Expectations and quality of life of cancer patients undergoing radiotherapy

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SUMMARY

Expectations, real or false, affect the way patients respond to their illnesses. We assessed therapy-related expectations in relation to global quality of life in 55 cancer patients before and after radiotherapy.

Factor analysis indicated that therapy-related expectations come into three broad categories—pain/emotional control, healing and tumour/symptom control. 35 patients expected 'healing' even though curative treatment was intended in only 19 and all patients had been fully informed. The expectation of healing was associated with high quality of life, and the same was true of perception of healing after radiotherapy. In the group as a whole, quality of life was little altered by radiotherapy, but it became substantially worse in those patients who had expected healing but perceived that this had failed, even though physician-assessed Karnofsky status did not change.

These findings indicate that the expectation of healing, in cancer patients, is a component of a good global quality of life, whereas more limited expectations (pain control, tumour control) relate to lower quality of life. Patients' expectations deserve further study as a novel approach to improving care.

INTRODUCTION

Quality of life in cancer patients is the result of a complex interplay between objective health and psychosocial variables[1–3]. Knowledge of relevant psychosocial variables may help us gain a better understanding of the patient's perspective and ultimately may also help to improve patient care. In the present study we explored the role of patients' expectations towards therapy in seriously ill cancer patients undergoing inpatient radiotherapy[4].

Expectations are beliefs about future states[5]. The various ways in which expectations and objective health are interrelated have been summarized in three excellent review articles[6–8]. Expectations influence the perception and evaluation of illness, patients' help-seeking behaviour, the course of the diagnostic process, the degree to which ingredients or treatments are considered effective (placebo effect), and even doctors' prescribing behaviour[9–11]. Most notable for the present research, however, is the fact that expectations are related to health outcomes—as already demonstrated in patients undergoing coronary bypass surgery[12], breast cancer patients[13,14] and accident victims[15].

The present study investigated patients undergoing inpatient radiotherapy. This therapeutic context is of particular interest because two distinct treatment approaches exist[16–18]. The goal of the *curative* approach is healing in the sense of cancer remission and longer survival. When healing is no longer possible, therapy focuses on *palliative* care by reducing pain and providing psychosocial support, thus maintaining or improving patients' quality of life[19]. Sometimes the therapeutic goal will be in conflict with the patient's expectations, because expectations do not accurately reflect reality (they are influenced by factors such as wishful thinking[20–22]).

The goal of the present study was to analyse the interplay between patients' expectations, their quality of life and clinical variables (such as therapeutic approach and objective health status). Three questions guided our analysis. What is the relation between patients' expectations and the clinically defined therapeutic approach? Are patients' expectations related to their quality of life before therapy? Is quality of life after therapy related to the fulfilment of expectations regarding treatment?

PATIENTS AND METHODS

Patient characteristics

During a period of seven months, 55 (72%) of 76 consecutive patients were enrolled. According to the study protocol (approved by the local ethics committee), patients had to be admitted for inpatient radiotherapy, to be physically and mentally capable of completing a quality of

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Table 1 **Patient characteristics (*n*=55)**

Mean age, year	***66.8 (SD 10.5)***
Gender	
M	27
F	28
Site of tumour	
Lung	10
Gynaecological (various)	8
Breast	7
ENT	6
Prostate	5
Lymphoma	6
Plasmacytoma	4
Rectum	4
Others	5
Time since diagnosis	
<1 year	30
1–10 years	19
>10 years	3
NA	3
Therapeutic intention	
Curative	19
Palliative	36
Mean Karnofsky index	72.5 (SD 18.1)

SD=standard deviation; ENT=ear, nose and throat; NA=not available

life questionnaire, and to give signed informed consent. Of the 21 patients who did not participate, 13 were terminally ill and 8 were unwilling (6 men, 2 women). Table 1 shows the characteristics of the 55 patients who took part.

Curative patients included also those who were undergoing adjuvant therapy in addition to surgery (*n*=8). Curative and palliative patients did not differ in age or gender, but in certain clinical variables they did: the palliative group contained all patients with lung cancer, plasmacytoma, and bone metastases, and palliative patients had lower Karnofsky performance status.

Sample size

Duration of patient enrolment was set at approximately half a year so as to obtain a representative sample of radiotherapy inpatients. Calculations of mean differences in the global quality of life index between two groups were at the core of our statistical analyses. Alpha was set at 0.05 (two-tailed test) and beta at 0.20. On the assumption that standard deviation (SD) is 20 scale points and that mean differences between subgroups are 15–20 scale points, the size of each group should range between 16 and 28. Therefore, a total of 55 is sufficient to detect such differences[23].

Patient questionnaire

Quality of life

The patient questionnaire contained the EORTC QLQ-C30[24] and three PLC[25] scales, measuring ability to relax and enjoy, positive affect, and sense of social belonging (Table 2).

Expectations

At the time of the study, no standardized and validated expectation scale had been published. Therefore, we decided to compile a set of items that were representative of patients' expectations and that could be answered by a simple yes/no response. This expectation checklist was developed in cooperation with patients, physicians and nurses of the department of radiotherapy for the purposes of the present study. A set of 10 items emerged, preceded by the words, 'Which of the following expectations do you personally hold towards your radiation therapy? You may check any of the following items' (Table 3).

This checklist was pretested in ten radiotherapy inpatients and none of them expressed difficulties in answering it or raised concerns that important issues were missing. The method for assembling *ad-hoc* checklists of this kind has been reported elsewhere[26].

Post-therapy questionnaire

The items that tapped into patients' expectations at the beginning of the therapy reappeared in the second questionnaire measuring subjective success of the therapy.

Procedure

The ward physician explained to newly admitted patients the rationale of the radiotherapy. There is no written protocol, but it is the general policy of our radiotherapy department to inform patients about their disease state. Patients with a curative and/or adjuvant approach learned that radiotherapy has the potential to control the disease and that healing is possible. Palliative patients were told that the therapeutic goal is to lessen the burden of their illness; they also learned that cure is no longer possible, although an exact prognosis regarding survival time cannot be made.

Usually on the same or the next day the patients were approached by one of the two study nurses and were informed about the study. Once they had agreed and signed the consent form, the questionnaire was administered. The study nurse assisted patients who had trouble reading or understanding the questions. All details of the measurement situation were noted on a separate form by the investigator. The questionnaire was handed to the patients again at their

Table 2 **Quality of life indices: content, means, standard deviations and reliability**

			Before radiotherapy (n=55)		***After radiotherapy (n=46)***	
Indices	***No. of items***	***Content***	***Mean (SD)***	***α***	***Mean (SD)***	***α***
Global quality of life	2	Overall satisfaction with physical condition and quality of life	47.6 (24.0)	0.93	42.4 (20.5)	0.90
Physical functioning	5	Physical exercise and self-care	52.8 (32.9)	0.79	53.9 (28.2)	0.68
Role functioning	2	Work and home activities	46.4 (38.3)	0.47	42.0 (37.3)	0.55
Emotional functioning	4	Tension, worry, irritation, depression	60.7 (26.5)	0.72	61.0 (26.4)	0.78
Cognitive functioning	2	Concentrating, remembering	76.7 (29.3)	0.78	83.0 (25.5)	0.69
Social functioning	2	Family life and social encounters	62.7 (35.9)	0.74	65.6 (34.5)	0.69
Fatigue	3	Tired, need to rest, weak	48.8 (33.3)	0.88	56.5 (28.4)	0.75
Pain	2	Intensity of pain, pain-related impairment	43.3 (41.0)	0.92	40.2 (38.7)	0.90
Nausea/vomiting	2	Nausea, vomiting	16.1 (30.4)	0.90	31.9 (37.2)	0.84
Dyspnoea	1	Shortness of breath	29.7 (33.8)	—	28.3 (37.2)	—
Insomnia	1	Difficulty sleeping	38.8 (37.3)	—	34.1 (36.2)	—
Appetite loss	1	Loss of appetite	30.9 (37.3)	—	53.6 (38.1)	—
Constipation	1	Constipation	26.7 (37.1)	—	28.3 (38.5)	—
Diarrhoea	1	Diarrhoea	10.1 (23.2)	—	26.1 (34.4)	—
Financial difficulties	1	Financial problems due to illness	13.3 (27.7)	—	16.7 (27.9)	—
Joy/relax	8	Relax, forget worries, enjoy meals, sleep well, have fun, meeting one's needs, cope with everyday hassles	52.2 (17.3)	0.81	51.1 (15.0)	0.76
Positive affect	5	Attentive, good-natured, energetic, relaxed, optimistic	46.2 (21.7)	0.87	49.4 (20.8)	0.89
Sense of belonging	5	Close to beloved persons; acceptance and understanding	74.5 (17.3)	0.70	74.2 (13.2)	0.57

In the first six indices (global quality of life to social functioning) and the last three (joy/relax, positive affect and sense of belonging) high figures represent well-being. In the remaining indices (fatigue to financial difficulties) low figures represent well-being. All indices were linearly transformed, giving possible ranges from 0 to 100. Reliabilities are based on standardized Cronbach's alpha

discharge from hospital (four to six weeks after the first assessment).

Statistical analyses

Scale reliabilities were determined by Cronbach's alpha. The expectation checklist was subjected to a factor analysis (principal component method with varimax rotation). Differences between independent groups were computed by t-tests, Mann–Whitney tests (in the case of skewed distributions), and one-way analyses of variance (ANOVA). Before/after differences between expectation and subjective success rating were computed with the McNemar test, a nonparametric test for dichotomous variables. Other dependent comparisons were calculated with the dependent t-test or the Wilcoxon test (in the case of skewed distributions). In addition to these single-variable analyses, multiple linear regression analyses were computed, controlling for numerous possibly confounding variables within a single statistical model. Global quality of life was selected as the dependent variable and a set of demographic and clinical variables (age, gender, Karnofsky status, therapeutic intention, expectations) was entered simultaneously into the regression equation. The software package SPSS for Windows was used for all statistical analyses.

RESULTS

All 55 patients completed the first questionnaire, with only 0.04% of responses to single items missing, and 46 (84%) completed the questionnaire a second time at the end of radiotherapy. 9 patients were lost to follow-up, the reasons being death (1), rapid deterioration and consequent abandonment of radiotherapy (3), early and unexpected departure from the inpatient ward (2) and unwillingness to complete a second questionnaire (3). Scale reliabilities were

Table 3 **Expectations before therapy in relation to subjective success of therapy**

Expectation items	*Before therapy: % of patients with expectations (n=55)*	*After therapy: % of patients with subjective therapy success (n=46)*	*Significance*
Healing	58	26	$P<0.001$
Stop tumour growth	38	30	NS
Relief of tumour-related symptoms	36	17	$P<0.05$
Prevent metastases	27	15	NS
Prevent tumour relapse	27	24	NS
Pain relief	24	22	NS
Free from pain without medication	22	9	NS
Psychological stabilization	22	7	NS
Reduction of tumour size	18	15	NS
Prevent pain increase	15	9	NS
Mean no. of items	2.9	1.7	$P<0.002$

Multiple answers were possible on both the expectation and the success scale. Percentage values refer to the proportion of patients checking the particular item. Differences between before/after proportions were calculated with the McNemar test: NS=not significant

adequate (α=0.69–0.93) with the exception of role functioning (α=0.47) (see Table 2).

Before radiotherapy: relation between patients' expectations and therapeutic approach

The expectation most commonly expressed was that of healing: 58% of the patients thought that radiotherapy would cure them (Table 3, left column). The least popular item was 'prevent pain increase' (15%). Three independent factors accounted for 59% of the variance—pain/emotional control, healing, and tumour/symptom control (Table 4).

15 of 19 curative patients and 20 out of 36 palliative patients had at least one healing expectation (79% *vs* 56%, P=0.086). There was a significant difference between these two patient groups with regard to pain/emotional control expectations (21% *vs* 61%, $P<0.01$), and no difference regarding tumour/symptom control expectations (53% *vs* 58%). Healing expectations were inversely correlated with pain/emotional control expectations ($r=-0.27$, $P<0.05$) and tumour/symptom control expectations (r=0.28, $P<0.05$), whereas pain and symptom control were positively correlated (r=0.32, $P<0.02$).

Table 4 **Factor analysis of patients' therapy-related expectations**

	Factor		
	Pain/emotional control	*Healing*	*Tumour/symptom control*
Psychological stabilization	0.75		
Freedom from pain without medication	0.74		
Prevent pain increase	0.67		
Pain relief	0.49		
Healing		0.79	
Prevent metastases		0.76	
Prevent tumour relapse		0.73	
Reduction of tumour size			0.78
Stop tumour growth			0.72
Relief of tumour-related symptoms			0.58

N=55. Values represent varimax-rotated factor loadings

Table 5 **Quality of life indices as a function of therapy-related expectations and therapeutic intention**

	Expectations							
	Pain reduction		***Healing***		***Symptom control***		***Therapeutic intention***	
Indices	***Yes (n=26)***	***No (n=29)***	***Yes (n=35)***	***No (n=20)***	***Yes (n=31)***	***No (n=24)***	***Curative (n=19)***	***Palliative (n=36)***
Global quality of life	39.1	55.2*	54.5	35.4*	46.8	48.6	56.1	43.1
Physical functioning	38.8	65.3*	59.6	41.0*	50.0	56.5	59.5	49.5
Role functioning	26.9	63.8*	54.3	32.5*	38.7	56.3	52.6	43.1
Emotional functioning	51.4	68.9*	63.7	55.4	58.9	62.8	63.3	59.3
Fatigue	61.8	37.2*	44.8	55.8	52.5	43.9	53.2	46.5
Pain	70.5	18.9*	38.1	52.5	43.0	43.8	28.1	51.4*
Dyspnoea	26.9	32.2	24.8	38.3	38.7	18.1*	26.9	35.1
Insomnia	51.3	27.6*	31.4	51.7	44.1	31.9	35.1	40.7
Appetite loss	37.2	25.3	23.8	43.3*	30.1	31.9	29.6	33.3
Joy/relax	47.8	56.2	56.3	45.2*	52.6	51.7	53.1	51.8
Positive affect	43.7	48.4	51.8	36.3*	45.9	46.4	49.7	44.3
Karnofsky	68.5	76.2	76.0	66.5	70.3	75.4	83.2	66.9*

*Pairs of means that differ at $P<0.05$
Differences in means were computed by independent t-tests and in the case of skewed distributions (pain, dyspnoea, insomnia and appetite loss) by the Mann–Whitney test

Before radiotherapy: relation of quality of life to expectations

Univariate analyses: expectation domains and mean differences in quality of life scores

Descriptive statistics of the quality of life scales are summarized in Table 2. For the following analyses we divided the sample (*n*=55) into two subsamples holding or not holding particular expectations. For instance, the healing expectation group (*n*=35) comprised patients who checked at least one of the items that made up the healing factor (healing, prevent metastases, prevent tumour relapse); the comparison group (*n*=20) checked none of them. The same subsample grouping logic was applied to the pain/emotional control and tumour/symptom control expectation domains.

Table 5 summarizes those 11 of 18 quality-of-life indices that yielded significant differences. Patients who expected pain/emotional control from radiotherapy (*n*=26) had low global quality of life and low physical, role and emotional functioning. They scored particularly highly on pain, and also on fatigue and insomnia. In contrast, patients who expected healing (*n*=35) had better global quality of life, higher physical and role functioning, higher positive affect and greater ability to enjoy and relax; they also had less insomnia and less loss of appetite. The tumour/symptom control subgroup (*n*=31) contained 8 out of 10 lung cancer patients and therefore differed from others with regard to the dyspnoea symptom. Curative patients scored higher on the physician-assessed Karnofsky performance status.

Multiple variables affecting global quality of life before radiotherapy

For this analysis the global quality of life score was chosen as the dependent variable. The following variables were centred[27] and then entered simultaneously into the regression equation: age, gender (1=male, 2=female), Karnofsky status, therapeutic intention (1=curative, 2=palliative), healing expectation (1=yes, 0=no), pain reduction expectation (1=yes, 0=no) and tumour/symptom control expectation (1=yes, 0=no). A multiple regression coefficient of $R=0.54$ (adjusted $R^2=0.19$; $P<0.02$) emerged. Healing expectation was the only predictor variable that had a significant beta weight ($\beta=0.31$, $P<0.04$).

After radiotherapy: perceived success of therapy, fulfilment of expectations and quality of life

Expectations versus subjective therapy success

Subjective success of therapy did not match pretherapy expectations (see Table 3): percentage values of all items declined and the overall number of items chosen at the second measurement point was lower ($P<0.002$). With regard to single items, the most impressive drop emerged with regard to 'healing'—58% *vs* 26% ($P<0.001$). Also 'relief of tumour related symptoms' decreased significantly—36% *vs* 17% ($P<0.02$).

Quality of life before and after therapy

There were no pre/post differences regarding global quality of life and the functional quality of life indices (see Table 2). However, certain symptoms that are known to be typical therapy-related side-effects were more pronounced after therapy—namely, nausea/vomiting ($P<0.001$), loss of appetite ($P<0.002$), and diarrhoea ($P<0.004$).

Perceived therapy success and quality of life

In parallel with the expectation analysis we compared subgroups of patients who indicated either healing success (yes/no), pain/emotional control success (yes/no) or tumour/symptom control success (yes/no), the yes-category consisting of patients who checked at least one of these (Table 3). Patients indicating subjective healing success reported higher global quality of life (mean scores 49.5 *vs* 37.8, $P<0.04$), physical functioning (65.6 *vs* 46.2, $P<0.03$), positive affect (57.5 *vs* 44.2, $P<0.04$) and joy/relax (56.9 *vs* 47.3, $P<0.04$). Subjective tumour/symptom control was associated with more positive affect (56.7 *vs* 43.3, $P<0.05$). No quality of life differences were found with regard to the pain/emotional control category.

Non-fulfilment/fulfilment of expectations of expectations in relation to quality of life

This analysis was conducted by comparing patients who checked a particular item before and after therapy (expectation fulfilment) with those who checked it before but *not* after therapy (expectation non-fulfilment). The most striking results related to healing. Those whose healing expectations were not fulfilled ($n=15$), although similar to healing fulfilment patients ($n=11$) with regard to demographic and health variables (age, gender, bone metastases, tumour type) had particularly low mean levels of global quality of life (38.9), positive affect (45.7), and joy/relax (47.8) after therapy. The respective means were significantly higher in the healing fulfilment group—53.0 ($P=0.061$), 66.8 ($P<0.003$), and 61.6 ($P<0.03$).

Also, when we looked at global quality of life in the healing non-fulfilment group before and after radiotherapy, a considerable drop became apparent—mean 54.4 *vs* 38.9, $t(\mathrm{df}=14)=2.09$, $P=0.055$—although their physician-assessed Karnofsky performance status did not change significantly (71.3 *vs* 68.0). In the subgroup that did not expect healing and also indicated lack of healing success after therapy, global quality of life remained low (36.4 *vs* 38.6) and Karnofsky status decreased slightly (71.1 *vs* 63.2, $t[\mathrm{df}=18]=2.13$, $P<0.05$).

Multiple variables affecting global quality of life after radiotherapy

A set of demographic, clinical and expectation variables predicted global quality of life—multiple regression coefficient $R=0.53$ (adjusted $R^2=0.15$; $P=0.06$). Healing success was the only single variable that had a significant beta weight ($\beta=0.46$, $P<0.02$).

DISCUSSION

A striking observation was that the number of patients with healing expectations was almost twice the number treated with curative intent. More than half of those who received palliative therapy expected healing. These discrepancies were more extreme than those reported in an earlier study[4]. There were strong correlations between healing expectations and global quality of life. Healing expectation or perceived healing was the only single predictor significantly related to global quality of life, even when other variables such as Karnofsky performance status, therapeutic intention, age or gender were controlled for. An obvious question is, were patients' expectations realistic or unrealistic? From the high prevalence of healing expectations in this seriously ill group, one might suppose that the patients had a distorted lay notion of healing[28]. However, the factor analysis clearly rejects this interpretation. The very expression 'healing' constitutes a factor, together with the items 'prevent tumour relapse' and 'prevent metastases'; and this is exactly what is meant by healing from a medical standpoint. Furthermore, it seems unlikely that patients' poor understanding of the seriousness of their illness or imprecise doctor–patient communication accounted for the high prevalence of healing expectations. Many of the participants in this study had been cancer patients for at least a year, and it is the policy of the department of radiotherapy to discuss the rationale and goals of radiotherapy in detail with all patients before beginning treatment.

Why then were there so many patients with healing expectations? Certain cancer patients, we know, choose to deny or ignore the possible fatal outcome of their disease[29]. From a functional perspective it can be argued that the expectation of healing helps to maintain a high quality of life. Generally, optimists have more favourable coping strategies than pessimists—such as problem-focused coping, seeking social support and avoidance of competing activities[30]. Furthermore, there is now evidence that an optimistic cognitive style is indeed linked to physiological functioning and survival[31]. Nevertheless, we do not feel that our patients were blind and overoptimistic. Rather, the distribution of expectations across various levels of impairment suggests that patients' expectations contained realistic elements. When immediate health problems that could not be denied (pain, severe symptoms) became prevalent, patients' ambitions became more focused toward these and healing was no longer their primary goal. Our conclusion is that patients' expectations contained both realistic and unrealistic elements[32].

There are limitations of our study that relate to sample size (although carefully calculated before conducting the trial), the heterogeneity of diagnoses, and the non-experimental nature of the design. On the positive side, we should point out that the patient sample was representative for a whole county, since our radiotherapy department is the only institution of its kind in a region with 252 000 inhabitants—so this is equivalent to small-area analysis[33]. Furthermore, we used standardized quality of life instruments[24,25]. The expectation measure was specifically developed, in a process that included patients, nurses and doctors; in other words, the scale items reflected the thought-contents of the individuals under investigation. We intentionally avoided the highly artificial expectation measurement approach (standard gambling, time trade-off) used in medical decision-making studies[34].

Because of the correlational nature of this study we certainly cannot draw strong conclusions regarding causal relations. The exact temporal sequence of healing expectations and quality of life was not tested, but intuitively one might expect the relation, in the long run, to be bidirectional[35]. The value of correlational studies such as these is that they shed light on what patients mean when they report good or bad general quality of life on standardized questionnaires. Although developers began with the assumption that quality of life is a multidimensional construct, validation analyses rely heavily on demonstrating that the scores are contingent on the Karnofsky or ECOG index[36] or changes in objective health. Some might regard this as an argument against including quality of life assessment in clinical trials: why assess quality of life when its relationship to objective health is so strong? But social psychology[37–40] and modern outcome research[3] suggest that 'there must be more to it', and one research strategy is to explore a map of psychosocial variables that are associated with patients' subjective reports of their quality of life[41]. We have reported that cancer patients' reports of their somatic symptoms and their global quality of life are strongly correlated with factors including negative affect and self-related thinking[1,2,42], and this pattern of associated variables may have implications for patient care. Information and communication skills are crucial components of patient care,[43,44] so practitioners and researchers may find the present findings valuable. In particular, our observation of a before/after therapy drop in quality of life, in certain patients who expected healing but did not perceive the treatment to have been successful, highlights the need for good communication and effective monitoring strategies.

Further research is needed to demonstrate whether interventions that generate realistic expectations will lead to better quality of life. Also, it will be interesting to know whether our findings can be generalized to other forms of oncological treatment such as outpatient care and chemotherapy, and across the different cultures[45].

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