ONKOLOGIE

Radiotherapy: Impact of Quality of Life and Need for Psychological Care: Results of a Longitudinal Study

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Summary
Background: In the framework of a prospective longitudinal study, the quality of life (QoL) and support requirements of patients from a university hospital department of radiotherapy were evaluated for the first time by means of established psychodiagnostic questionnaires. *Patients and Methods:* At first, 732 patients were screened, of whom 446 (60.9%) fulfilled the criteria for inclusion; 39.1% did not (refusals 21.0%, low Karnofsky performance status 6.6%, management problems 3.4%, language barriers 3.0%, cognitive restrictions 2.6%, death 2.5%). Disease-specific aspects of QoL (Functional Assessment of Cancer Treatment – General, FACT-G) and moderating variables [Social Support Scale (SSS), Disease Coping (FKV), Self-Assessment Depression Scale (SDS), and Self-Defined Care Requirements (BB)] were self-rated by patients with different tumor types before radiotherapy (T1), after radiotherapy (T2), and 6 weeks after the end of radiotherapy (T3). We studied 265 patients (157 male, 108 female; median age 58.6 years) with complete data of three time points. *Results:* In general, QoL of patients decreased significantly over all time points in all subscales. Social support was rated high and remained constant throughout the treatment. Apparent coping mechanisms were active problem-oriented coping, leisure activities, and self-support. The patients' depression proved to be an important and constant factor without significant changes. The support requirement is characterized by the need for more medical information and dialogue with a physician. *Conclusions:* Early specific support from personnel with radiotherapeutic skills, during the disease-coping process as well as during rehabilitation, should be a permanent component of an integrated radiooncological treatment schedule.

Zusammenfassung
Hintergrund: Im Rahmen einer prospektiven Longitudinalstudie wurden auf der Grundlage von etablierten Instrumenten der Psychodiagnostik erstmalig systematisch die Lebensqualität (QoL) und der Betreuungsbedarf von Patienten einer strahlentherapeutischen Universitätsklinik evaluiert. *Patienten und Methodik:* 732 Patienten wurden vorläufig in die Studie aufgenommen; davon erfüllten 446 (60,9%) die Einschlußkriterien, 39,1% nicht (Ablehnung 21,0%, niedriger Karnofsky-Status 6,6%, organisatorische Probleme 3,4%, Sprachbarrieren 3,0%, kognitive Einschränkung 2,6%, Tod 2,5%). Krankheitsspezifische Aspekte der QoL («Functional Assessment of Cancer Treatment, General», FACT-G) und Moderator-Variablen [«Social Support Score» (SSS, soziale Unterstützung), «Self-Rating Depression Scale» (SDS, Depressionsskala), «Freiburger Fragebogen zur Krankheitsverarbeitung (FKV) und selbstdefinierter «Betreuungsbedarf» (BB)] wurden zu Beginn (T1), am Ende der Strahlentherapie (T2) und 6 Wochen nach Strahlentherapie (T3) abgefragt. 265 Patienten mit unterschiedlichen Tumorerkrankungen (157 Männer, 108 Frauen; medianes Alter 58,6 Jahre) und kompletten Daten zu T1–T3 nahmen an der Untersuchung teil. *Ergebnisse:* Eine signifikante Abnahme der Lebensqualität wurde zu allen Untersuchungszeitpunkten in allen Subskalen beobachtet. Die erlebte soziale Unterstützung war über alle Erhebungszeitpunkte hinweg hoch. Ausgeprägte Krankheitsverarbeitungsmechanismen sind «aktives problemorientiertes Coping» sowie «Ablenkung und Selbstaufbau». Depression bei Patienten erwies sich als wichtiges und konstantes Merkmal über den gesamten Untersuchungszeitraum hinweg. Der Betreuungsbedarf wurde bestimmt durch den Wunsch nach mehr Sachinformation und nach Gesprächen mit einem Arzt. *Schlußfolgerungen:* Frühzeitige spezifische Unterstützung im Krankheitsverarbeitungsprozess und in der Rehabilitationsphase durch Personal mit strahlentherapeutischen Fachkenntnissen sollte fester Bestandteil eines integrativen radioonkologischen Behandlungskonzeptes sein.

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Introduction

The health-related quality of life (QoL) of tumor patients has become more and more important during the last years because of optimized treatment schedules and the resulting increased survival rate. Apart from physical symptoms and the ability to function in daily life, psychosocial factors are also of crucial importance for the patients' QoL. Health-related QoL is a multidimensional construct that should be assessed by measuring the functioning and well-being of a patient in the following dimensions: physical, emotional and mental, social and daily life [1]. Besides this also psychosocial and emotional aspects are of crucial importance for patients. In contrast to clinical research up to now, the aim of our investigation is to describe main factors of QoL and moderating variables for cancer patients receiving radiotherapy. Of special interest are the influence of radiooncological treatment on well-being and the resulting care requirements. During radiotherapy, in addition to psychosocial distress related to cancer, patients suffer the consequences of stressful treatment. Typical side effects of radiotherapy were observed: among others, tiredness, decrease in appetite, nausea and depression. Also phsychological side effects such as anxiety about the dimension of radiotherapeutic devices, isolation of therapy rooms, and the fear of being at the mercy of invisible radiation energy and of the medical personnel administering treatment were observed [2].

Results of clinical studies which evaluate relevant aspects of the QoL of patients under radiotherapy are available only to a limited extent [3–6].

The aim of this study, therefore, is to investigate extensive longitudinal data based on established, psychometric instruments of psychodiagnosis in order to evaluate the QoL influenced by radiation of patients. Our intention was to verify whether the expected decrease of QoL was observed and whether it resulted in lower QoL of radiation-treated patients in comparison with other tumor patients or patients with chronical disease. The influence on psychosocial well-being and requirement for care was of special interest.

Patients and Methods

Disease-specific aspects of QoL and moderating variables were self-rated by patients with different tumor types before radiotherapy (T1), after radiotherapy (T2), and 6 weeks after the end of radiotherapy (T3). Completion of assessment tables took between 20 and 40 min. Radiotherapy-induced changes in QoL and moderating variables were calculated over the assessment points. Generally, 6 weeks after radiotherapy acute side effects are observed, and an improvement of QoL in general or statisfaction with QoL was expected. The following instruments were utilized:

Quality of Life Instruments

Functional Assessment of Cancer Treatment – General (FACT-G), Version 3 [7]
For general insight in the disease-specific aspects of QoL of tumor patients the Functional Assessment of Cancer Treatment (FACT) was developed. The FACT-G count of five subscales evaluating physical, social/family, emotional and functional well-being and the patient's relationship with doctors was analyzed. These various QoL domains were assessed as a function of treatment with 29 items; each item scored on 1–5 categories.

Moderating Variables

Important variables moderating the QoL of patients under radiotherapy are the following:

Social Support Scale (SSS) [8]
Registers the perceived social support with 20 items, divided into three subscales (cognitive, emotional, practical), and is self-rated by the patients.

Freiburg Questionnaire Coping with the Disease (Freiburger Fragebogen zur Krankheitsverarbeitung, FKV) [9]
Measurement of different coping strategies on the basis of 35 items in five subscales (active problem-oriented coping, distractions, spirituality, minimizing importance, depressive coping).

Self-Assessment Depression Scale (SDS) [10]
Symptoms of depression (20 items), allocated to four subscales, are evaluated by the patients.

Care Requirements (Betreuungsbedarf, BB), Self-Developed Instrument
Patient's self-assessment to quantify the need of psychosocial support by third persons as well as care requirements: 9 categories (psychosocial support by doctor/psychotherapist, hospital chaplain, information, other patients, self-help groups, change of job/retraining, pension, nursing care).

Statistics

Statistical evaluations were carried out with SPSS$^{©}$. Repeated measurements of variance were analyzed at time points T1, T2 and T3 with MANOVA (multiple analysis of variance).

Results

From November 1997 to May 1999, 732 patients in the department of radiotherapy at Klinikum Grosshadern, Ludwig Maximilian University, Munich, were screened for the study. Of these, 446 patients (60.9%) fulfilled the criteria for inclusion; 39.1% did not (refusals 21.0%, low Karnofsky performance status 6.6%, management problems 3.4%, language barriers 3.0%, cognitive restrictions 2.6%, death 2.5%). In 265 patients complete psychometric and clinical data of T1–T3 was collected (table 1).

First we are describing results of investigations of different concepts of QoL. In general, the QoL of patients decreased significantly over the assessment points in all subscales with exception of functional well-being (table 2). The physical well-being decreased at the end of therapy with a slight increase 6 weeks after radiotherapy, not reaching baseline quality ($p < 0.001$). Emotional well-being ($p = 0.030$), relationship to family/friend ($p < 0.001$), and relationship to doctor ($p < 0.001$) continuously decreased to T3. These tendencies were also shown in the total score ($p < 0.001$).

The social support of tumor patients under radiotherapy as a moderator variable of QoL was rated relatively high with a score of 4.23–4.27 on a scale from 1 to 5; the mean showed no difference between the three subscales and over the course of the investigation.

In the course of the investigation the most prominent coping mechanisms of the patients showed to be active problem-oriented coping and distractions. Depressive coping mechanisms,

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Table 1. Medical and sociodemographic data of 265 patients with complete T1–T3 data

Age, years		
Median	58.6	
Range	19–93	

	n	%
< 45	47	17.7
45–≤60	94	35.5
> 60	124	46.8
Gender		
Female	108	40.8
Male	157	59.2

Medical data	n	%
Diagnosis		
Mamma carcinoma	57	21.5
Urogenital tumor	44	16.6
Gastrointestinal tumor	34	12.8
Head/neck cancer	34	12.8
Lymphoma	34	12.8
Lung cancer	19	7.2
Brain tumor	16	6.0
Soft-tissue sarcoma	10	3.8
Other	17	6.5
T status[a]		
T1	46	17.4
T2	62	23.4
T3	40	15.1
T4	32	12.1
Tx	28	10.6
N status[a]		
N0	77	29.1
N1	58	21.9
N2	29	10.9
N3	4	1.5
Nx	40	15.1
M status		
M0	137	51.7
M1	40	15.1
Mx	31	11.7

Sociodemographic data	n	%
Karnofsky index		
≥ 90	172	64.9
< 90	93	35.1
Partner		
Yes	189	80.8
No	45	19.2
Children		
Yes	201	77.3
No	59	22.7
Family status		
Single	36	13.6
Married	191	72.1
Separated, divorced or widowed	38	14.3

[a] n = 208 (57 patients with lymphoma, etc.).

minimizing the importance of disease, and wishful thinking played a less important role. A significant decrease from T1 to T3 was seen in active problem-oriented coping mechanisms (p < 0.001) (fig. 1).

The patients' depression proved to be an important and constant factor without significant changes during treatment (T1 and T2) and after therapy (T3). The mean score on a scale from 0 to 50 was 36.8–37.5.

Care Requirements (BB)
During the course of the investigation, patients showed an above-average need for further information about treatment options and side effects and for support from a doctor or psychotherapist. Up to 6 weeks after radiotherapy patients formulated a limited need of occupational support, advice about home nursing, and psychological support from a hospital chaplain (table 3).

High levels of health-related QoL correlated with high scores of social support and low levels of depression. Coping mechanisms of these patients were less depressive and showed less minimizing of importance of disease than those of patients with low levels of health-related QoL. Despite a high QoL there was a positive correlation with need of care requirements (table 4).

Discussion

We investigated a heterogeneous sample of cancer patients to study the specific effects of radiotherapy on patients with tumor diseases with respect to medical aspects, their QoL and moderator variables of QoL.

Our study showed values similar to those of Cella et al. [7], who investigated a comparable heterogeneous sample of tumor patients: In contrast to general expectations, a decrease of QoL by radiotherapy was not observed. In the physical well-being component, a decrease of QoL was observed at T2 due to side effects with an expected increase of QoL at T3, these results being comparable to those of other authors [6, 11, 12].

Aspects of emotional well-being and relationship to family and friends decreased at T3; at this time point, also a lack of daily support and treatment by medical staff became obvious. In fact, this seems to be a general problem of patients with chronic diseases.

Tumor patients under and after radiotherapy with a high level of QoL had a high score of social support, good coping mechanisms (active problem-oriented coping and distractions), more care requirements (information), and a low score of depression. One moderator variable of QoL is social support measured with the SSS. Social support is an important mechanism of protection against psychological stress of patients in dealing with tumor disease [13], and can have a positive influence on the rehabilitation of these patients. Social support also has an effect on survival depending on the type and spread of disease [14].

In 181 cancer patients under radiotherapy, Irwin et al. [15] were able to show a significant decrease in anxiety and depression after completion of therapy. In our study, the depression scores remained constant throughout the course of treatment. Whether this could be interpreted as a disturbed ability to cope with the disease or whether the therapy and its side effects may have had an impact on coping and the perceived intensive distress which normally accompanies malignant disease [16, 17] is still an open question. Depressed patients receiving radiotherapy

Table 2. Functional assessment of cancer treatment (FACT-G) and total values at defined time points T1, T2 and T3 (n = 265)

	T1		T2		T3		Significance
	M	SD	M	SD	M	SD	p
Physical well-being (range 0–28)	20.5	5.6	19.2	6.3	20.5	6.0	< 0.001
Social/family (range 0–28)	21.0	4.5	20.3	4.4	19.9	4.3	< 0.001
Doctors (range 0–8)	6.6	1.4	6.3	1.5	6.2	1.5	< 0.001
Emotional well-being (range 0–20)	14.8	3.8	14.7	3.8	14.4	4.0	0.030
Functional well-being (range 0–28)	17.2	5.4	17.1	5.5	17.2	5.5	n.s.
Total score (range 0–112)	80.2	14.7	77.8	15.1	78.4	15.9	0.001

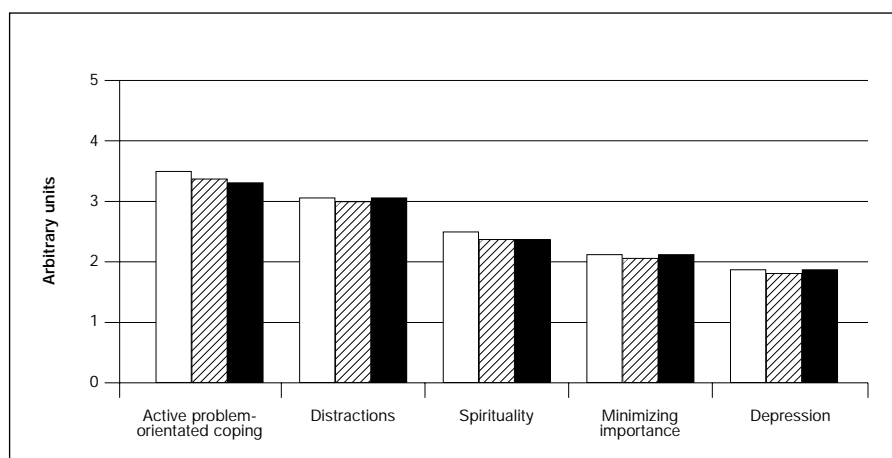M = Mean value; SD = standard deviation; n.s. = not significant.

Fig. 1. Coping with cancer (FKV) subscales at defined dates T1 (□), T2 (▨) and T3 (■) (n = 265).

Table 3. Subscales of care requirements and total values at defined time points T1, T2 and T3 (n = 265)

Care requirements	T1		T2		T3		Significance
	M	SD	M	SD	M	SD	p
Psychosocial support							
Doctor	2.4	1.3	2.2	1.3	2.5	1.3	0.004
Psychotherapist	2.1	1.4	2.1	1.4	2.1	1.3	n.s.
Hospital chaplain	1.6	0.9	1.7	1.0	1.7	1.0	n.s.
Information	3.7	1.3	3.5	1.3	3.4	1.4	0.023
Other patients	2.0	1.3	2.0	1.3	2.0	1.3	n.s.
Self-help group	1.9	1.2	1.9	1.2	1.7	1.1	0.011
Change of job / retraining	1.5	1.0	1.4	0.9	1.5	1.0	n.s.
Pension	1.8	1.4	1.9	1.3	1.9	1.4	n.s.
Nursing care	2.0	1.4	1.7	1.2	1.8	1.3	0.020

M = Mean value; SD = standard deviation; n.s. = not significant.

should be identified and offered psychological and medical support [18]. Through appropriate support a better compliance, fewer side effects, and more successful rehabilitation may be achieved. In the context of coping with their disease, patients are confronted with fear, worry, and grief. Reactions to therapy may become pervasive or cause distress. Eventually, patients may develop acute anxiety or depression requiring treatment [19]. The positive effect of increased QoL on survival is

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Table 4. Correlation of QoL instrument FACT-G with moderating variables Social Support Scale SSS, Coping with Disease FKV, Self-Assessment Depression Scale SDS, and Care Requirements BB

		FKV					SSS	SDS	BB				
		active problem oriented	dis- traction	mini- mizing impor- tance	depres- sion	spiri- tuality	total score	total score	doctor	infor- mation	patient group	psycho- therapist	self- help group
FACT Family	Pearson correlation	0.107	0.064	– 0.150	– 0.173	0.063	0.379	– 0.272	0.078	– 0.016	0.073	0.011	– 0.025
	significance	0.087	0.303	0.017	0.005	0.317	0.000	0.000	0.218	0.805	0.251	0.868	0.690
	n	259	259	251	259	258	255	223	249	2149	247	250	249
FACT Doctor	Pearson correlation	0.038	– 0.025	0.012	– 0.216	– 0.019	0.297	– 0.198	0.051	0.049	0.047	0.104	0.074
	significance	0.543	0.689	0.857	0.001	0.767	0.000	0.003	0.431	0.442	0.469	0.102	0.249
	n	255	255	248	255	254	252	221	245	246	244	246	246
FACT Emotional	Pearson correlation	– 0.140	– 0.163	– 0.300	– 0.672	– 0.092	0.120	– 0.620	0.154	0.063	0.217	0.282	0.188
	significance	0.024	0.009	0.000	0.000	0.139	0.055	0.000	0.016	0.319	0.001	0.000	0.003
	n	259	259	252	259	258	256	224	247	249	247	248	249
FACT Functional	Pearson correlation	0.008	0.071	– 0.127	– 0.362	0.018	0.228	– 0.722	0.156	0.065	0.203	0.077	0.148
	significance	0.894	0.253	0.043	0.000	0.769	0.000	0.000	0.014	0.309	0.001	0.228	0.019
	n	260	260	253	260	259	256	225	248	249	248	249	250
FACT Total score	Pearson correlation	– 0.031	– 0.054	– 0.259	– 0.560	– 0.078	0.321	– 0.785	0.188	0.094	0.252	0.194	0.191
	significance	0.631	0.397	0.000	0.000	0.219	0.000	0.000	0.004	0.147	0.000	0.003	0.003
	n	249	249	243	249	248	245	216	240	240	239	240	241

still discussed controversially. Ringdal et al. [20] described the predominance of disease-related factors whereas, in their opinion, psychosocial factors have only modulating influence. An active problem-oriented coping style and low emotional distress may positively influence survival by improving compliance with medical treatment [21].

While, to a large extent, acute psychological reactions to the diagnosis were similar in most patients, each developed his/her individual coping pattern. It was therefore of great importance to identify those factors in patients indicating a good or bad coping strategy [22], which would make it possible to select appropriate therapies in the future. In the course of our study, coping strategies of patients who received radiotherapy remained relatively stable. Most common were active problem-oriented coping, distraction and self-help; only problem-oriented coping decreased significantly (p < 0.001). Social withdrawal seems to play a significant role; this behavior is interpreted as a specific coping reaction to cancer with the aim of self-stabilization. In the opinion of psychooncologists there is a pressing need for psychosocial care [23, 24]. On the other hand, there is a low acceptance of established psychosocial care [25]. There is no doubt that clinical indications for psychosocial care are more obvious to medical personnel than to the patients themselves. Nevertheless, a professional intervention must be applied with care to avoid endangering the mental stability of the patient. Distraction and self-help, as well as suppression are phase-specific coping mechanisms, which should not be used forcibly.

In our study the greatest need for psychosocial care evolves during the period up to 6 weeks after completion of radiotherapy; particularly, there is need for additional information about therapies and side effects as well as about psychological care and counseling from the doctors' side. In contrast to findings in the literature this points to active problem-oriented coping with cancer and its treatment as well as with psychosocial problems observed specifically in radiotherapy patients.

In an investigation of Annunziata et al. [26], well-informed patients were not more content with medical and psychosocial care than less well-informed patients. A higher rate of life satisfaction was evident in patients who were content with the type of information received, whether or not they belonged to the group of well-informed or less well-informed patients.

There is no doubt that accompanying psychosocial care of radiooncology patients does support the process of adaptation to disease and improve life satisfaction. Cunningham at al. [27] investigated a manualized treatment modality with supportive expressive group psychotherapy for patients and their relatives and assessed it as cost-effective and helpful to improve QoL.

Early and adequate rehabilitation is the aim. Patients ask for additional information about the disease and for opportunity to discuss psychological problems with a doctor, they and prefer patient-centered communication [28]. Both disease and therapy require health professionals who have relevant qualifications and expertise in radiotherapy and psychooncology.

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