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The Meaning of Breast Cancer

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Breast cancer patients' perception of illness could influence preferences in decision-making. According to Lipowsky, the meaning of illness might influence coping abilities and he suggests eight categories of meaning as prevalent in our culture: 'challenge', 'enemy', 'punishment', 'weakness', 'irreparable loss', 'relief', 'strategy' and 'value'. In this study 187 Swedish breast cancer patients chose one of these eight categories as their meaning of breast cancer. 'Challenge' was chosen most often, by 33% of all patients and by 40% of patients in middle life (51–65 years). Older patients ($\geq$ 66 years) chose 'challenge' less frequently (17%) but chose 'relief', 'strategy' or 'value' more often than younger patients. The few patients with metastatic disease chose 'enemy', 'punishment', 'weakness' and 'irreparable loss' more often than patients in the earlier stages of disease. There were differences in perception of illness depending on patients' age and stage of disease but not depending on their preferences in decision-making.

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The meaning that breast cancer patients attribute to their disease reflects psychological as well as cultural factors. Today, patients' subjective meaning of illness might also be influenced by the political debate encouraging consumer attitudes towards healthcare, which demands improved patient information and increased patient participation in treatment decisions. Our 'health culture', which encourages fighting spirit and describes the immune system in military terms, presumably affects patients' perceived meaning of illness and assumed patient roles.

In 1970 Lipowski, a Canadian psychiatrist, stated that patients' perceived meaning of illness would influence their choice of coping strategies, which might spell 'the difference between optimum recovery and psychological invalidism' (1).

According to Lipowski, coping behaviour is a result of multiple factors—intrapersonal, disease-related and environmental. Intrapersonal factors include age, personality, intelligence, skills, values, beliefs and timing of illness in the life cycle. Environmental factors include, for example, the patient's social relations. All these factors contribute to patients' subjective meaning of illness that influence the choice of coping strategies. Patients' subjective meaning of illness might change with time from diagnosis and during the course of the disease.

Lipowski suggested eight meanings of illness as relevant for patients in the Western world: *challenge*, *enemy*, *punishment*, *weakness*, *irreparable loss*, *relief*, *strategy* and *value*. *Challenge* is the meaning leading to active and adaptive coping strategies and is hence socially desired. *Value*—that illness and suffering have an intrinsic value—is said not to be prevalent as a meaning of illness in our hedonistic society. Lipowski gave his interpretations of all eight categories (Table 1). Lipowski's thesis from 1970 has had an impact on the debate and on the development of the concept of coping.

In Europe, Antonovsky's concept of a 'Sense of Coherence' has gained considerable attention representing ideas related to Lipowski (2,3). According to Antonovsky, a patient's experience of health is related to her or his 'Sense of Coherence' in an individual, societal and cultural context. The 'Sense of Coherence' starts to develop during childhood and 'represents a web of linkages between the person and her or his world'. Health is not a condition of 'healthy or ill' but represents a health continuum, the position varying with time. Thus, the definition of health is relative and allows for health even in a situation of diagnosed disease. This can be related to Lipowski's thesis that intrapersonal, disease-related and environmental factors have an influence on a patients's subjective meaning of illness.

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Table 1

Meaning of illness with abbreviated interpretations based on Lipowski. Results for 187 breast cancer patients

Category	Interpretation	No. (%) n = 187
1. Challenge	The disease is perceived as any other task in life that can be mastered with means and resources available.	62 (33)
2. Enemy	The disease is perceived as an attack by hostile forces, internal or external.	42 (22)
3. Irreparable loss	The disease is perceived as an overwhelming loss that nothing can replace. For some individuals even a seemingly minor loss of function may do this.	29 (15.5)
4. Punishment	The disease is perceived as just or unjust. It can be regarded as a means for atonement, forgiveness.	16 (8.6)
5. Weakness	The disease is perceived as a failure, a sign of loss of control with negative moral implications. A feeling of shame may be involved.	14 (7.5)
6. Value	The suffering related to the disease is perceived as something valuable, as a way to develop and mature.	14 (7.5)
7. Relief	The disease is perceived as a respite from demands and responsibilities to be strong or a respite from a current crisis.	7 (3.7)
8. Strategy	The disease is perceived as a technique to secure attention, support or compliance from others.	3 (1.6)

A research model on decision-making was initiated by Degner (4) and continued in Great Britain (5) and Sweden (6). In Canada and Great Britain the preference instruments have been completed by a test of meaning of illness as developed by Lipowski (pers. comm. (7)). We sought to fulfil the research collaboration by testing Lipowski's instrument on the Swedish breast cancer patients who took part in our decision-making study (6).

Challenge was the category chosen most often in both Canada, by 57% of the patients (pers. comm.), and in Great Britain, by 62% (7). The second most common choice was *value*, chosen by 27% in Canada and 14% in Great Britain. The third choice in both countries was *enemy*, chosen by 8% and 13%, respectively.

The aims of the present study were 1) to investigate the meaning that Swedish breast cancer patients attribute to their disease; 2) to examine differences in distributions of meaning of illness by patients' age, education, stage of disease, time from diagnosis, patients' reported information needs and preferences for participation in treatment decisions (6).

Our hypothesis was that *challenge* was likely to be the dominating choice, especially among younger and better-educated patients and by patients interviewed when more time had elapsed since breast cancer diagnosis. Our second hypothesis was that patients who preferred to be active or cooperative in treatment decisions would choose *challenge* more often than other patients.

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 department at Radiumhemmet, Karolinska Hospital in Stockholm. Eligible patients were those who had been diagnosed with breast cancer within the last 18 months; had undergone primary surgery; were under 75 years of age; showed no sign of mental illness; had not been previously diagnosed with cancer and were able to speak and read Swedish.

A total of 201 patients (77%)) agreed to participate in the decision-making study (6) and were interviewed between July 1994 and March 1995. Most of them also participated in this study (187 patients, 93%). Fourteen patients (7%) did not find any of the categories appropriate for their subjective meaning of illness. The sample was stratified into two groups: 1–6 months and 7–18 months after breast cancer 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'; and 3) High: university.

The Ethics Committee of the Karolinska Hospital approved the study.

Procedure

One or two days prior to a regular appointment with their physician at the breast cancer clinic, the patients were informed by telephone about the study by a research assistant. 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 their 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. Patients willing to participate were interviewed the same day.

The information about the study and the interviews were conducted by two research assistants. As the research design and tools were adopted from a Canadian research group, the research tools had been translated from English to Swedish and then back to English again, according to

standard procedures. The translations were undertaken by professionals in cancer care.

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.

Methods

1. Meaning of illness. To establish 'the meaning of illness' in the context of breast cancer, the patient was presented with eight cards, each containing—written in block letters—one of the categories defined by Lipowski (1) (Table 1). The cards were laid out in random order on the table in front of the patient. The patient was asked if she needed an explanation of one or more of the categories, in which case the research assistant read aloud an abbreviated interpretation based on that of Lipowski (1) (Table 1).

The patient was asked to select the card with the category that best described what the breast cancer experience meant to her at the present moment and to explain the selected category in her own words. The research assistant wrote down the explanation.

2. Information needs. This part of the interview aimed at establishing a profile of information needs for women with breast cancer and has been reported (6). The patients ranked nine categories of information covering medical, psychological and social issues. A paired comparisons method was used to make it possible for the patients to rank as many as nine items.

3. Participation in treatment decisions. A card-sorting procedure developed by Degner & Sloan (8) was used to determine preferences for participation in treatment decisions and has been reported (6). Five cards described, in words and pictures, five potential roles for patients in relation to their physicians when treatment decisions are made: A, B, C, D and E (see Fig. 1).

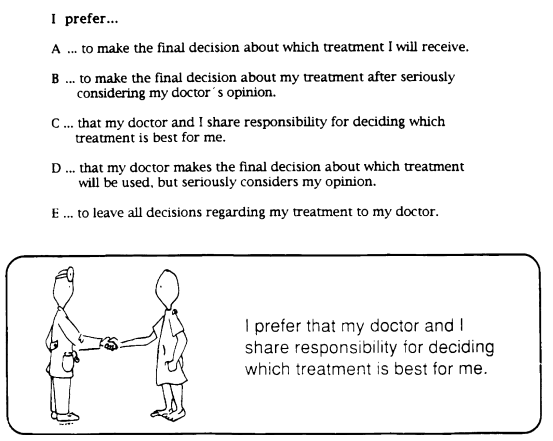

Fig. 1. Five patient roles describing potential patient–physician relations in treatment decisions. The diagram illustrates alternative C—the most collaborative role.

A paired comparisons procedure was used to produce a ranking order of all five patient roles. In the present study we used the results of patients' first preference.

The patient was then asked to pick up the card representing the patient role that best described her actual role in relation to her doctor when treatment decisions were made (see Fig. 1).

Analyses

Analyses were based on two different classifications of the categories.

1. Based on their choices, the participants were divided into three groups. The first group consisted of patients who had chosen the most frequently chosen category—*challenge*. The second group comprised patients who had chosen one of the remaining categories indicating a 'positive' meaning of illness (*value*/*relief*/*strategy*). The third group consisted of patients who had chosen a category indicating a 'negative' meaning of illness (*enemy*/*punishment*/*weakness*/*irreparable loss*).
2. Based on their choices, the participants formed three groups according to a classification used by Degner (pers. comm.). The first group consisted of women who had chosen the category *challenge*, the second group consisted of those who had chosen *value* and the third group consisted of those who had chosen *enemy*/*punishment*/*weakness*/*irreparable loss*. These groupings were derived from the women's descriptions of meaning in a qualitative analysis that preceded the subsequent quantitative analysis. The remaining categories *relief*/*strategy* were deleted in the Canadian study owing to insufficient numbers to make comparisons.

Chi-square analysis was used to investigate possible differences in distributions between the groups regarding age, education, time from diagnosis, stage of disease at diagnosis and interview, information needs and patients' preferred and actual role regarding participation in treatment decisions.

Patients' interpretations of their chosen categories were compared with the interpretations made by Lipowski (1) (Table 1).

RESULTS

Most of the patients chose *challenge* (33%) as their perceived meaning of illness (Table 1). *Enemy* was the second choice (22%) and *irreparable loss* the third most common choice of patients (15.5%).

The eight meanings of illness were classified into three groups (Table 2). Chi-square analyses of subgroups showed that patients' age had an impact—*challenge* was chosen by significantly more patients in middle life (51–65

Table 2

Two groupings of categories regarding meaning of illness according to text

Group of categories	No. (%) n = 187	Group of categories according to Degner	No. (%) n = 177
1. Challenge	62 (33)	1. Challenge	62 (35)
2. Enemy/Punishment/Weakness/Irreparable loss	101 (54)	2. Enemy/Punishment/Weakness/Irreparable loss	101 (57)
3. Value/Relief/Strategy	24 (13)	3. Value	14 (8)

years, 40%) and by fewer patients in the oldest age group ($\geq$ 66 years, 17%) ($p = 0.014$) (Table 3). *Relief*, *strategy* and *value* were chosen by more patients over 66 years (29%) than by patients in the youngest and middle-age groups (11% and 7%, respectively) ($p = 0.014$).

Stage of disease influenced meaning of illness (Table 3). All six patients with distant metastases at the time of diagnosis chose *enemy*, *punishment*, *weakness* or *irreparable loss* as their meaning of illness. Although the number of patients was small, the result was statistically significant ($p = 0.025$). Of the 14 patients with metastatic disease at the time of interview, 10 patients chose *enemy*, *punishment*, *weakness* or *irreparable loss* and 4 patients chose *challenge*. The difference was close to being statistically significant ($p = 0.064$).

There were no statistically significant differences in meaning of illness when other subgroups were considered (educational level, time from diagnosis) or when considering patients' information needs or preferred and actual roles in treatment decisions (data not shown). Highest priority was given to the same three information needs, and in the same order, in all three groups regarding meaning of illness as for all patients (6)—i.e. chances of cure, stage of disease and different types of treatment (data not shown). The distribution for meaning of illness by preferred patient roles is presented in Table 3.

Our data were also analysed with the same grouping as that reported by Degner et al. (Table 2) (pers. comm.). With this grouping of our data, χ^2 analyses of subgroups led to statistically significant differences only for different age groups ($p = 0.009$) (data not shown). Patients in middle life (51–65 years) chose *challenge* more often (42%) and patients older than 65 years more seldom (19%) than all patients (35%). Patients in the oldest age group (22%) chose *value* more frequently than younger patients. There were no statistically significant differences in meaning of illness by other subgroups (education, stage of disease, time from diagnosis) or by information needs, or preferred and actual role in treatment decisions.

Patients' subjective interpretations of their selected meaning of illness

As many as 120 patients (64%) of the patients were able to explain in their own words how they interpreted the meaning of illness that they had chosen.

Patients who chose *challenge* interpreted the word as: 'the disease must be managed', 'a challenge to get well' and 'something you have to go through'.

Enemy was explained in words such as: 'something that threatens me', 'something bad in my body that frightens me', 'strange, uncontrollable, inconceivable' and 'poisonous, unfamiliar'.

Irreparable loss was described as 'something that cannot be repaired', 'life is lost', 'loss of health', 'loss of security' but also 'loss of a part of the body that means a great deal'.

Punishment was interpreted as: 'I have been a smoker', 'what have I done that gave me this?' and 'I often joke that I have committed so many sins that now I am getting my punishment.'

Weakness: 'physical weakness', 'I have never felt strong and confident in myself' and 'it's in the upbringing—you are weak if you are ill'.

Table 3

Differences in categories of meaning by age, stage of disease and preferred patient roles in decision-making

Group of categories	No. (%) n = 187	Age $\leq$50 y n = 82	Age 51–65 y n = 70	Age $\geq$66 y n = 35	Stage 4 at diagn. n = 6	Stage 4 at interview n = 14	Pat. role A n = 4 (2)	Pat. role B n = 19 (10)	Pat. role C n = 41 (22)	Pat. role D n = 104 (56)	Pat. role E n = 19 (10)
1. Challenge	62 (33)	28 (34)	28 (40)	6 (17)	0 (0)	4 (29)	1 (25)	6 (32)	18 (44)	32 (31)	5 (26)
2. Enemy/ Punishment/ Weakness/ Irreparable loss	101 (54)	45 (55)	37 (53)	19 (54)	6 (100)	10 (71)	3 (75)	11 (58)	16 (39)	60 (58)	11 (58)
3. Value/Relief/ Strategy	24 (13)	9 (11)	5 (7)	10 (29)	0 (0)	0 (0)	0 (0)	2 (10)	7 (17)	12 (11)	3 (16)

Value was interpreted as 'a help to mature', 'experience', 'I don't take everything for granted, material things are not so important' and 'I think differently and appreciate small things.'

None of the four patients that chose *relief* interpreted it in the same way as Lipowski (1) (Table 1). The patients said: 'a relief when I was told what it was', 'a relief that I did not need radiotherapy', 'a relief to get rid of it as it was cancer in situ' and 'a relief that it is over'.

Neither of the two patients who chose *strategy* interpreted it in Lipowski's terms (Table 1): The patients said:'you have to reconsider, it means changes, consider how to handle the situation' and 'close to challenge'.

DISCUSSION

The most important findings were that *challenge* was the most frequently chosen meaning of illness among all patients in the study and especially among patients in middle life. These results were congruent with our hypothesis.

Today, most newly diagnosed breast cancer patients will be cured of the disease by surgery and adjuvant therapies (9). When asked about information needs, patients consider 'chance of cure' and 'stage of disease' as top priorities (6, 4). Receiving this information at diagnosis will add to the possibility of their adopting a realistic attitude—managing uncertainty becomes a major challenge.

Many patients are convinced that other factors than those related to tumour biology have a strong impact on the development and course of a cancer disease. This might influence an active attitude like accepting a challenge.

Some patients who chose *challenge* stressed that nearer to the time of breast cancer diagnosis they would have chosen another category. They said: '*challenge* now—but all categories have been present during the process.' '*punishment* or *enemy* between operation and other treatment.'

These statements were congruent with our hypothesis that more patients would chose *challenge* when more time had elapsed since diagnosis of breast cancer. Statistically, however, there were no significant differences to be found regarding time from diagnosis. These findings are consistent with those of the Canadian study (pers. comm.).

Our hypothesis, that patients who wanted to be active or cooperative in relation to their physicians would view *challenge* as their meaning of illness, was not confirmed. However, it is important to note that, in contrast to Lipowski, some Swedish patients had an active interpretation of other categories than *challenge*.

Thus some patients' interpretations of *challenge* and *enemy* came very close—one patient explained: '*challenge*, in fact an enemy, but it will be defeated'.

This is in contrast to the central point in Lipowski's interpretation of *enemy*: 'disease is viewed as an invasion by inimical forces, internal or external… the usual emotional concomitants of this meaning are anxiety, fear and/or anger' (1). Most of our patients who chose *enemy* confirmed this interpretation of *enemy*.

The few patients with incurable breast cancer (stage 4) (Table 3) clearly chose their meaning of illness from the group *enemy/punishment/irreparable loss/weakness*. However, in our clinical experience, many patients in this situation keep on working through their losses, bravely fighting against hopelessness.

Nine patients out of 29 that chose *irreparable loss* explicitly meant the loss of a breast—'a part of the body that means a great deal'. This reflects the fact that breast cancer at all times has had a special loading, as the breast is associated with attractiveness, sexuality, fertility and motherhood. Lipowski interprets the choice of *irreparable loss* negatively: 'for some individuals even minor loss of function, particularly one having high personal value, may signify overwhelming loss and damage which nothing can replace. This attitude is particularly liable to lead to depression, hostility and resistance to rehabilitation measures, even to suicide' (1). In our opinion this is an over interpretation of the choice of *irreparable loss*. In the rehabilitation process following a breast cancer diagnosis, we fully respect patients' grief and help them to mourn the loss of the breast in the search of finding new goals. Other patients, however, broadened the concept and described the *irreparable loss* of 'health', 'safety' or 'life', perhaps coming closer to Lipowski's interpretation.

As many as 14 patients chose *value*, which according to Lipowski, 'is not present in our hedonistic society' where everything is said to counteract illness (1). Lipowski, however, also gives examples from the literature and states that some individuals are convinced that illness may contribute to personal development. One of them was Proust, who wrote that his asthma saved him from idleness and made him work harder to complete a monumental novel before his death.

Most of our patients who chose *value* were more than 65 years old (data not shown). Their choice perhaps reflects a process of realizing that life needs caring for as long as it lasts. The experience of breast cancer might have highlighted that process.

Obviously some patients who chose *relief* interpreted the word differently from Lipowski (1). Patients felt relief: 'to know what was wrong', 'not to need radiotherapy', 'to get rid of it' and 'that it is over'. This is not what Lipowski meant: 'a welcome respite from demands and responsibilities of being well or from some current interpersonal crisis or economic problem'.

Strategy was interpreted as 'you have to reconsider—it means changes—think about how to handle the situation' and 'it's close to challenge'.

This reflects attitudes of resistance and adjustment and seems far from Lipowski's interpretation: 'Being sick and

disabled is used as a technique to secure attention, support and compliance from others' (1).

In Canada and Great Britain *challenge* was chosen by even more patients than in Sweden, 57% and 62%, respectively, compared with 33% in Sweden (pers. comm. (7)). This result is perhaps due to cultural differences with, as reported earlier, more active breast cancer patients regarding preferred patient roles in Canada and Great Britain (4, 5).

The results might to some extent also be due to differences in the research procedure. In Canada and Great Britain the patient selected a card with one of the eight categories *including Lipowski's interpretation* of the category (pers. comm. (7)) (Table 1). The patient was then asked to comment on the reason for her choice and the research assistant wrote this down. Our result reflects patients' choices of meaning of illness and for the majority of patients (64%) also *patients' own interpretations* of the categories.

We found it interesting that our patients' own interpretations of the eight categories reflect a greater determination to keep active and fight against the disease than Lipowski's interpretations (1).

This supports Lipowski's idea that patients' subjective meaning of illness is a reflection of the interplay between the breast cancer patient and contemporary society. Comparing women of our time to women of Lipowski's time, it is clear that women today are generally better educated and are more likely to be working in a profession than women in the 1970s, which may influence women's self-image as patients. Patient information is becoming increasingly important—the importance of the Internet as a distributor is as yet not possible to estimate. The patient–doctor relationship is becoming more cooperative with better-informed patients. The importance of patient unions is increasing, especially regarding breast cancer—in the US and Canada the movement is even called breast cancer activism.

For clinicians, this development is of major significance. Patients regard information given by their doctors as being one of the most important types of emotional support (10). Several reports are critical of the amount and quality of patient information given (11–13) and others report that patients seek every conceivable kind of information, whether good or bad (14). Unfortunately, the importance of physicians' communication skills has been neglected (15–17).

Lipowski's eight categories describing meaning of illness are not useful without also asking the patient to interpret the category chosen. However, to offer patients the opportunity to express and describe their view of meaning freely and in their own words will always be meaningful as one of the many pieces in the complex basis of successful communication.

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REFERENCES

1. Lipowski ZJ. Physical illness, the individual and the coping processes. Psychiatry in Med 1970; 1: 91–102.
2. Antonovsky A. Unraveling the mystery of health: how people manage stress and stay well. San Fransisco: Jossey-Bass Inc., Publishers, 1987.
3. Antonovsky A. The structure and properties of the sense of coherence scale. Soc Sci Med 1993; 36: 725–33.
4. Degner LF, Kristjanson LJ, Bowman D, et al. Information needs and decisional preferences in women with breast cancer. JAMA 1997; 277: 1485–92.
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. Wallberg B, Michelson H, Nystedt M, Bolund C, Degner LF, Wilking N. Information needs and preferences for participation in treatment decisions among Swedish breast cancer patients. Acta Oncol 2000; 39: 467–76.
7. Luker KA, Beaver K, Leinster SJ, Owens RG. Meaning of illness for women with breast cancer. J Adv Nurs 1996; 23: 1194–201.
8. Degner LF, Sloan JA. Decision making during serious illness: what role do patients really want to play? J Clin Epidemiol 1992; 45: 941–50.
9. Bergh J, Jönsson P-E, Glimelius B, Nygren P. A systematic overview of chemotherapy effects in breast cancer. Acta Oncol 2001; 40: 253–81.
10. Slevin ML, Nichols SE, Downer SM, et al. Emotional support for cancer patients: what do patients really want? Br J Cancer 1996; 74: 1275–9.
11. 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.
12. Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making? JAMA 1984; 252: 2990–4.
13. Fallowfield LJ, Ford S, Lewis S. No news is not good news: information preferences of patients with cancer. Psycho-Oncol 1995; 4: 197–202.
14. Jenkins V, Fallowfield L, Saul J. Information needs of patients with cancer: results from a large study in UK cancer centres. Br J Cancer 2001; 84: 48–51.
15. Cassileth BR, Zupkis RV, Sutton-Smith K, et al. Information and participation preferences among cancer patients. Ann Int Med 1980; 92: 832–6.
16. Fallowfield LJ. Counselling and communication in oncology. Br J Cancer 1991; 63: 481–2.
17. Fallowfield L, Jenkins V. Effective communication skills are the key to good cancer care. Eur J Cancer 1999; 35: 1592–7.