scaling and related analytic procedures. Manitoba Nursing Research Institute Technical Report 11. University of Manitoba, Canada; 1994.
25. Sloan J. Using SAS software to analyze paired comparison data via Coomb's unidimensional unfolding model. Proceedings of the 19th SAS Users' Group International (SUGI), Dallas, 1994.
26. Edwards AL. Circular triads, the coefficient of consistence and the coefficient of agreement. In: Maranell GM, ed. Scaling: a sourcebook for behavioral scientists. Chicago, Ill: Aldine, 1974: 98–106.
27. Coombs CH. A theory of data. New York: John Wiley & Sons, 1964.

28. Luker KA, Beaver K, Leinster SJ, et al. The information needs of women newly diagnosed with breast cancer. J Adv Nurs 1995; 22: 134–41.
29. Neufeld KR, Degner LF, Dick JAM. A nursing intervention strategy to foster patient involvement in treatment decisions. Oncol Nurs Forum 1993; 20: 631–5.
30. Meredith C, Symonds P, Webster L, et al. Information needs of cancer patients in west Scotland: cross sectional survey of patients' views. Br Med J 1996; 313: 724–6.
31. Fallowfield LJ. Giving sad and bad news. Lancet 1993; 341: 476–8.
32. Fallowfield LJ. Counselling and communication in oncology. Br J Cancer 1991; 63: 481–2.
33. Fallowfield LJ. Can we improve the professional and personal fulfilment of doctors in cancer medicine? Br J Cancer 1995; 71: 1132–3.
34. Lederberg MS. The psychological repercussions of New York State's do-not-resuscitate law. An American experience with mandated 'truth-telling'. In: Ann NY Acad Sci 1997; 809: 223–36.
35. Aspegren K, Birgegård G, Ekeberg Ö, et al. Improving awareness of the psychosocial needs of the patient—a training course for experienced doctors. Acta Oncol 1996; 35: 246–8.
36. Maguire P, Faulkner A. Improve the counselling skills of doctors and nurses in cancer care. Br Med J 1988; 297: 847–9.