

Information and decision making: Patients' needs and experiences in the course of breast cancer treatment

Barbara A. Vogel ^{*}, Juergen Bengel, Almut W. Helmes

Department of Rehabilitation Psychology and Psychotherapy, University of Freiburg, Germany

Received 28 August 2007; received in revised form 26 October 2007; accepted 24 November 2007

Abstract

Objective: This study explored breast cancer patients' preferences and experiences in receiving information and decision making in the course of the first 6 months of cancer treatment.

Methods: Participants were 135 German breast cancer patients, recruited within a week of either surgery or the beginning of neo-adjuvant chemotherapy. Women were asked to complete a self-explanatory questionnaire at baseline and 3 and 6 months later.

Results: There was a significant decrease in the importance of specific information needs. The quality of received information through the physician was rated significantly better at baseline than 6 months later. Nearly half of all patients changed their decision making preference at least at one assessment point. Shared decision making rarely took place in the first 6 months of treatment.

Conclusion: Breast cancer patients' information needs and decision making preferences can change during treatment. Future research should analyse which patients change their decision making preference under which circumstances.

Practice Implications: Physicians need to investigate the decision making preferences and information needs of their patients in the course of treatment. Patient oriented communication skills might be helpful to meet patients' preferences and needs.

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Keywords: Breast cancer; Decision making preferences; Information needs; Longitudinal study

1. Introduction

Information exchange and treatment decision making are of great importance in cancer care. Without controversy, the provision of information is considered to be a therapeutic intervention and is part of standard care [1]. According to a review the benefits of information for cancer patients include a decrease in anxiety and insecurity and an increase of compliance, realistic expectations and patient participation [2]. In order to fulfil patients' needs and to help patients cope with cancer, research has focused on information needs of cancer patients. Research has indicated that the vast majority of patients wants to be extensively informed regardless of whether it is positive or negative [3–6]. However, there is a substantial variability among patients what information is considered

important and for what purpose the information is needed [7–9].

According to a review by Mills and Sullivan [2] information on treatment and side effects, extent of the disease, prognosis, and self-care are most relevant for cancer patients. A more recent review summarizing 112 articles from 1980 to 2003 found that the three categories treatment related information, cancer specific information and rehabilitation information were most prominent for cancer patients [10]. To meet cancer patients' information needs we need to understand how their needs change over time. But our knowledge on information needs along the continuum of care is limited, since very few longitudinal studies exist. So far, most studies used cross-sectional or retrospective designs. One review included cross-sectional and longitudinal studies and concluded that information needs vary over time [11]. Around diagnosis most patients preferred information on the likelihood of cure, treatment options and the stage of the disease. At the beginning of the treatment information on the treatment was particularly important, but also information on the disease, medical tests and the recurrence. During post-treatment patients still wanted information regarding recovery but also regarding

^{*} Corresponding author. Abteilung fuer Rehabilitationspsychologie, Institut fuer Psychologie, Universitaet Freiburg, 79085 Freiburg, Germany.
Tel.: +49 761 203 3041; fax: +49 761 203 3040.

E-mail address: vogel@psychologie.uni-freiburg.de (B.A. Vogel).

the risk for other family members of getting cancer and information about self-care and rehabilitation. Information does not only allow patients to better cope with their illness, information is also an essential requirement for patient participation in decision making. Treatment decision making in cancer care has become more difficult for cancer patients and their physicians over recent years: the number, complexity and side effects of different therapies make it difficult to assess costs and benefits of different treatment options. Therefore, it is difficult for physicians to choose the right treatment without knowing the patients' preferences. Patient participation in decision making is also strongly advocated because it enhances cancer patients' control over their health care and results in more patient oriented decisions [12] and may lead to better health outcomes [13–15]. However, not all cancer patients want to participate in decision making and the preferences for involvement of cancer patients vary substantially in different studies [4,16,17]. More than half of all cancer patients experience a mismatch between preferred and actual decision making role [18–22]. There is evidence that a mismatch between preferred and actual decision making role is associated with reported difficulties in decision making, lower patient satisfaction and decisional regret [22–24].

Similar to the research on information needs in the course of treatment, there are only few studies on the stability of cancer patients' decision making preferences over time. One study examined the decision making preferences of 21 lung cancer patients for a hypothetical lung cancer treatment scenario in relation to their recalled former desired involvement. Half of all patients changed their preference (median since real treatment decision was 8.3 months), 7 patients preferred more and 3 less involvement [25]. The results of this study are limited, because of the small sample size and the retrospective design. To our knowledge there are only two studies with cancer patients using a longitudinal design, one assessing short-term changes in decision making preferences [26] and one long term changes [13]. Butow et al. assessed decision making preferences of 80 cancer patients before and immediately after their consultation in an out-patient clinic. Most patients (73%) maintained their preference from pre- to post-consultation, while 24% preferred more and 2% less involvement. It was possible to assess the decision making preferences of 40 of the 80 patients at their next consultation (usually 3–6 months later). By the time of the second consultation 31% preferred the same level of involvement, 46% preferred more and 23% preferred less involvement. The authors concluded that decision making preferences were relatively stable in the short term but shifted considerably already after 3–6 months. A limitation of this study was that the time between the first and the second assessment-point and the time since diagnosis were not controlled. The study of Hack et al. [13] analysed decision making preferences of 205 breast cancer patients at baseline (diagnosis within the last 6 months) and 3 years later. Most patients (52%) changed their preference compared to their actual role at baseline and tended towards a stronger preference for active and collaborative involvement. Patients of this study were 3.5

times more likely to move toward wanting more active than passive involvement. However, it has to be considered critically, that the patients' role preferences 3 years after baseline were not assessed for a real life treatment decision; patients instead were asked to imagine that they had to proceed through the treatment process again. So far no study assessed whether the concordance between preference and experience changes over time.

The purpose of the present study was twofold. First, we wanted to analyse breast cancer patients' information needs and experiences with information receiving in the course of the first 6 months of treatment. We wanted to know which topics are most relevant for patients at the beginning of treatment and after 3 and 6 months and how patients rate the quality of the information received. Second, we wanted to investigate the stability of breast cancer patients' decision making preferences and experiences in the first 6 months of treatment. We wanted to know if patients experience decisional congruence between preferred and actual role and if that changes over time.

2. Methods

2.1. Sample and method

A consecutive sample of women with a diagnosis of breast cancer was approached to participate in the study at the two breast cancer centers in Freiburg, Germany. Other eligibility criteria included: age 18–75, first time breast cancer diagnosis and no evidence of metastases. Study staff approached patients within a week of beginning their initial treatment (either mastectomy, breast conserving therapy or neo-adjuvant chemotherapy). Patients were asked to complete a self-explanatory questionnaire and return it in a sealed envelope. All study participants provided written informed consent. Three and 6 months after baseline assessment all participants received the questionnaire again via mail and were asked to return it in a pre-paid envelope within 2 weeks. Patients who did not return the questionnaire were reminded after 3 weeks by telephone to send it back. Additionally, information on time of diagnosis and type of treatment (surgery or neo-adjuvant chemotherapy) was obtained from the medical records. The study protocol was approved by the German Psychological Association's Institutional Review Board.

2.2. Measures

2.2.1. Information

We used eight items to assess the specific cancer related information needs adapted from Schofield et al. [27]. Patients were asked to indicate the importance of the following eight topics on a 5-point scale (ranging from 1 = "not important at all" to 5 = "extremely important"): information on diagnosis, prognosis, treatment, medication and side effects, examinations and medical tests, aftercare, support services and impact of illness and treatment on social, family and sexual life. We measured quality of received information with the following two items: "How well were you informed by your responsible

physician or other health care professionals?” and “How well were you informed overall (by your physician, books, internet, etc.)?”. The response structure for these two questions was a scale of 1–4, with 1 meaning “badly” and 4 meaning “very well”.

2.2.2. Participation

A German translation of the Control Preference Scale (CPS) from Degner and Sloan [28] was used to elicit patients' preferences and experiences for treatment decision. This scale has been used in most studies concerning patient participation and assesses the preferred and actual decision making role. The scale differentiates between a passive, active or collaborative decision making role.

Satisfaction with the decision making process was measured with the item “I am satisfied with the process by which the treatment decision was made” on a 4-point scale (ranging from 1 “completely disagree” to 4 “completely agree”). This item was adapted from Keating et al. [22].

2.3. Analysis

Statistical analyses included descriptive statistics for all measures. We used analysis of variance for repeated measures and Bonferroni post hoc tests, comparing T1 and T2, T2 and T3 and T1 and T3 for all continuous variables to test for differences in variables over time. Analysis of variance for repeated measures also examined differences in the importance between the eight specific information topics for each assessment point separately. The Pearson Chi-square statistic was conducted to test for differences over time in decision making preference. A Cochran *Q*-test was conducted to test whether the rate of congruence changed over time.

3. Results

3.1. Patient characteristics

In total, 243 patients were invited to participate, 135 women agreed to participate, 108 women declined, representing an absolute response rate of 56%. Patients who refused participation most commonly reported no interest in the research subject or stated that they were too distressed to participate.

Few women were lost to follow up at 3 (T2) and 6 (T3) months: 10 women of the 135 participants indicated that they did not wish to continue in the study at T2, producing a response rate of 93% and a sample size of 125. At 6-month follow-up, data were available for 118 patients, 6 patients did not wish to continue in the study and one patient had died of cancer.

Table 1 presents the characteristics of the study participants. The participants in this sample were on average 54 years old, ranging from 19 to 75. About 71% of all women were married and more than three fourths had children (78%). Nearly 31% had graduated after 13 years of schooling. More than half of all participants were full or part time employees (51%). The

Table 1
Patient demographics and characteristics

	%	N = 135
Age		
Mean age (S.D.)	53.9 (10.9) years	135
Range	19–75	
Marital status		
Married	71.1	96
Single	11.9	16
Divorced/separated	11.9	16
Widowed	5.2	7
Living with a partner		
Yes	80.5	103
No	19.5	25
Children		
No	22.2	30
Yes	77.8	105
Duration of school-education		
13 years of school education	30.6	41
10 years of school education	26.9	36
9 years of school education	42.5	57
Employment status		
In training	0.8	1
Full time employed	24.8	33
Part time employed	26.3	35
Unemployed	3.8	5
Retired	25.6	34
Housekeeping	15.0	20
Else	3.8	5
Treatment		
Neo-adjuvant treatment	22.2	30
Breast-conserving treatment	42.2	57
Mastectomy	35.6	48

majority underwent surgery (36% mastectomy and 42% breast conserving treatment) while 22% underwent neo-adjuvant treatment.

3.2. Information

All specific information needs except one changed over time. There was a significant decrease in the importance of information on diagnosis, prognosis, treatment, support services and impact of illness and treatment from T1 compared to T2 and T3 (see Table 2). Concerning these topics patients had the highest information needs at beginning of treatment, with a decrease of needs in the course of treatment. There was a significant decrease in the importance of information on medication and side effects from baseline to 6-month follow-up. Information on aftercare was most important at T3 followed by T1 and then T2. The difference was statistically significant between T1 and T2 and between T2 and T3. There was only one specific information which was equally important at all assessment points: information on examination and medical tests. Table 2 shows means and effect sizes for all specific information needs.

Separate analysis for each assessment point showed that information topics differed in their importance (T1: $F = 43.92$,

Table 2
Needs and experiences in the course of cancer treatment

Item/scale (N = 118)	Mean T1	Mean T2	Mean T3	F-Score	p-Value	χ^2
Diagnosis	4.0	3.3	3.4	35.25	.000	.236
Prognosis	3.9	3.6	3.6	8.08	.000	.066
Treatment	4.1	3.9	3.8	8.76	.000	.073
Medication & side effects	3.9	3.8	3.6	5.085	.007	.042
Examination & medical tests	3.8	3.7	3.6	2.67	.071	.023
Aftercare	3.9	3.7	4.0	6.49	.002	.053
Support services	3.1	2.8	2.8	8.07	.000	.066
Impact of illness and treatment	3.2	2.9	3.0	7.48	.001	.062
Information from physician	3.1	3.0	2.8	6.18	.002	.054
Overall information	3.0	3.0	3.0	.26	.758	.002

d.f. = 5.6, $p = <.001$; T2: $F = 45.95$, d.f. = 5.64, $p = <.001$; T3: $F = 44.04$, d.f. = 5.02, $p = <.001$). Information on support services and information on impact of illness and treatment were significantly less important compared to all other information topics at all assessment points. In addition, information on diagnosis was significantly less important at T2. At T3 information on aftercare was significantly more important than all other information topics.

Patients rated both the quality of received overall information and the quality of received information from the physician as high (see Table 2). There was no significant change in the quality of overall received information over time; however the quality of information through the physician was rated significantly better at baseline compared to T3.

3.3. Decision making

Table 3 shows patient decision making preferences and experiences at baseline and at 3- and 6-month follow-up. On average, 38% of the patients preferred the physician to make the decision about the treatment and 27% wished to share the decision while 35% wanted to make the decision on their own.

Overall, half of all patients had a stable preference and 50% changed their preference at least at one assessment-point. However, changes in preference did not reach statistical significance ($\chi^2 = 5.28$, d.f. = 2, $p = .071$). Fig. 1 shows changes in participation preference in relation to the formerly preferred decision making role. Examination of

congruence between preferred role at baseline and preferred role at T2 showed that 39% changed their preferred role. Compared to the preference at baseline 13% preferred less and 25% more involvement, 62% preferred the same level of involvement as at baseline. At T3, 68% had the same preference as at T2, 15% preferred less and 17% more involvement.

Table 3 shows also patient decision making experiences at T1, T2 and T3. Only patients who made a treatment decision at the respective assessment point were included in the analysis. Therefore, we included 104 patients (83%) at T2 and 64 patients (55%) at T3 and calculated weighted means. On average, nearly half of all patients (48%) stated that they did not participate, while one third of all patients (35%) stated they actively participated. Only 17% stated that shared decision making had taken place.

At baseline 63% experienced concordance in preferred and actual roles compared to 76% at T2 and 71% at T3. On average, 70% were able to fulfill their preferred decision making role. Congruence between preferred and assumed role did not change over time (Cochran- $Q = 3.06$, d.f. = 2, $p = .217$). Satisfaction with decision making was high (on average: 3.5) and did not change over time ($F = .17$, d.f. = 2, $p = .845$).

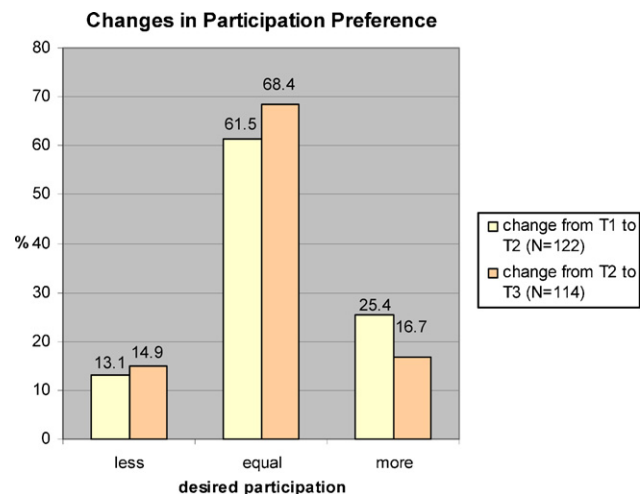


Fig. 1. Changes in participation preference.

Table 3
Preferences and experiences in decision making

	T1 (N = 134)	T2 (N = 123)	T3 (N = 115)	Total
Preference (%)				
Passive	40.3	39.0	34.8	38.0
SDM	29.1	22.8	30.4	27.4
Active	30.6	38.2	34.8	34.5
	T1 (N = 133)	T2 (N = 103)	T3 (N = 62)	Total
Experience (%)				
Passive	51.9	45.6	43.5	48.3
SDM	13.5	18.4	21.0	16.8
Active	34.6	35.9	35.5	35.2

4. Discussion and conclusion

4.1. Discussion

The purpose of this study was to examine the preferences and experiences in receiving information and decision making in the course of breast cancer treatment from the patients' perspective. The analysis of the information needs showed that patients want a great amount of specific information concerning their illness and treatment. This finding was in line with earlier studies [5,29]. All specific information needs except one changed over time. As expected, patients have the highest information needs at beginning of treatment, with a decrease of needs in the course of treatment. This is in line with earlier results from Butow et al. [26]. In this study information needs changed with the majority wanting less detailed information 3 to 6 months later in treatment. Nevertheless, the specific information needs of patients of our study remained high even at follow-up. This result is in line with another study where women also continued to have high information needs [30]. The comparison of all specific information topics revealed that information on support services and information on impact of illness and treatment were significantly less important at all assessment points.

Patients rated the quality of received information as high at all assessment points; however, there was a significant decrease in the satisfaction with the information giving through the physician from baseline to 6-month follow-up. It is unclear whether this is due to more critical patients or due to a deterioration of physicians' performance in information giving in the course of treatment.

This study is the first one to use a longitudinal design in order to analyse decision making preferences and experiences of breast cancer patients in the first 6 months of initial treatment. Our study found that on average 38% preferred the physician to make the decision, 27% wished to share the decision and 35% wished to decide alone. Other studies with breast cancer patients found lower preferences for passive decision making (e.g. [21,22,24,31,32]). These studies used only one assessment-point, in the first months of treatment. In contrast to our study, in these studies most patients preferred a collaborative decision making role. So far it is unclear why so many patients of our study wished no involvement. Reasons could be cultural differences or differences in the health care systems.

Statistically, preferences for decision making did not change in the first 6 months after initial treatment, however, there was a considerable variability in the decision making preferences over time. Overall, 50% had a stable role preference, while 38% at 3 months and 32% at 6 months follow-up changed their preference. These results confirm earlier results from Butow et al. [26] and suggest that preferences for involvement vary in the short term and tend to depend on state or situation. In contrast to the results of Butow et al. more patients in our study (50% versus 31% in the study of Butow et al.) had a stable decision making preference.

At 3-month follow-up nearly twice as many patients who changed their preference compared to baseline, preferred more

involvement (25% versus 13%), at T3 patients wished equally more (17%) and less (15%) involvement. In summary, during the first 6 months of treatment role preferences can change, but the direction is not clear. The picture for long-term effects may be different: in a study [13] with a 3 year follow-up 52% of breast cancer patients preferred more involvement for a hypothetical treatment decision compared to their assumed role 3 years ago.

Similar to previous studies (compare 13, 22) satisfaction with decision making was high. Compared to previous study results in which more than half of all cancer patients experienced a mismatch between preferred and assumed decision making role [20–22,33] the rate of congruence between preferred and assumed role in our study was high (on average 70%). The high concordance in our study could be due to the high number of patients preferring a passive role, which was the standard role in the past. This is the first study assessing the rate of congruence in the course of treatment. Our results show that the rate of congruence did not improve over time as one might expect due to an increase of physicians knowledge of patients' preferences. However, the rate of congruence started out high at baseline (63%), so it would have been difficult to improve the rate further.

There are some limitations to the study that need to be considered: first, we used categories (e.g. information on treatment) to assess patients' information needs. The use of categories allows getting an overview of what topics are relevant for patients. However, previous research has shown that specific information relating to one category can differ in their importance to patients [9]. Therefore, the use of categories allows only a first insight into the preferences. More research assessing information needs between the different categories in the course of treatment is needed. Secondly, this study used patient self-reports to investigate whether or not the decision making preferences of the patients were being met. No observational measurement was used to assess the decision making experience of the patients. The patients' view of shared decision making may be different from that of health professionals [21,34]. Finally, concerns have been raised about the validity and reliability of the CPS showing that the role label approach of the CPS might be too simplistic to capture the complexity involved in decision making [35,36]. Like other studies in the field, we were able to assess only some determinants of the complex process of information exchange and decision making. Other aspects like stage of disease, kind of treatment decisions (e.g. hormone therapy, breast reconstruction and chemotherapy) or personality of the physician, all may have an impact on the patients' needs or experiences and were not assessed. Nevertheless, this study allows for the first time an insight into preferences and experiences of cancer patients regarding information and decision making in the course of the first 6 months of treatment.

4.2. Conclusions

This study showed that breast cancer patients have high information needs and there is no dramatic change in those

needs in the first 6 months of treatment. Unlike anecdotal information in clinical settings, patients were generally satisfied with the information process and felt that their needs were met by their physicians. Contrary to the general trend to involve patients in cancer care a relatively low number of patients in this German sample wanted to share the decision with the physician. Shared decision making from the patient view rarely took place.

Our results obtained from breast cancer patients facing real treatment decisions in a longitudinal design make clear that decision making preferences are no static.

4.3. Practice implications

The finding that not all patients want to be involved in decision making proves the need to evaluate the decision making preference on an individual basis. The fact that almost half of all patients changed their decision making preference in the first 6 month of treatment puts even more emphasis on this. Therefore, physicians should assess patients' decision making preferences not only in the beginning of treatment but during the entire course of it. In order to use the benefits of patient participation efforts should be made to ensure that at least those patients who want to be involved in decision making are able to have their expectations met. Physicians may need training to better conceive and meet patients' participation needs. Patient oriented communication skills might be useful to meet this task.

Disclosures

We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Acknowledgement

This research grant was funded by the Landesstiftung Baden-Wuerttemberg, Germany.

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