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Normative Data for Functional Assessment of Cancer Therapy

General Scale and its Use for the Interpretation of Quality of Life Scores in Cancer Survivors

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The aims of this study were to derive population-based reference values for the Functional Assessment of Cancer Therapy Scale–General (FACT-G) and to investigate the impact of sociodemographic variables (e.g. age, sex, health status) on these quality of life (QOL) scores, and to compare the normative QOL scores with those of various groups of cancer survivors. A random sample of 2 000 members of the Austrian public were sent questionnaires containing the FACT-G and questions relating to demographic data and health status. A total of 968 questionnaires were returned giving an overall response rate of 50.6% (females 48.3%, age 49.3 ± 16.8). Subjects with higher education reported higher QOL values; divorced and widowed persons had significantly lower QOL scores. Higher age was also associated with lower QOL scores. After bone marrow transplantation, patients generally showed lower QOL scores than the age- and sex-matched population-based sample, whilst in breast cancer survivors there was reduced QOL regarding social well-being. Survivors of Hodgkin's disease were found to have higher functional and social well-being scores than those of the general population sample. Sociodemographic variables should always be taken into consideration when interpreting QOL scores. Furthermore, unless patient data are compared with normative values, phenomena such as adaptation and response shift might be missed or misinterpreted.

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Assessment of quality of life (QOL) is now a widely used parameter in clinical oncology research, and over the past decade it has become important to establish valid and reliable instruments to assess the QOL of cancer patients (1). As a result of research in this area, several cancer-specific QOL instruments have been developed, including the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (2), the Functional Assessment of Cancer Therapy Scale-General (FACT-G) (3), the Functional Living Index Cancer (FLIC) (4) and the Rotterdam Symptom Checklist (RSCL) (5).

The main purpose of these questionnaires in clinical trials is to provide an additional outcome measure when comparing different oncological treatment regimens, the questionnaires usually being administered at different stages of the disease and at various times in the course of treatment.

When interpreting QOL scores, the focus may not only be on the comparison of treatment groups but also on more descriptive aspects of the data in relation to the overall range of the scale, i.e. the maximum and minimum possible scores. For example, after undergoing radiotherapy, if a breast cancer patient scores 73 out of 100 in the physical domain of a QOL questionnaire, what does this mean for the patient's subjective physical well-being? A comparison with the maximum possible score of 100 would probably reveal little meaningful information and might underestimate the patient's perceived QOL (as healthy controls would probably not score 100), and therefore overestimate the negative impact of the disease and its treatment (6).

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Reference values relating to the general population are clearly needed for the interpretation of such QOL scores, so that scores obtained by cancer patients can be compared with those of a matched control group of persons who are not suffering from cancer.

Databases of normative values for the general population are available only for a few cancer-specific QOL inventories. For example, there are four investigations reporting such reference data for the EORTC QLQ-C30 (6–9). In these studies QOL values were analysed according to age groups and gender and it was found that QOL scores differ between these sociodemographic variables on most of the subscales. Moreover, in a meta-analysis carried out by Fayers (10) it was shown that QOL values also differ across countries. Gandeck et al. obtained similar results for the SF-36 as a generic QOL assessment instrument (11).

There is only one recently published article by Cella et al. (12) reporting on population-based reference data for one of the most widely used QOL questionnaires in oncological research, the FACT-G, the core questionnaire of the Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System (13). The FACIT (formerly FACT) was originally designed for cancer patients and, like the EORTC QOL questionnaire, is modular in design, consisting of a generic core questionnaire (FACT-G) and site-specific modules (3, 13)—for example, for use with patients with breast, colorectal or lung cancer.

In the above-mentioned investigation by Cella et al. (12), normative data for the Functional Assessment of Cancer Therapy–Anaemia (FACT-An) questionnaire were used to evaluate the effect of treatment with epoetin alpha on QOL, but no detailed analysis regarding the impact of sociodemographic variables on the normative QOL values derived was provided.

In order to address the problem of a lack of reference data for the FACT-G, the primary objective of the present study was to derive norms for a German-speaking population (Austria). In addition to this main objective, two further issues were also investigated: 1) the impact of sociodemographic variables such as health status, age, sex, marital status and educational status on QOL scores and 2) the use of FACT-G reference data by interpreting QOL scores in different types of cancer survivors.

In addition, a comparison between the derived FACT-G norms and the US reference sample from Cella et al. (12) is presented.

MATERIAL AND METHODS

A sample of 2 000 subjects (age ≥ 18 years) drawn from the Austrian population were randomly selected from the official telephone register. Subjects were then sent a questionnaire by post containing the German version of the FACT-G, and questions concerning demographic data and health status. In an accompanying letter, the subjects were given information about the aims of the study, emphasizing their voluntary participation and including an assurance of complete confidentiality. They were asked to return the questionnaires in a prepaid envelope provided. Three weeks later, a reminder was sent to all non-respondents. All questionnaires were posted in April 2002.

In order to examine how representative the sample was of the whole Austrian population, information regarding the national distribution of sociodemograhic parameters was requested from the Austrian Central Office of Statistics.

Patient samples

The QOL data of the normal population sample were compared with previously published QOL data of 3 groups of patients who had survived Hodgkin's disease (n = 126, 50.8% female, age 44.6 ± 14.0, time since initial diagnosis 9.1 ± 7.0 years, Greil et al. (14)), breast cancer (n = 87, age 53.9 ± 8.7, time since initial diagnosis 4.5 ± 4.4 years, Holzner et al. (15)) or bone marrow transplantation (BMT) (n = 56, 38.2% female, age 34.0 ± 9.7, time after transplantation 3.7 ± 3.2 years, Kopp et al. (16)). All of these cancer patients were in complete remission.

Quality of life instrument: FACT-G

The FACT-G (version 4) is the core questionnaire of a collection of QOL inventories focusing on chronic illness (FACIT; 3, 13). It is used internationally and has undergone extensive psychometric testing: test–retest reliability coefficients range from 0.82 to 0.92, internal consistency of subscales measures range from 0.60 to 0.89 (3, 17). The FACT-G is designed for self-assessment and consists of 27 items to be rated on a 5-point Likert scale. Patients can complete the FACT-G within about 10 min.

Each of the inventory questions is scored from 0 (worst possible QOL) to 4 (best possible QOL) with some items being reversed. In addition to an overall quality of life score (the sum of all items), there are subscales for the areas of physical well-being, social well-being, emotional well-being and functional well-being.

The FACT-G contains 6 items (item no. GP5: I am bothered by side effects of treatment; GS4: My family has accepted my illness; GS5: I am satisfied with family communication about my illness; GE2: I am satisfied with how I am coping with my illness; GE3: I am losing hope in the fight against my illness; GF4: I have accepted my illness) with wording that relates only to persons who are ill. Consequently, these items were dropped in order not to confuse the respondents. FACT-G subscales and total scores were then pro-rated, as was done in Cella et al. (12), to obtain scores comparable to the complete assessment.

Data analysis and statistical methods

The subscores of the FACT-G were calculated according to the directions provided in the FACIT-Manual (all subscales are scored in such a way that higher values mean higher QOL; Cella (13)). Missing data were also treated according to the manual scoring guidelines.

Participant health status was divided into three categories: healthy, mild chronic disease and severe chronic disease. Category allocation was done by the physicians on the basis of the statements made by the respondents concerning their disease status (e.g. mild chronic disease: arthritis, high blood pressure; severe chronic disease: stroke, chronic heart failure, multiple sclerosis, etc.). Common, age-related impairments, such as reduced visual acuity, were not taken into account.

Participants were also grouped by age into one of the following six age categories: 18–29 years, 30–39 years, 40–49 years, 50–59 years, 60–69 years and > 70 years. A further variable was introduced by dividing participants into three groups, according to their education (low, medium and high levels of education).

The internal consistency of the subscales of the questionnaire was evaluated using Cronbach's alpha. It was considered acceptable if the coefficient a exceeded 0.70.

A series of ANCOVAs (analyses of covariance) were used to investigate the effect of age on QOL subscores for physical, emotional, functional and social well-being. The analyses used age as a between-subject factor and the demographic variables of sex and education as covariates. ANCOVA was also used to investigate the effect of sociodemographic variables on the QOL subscores. In these analyses, health status, sex, marital status and education were used as between-subject factors and age as a covariate. All *post hoc* analyses were carried out using the Tukey method.

Comparisons between the normal population sample and the groups of cancer survivors were made using the t-test for independent samples. To obtain comparability regarding sex and age, the normal population data were weighted according to the sex and age distribution in the respective patient samples. To quantify differences between groups, effect sizes were determined.

Table 1

Sociodemographic data of the general population

Number	Female n = 447 (48.3%)	Male n = 479 (51.7%)	Total sample n = 926
Age			
Mean ± SD	49.3 ± 16.8	50.6 ± 16.5	50.0 ± 16.6
Range (years)	18.8–96.2	18.6–95.3	18.6–96.2
18–29	12.5%	10.4%	11.4%
30–39	23.9%	21.5%	22.7%
40–49	18.8%	20.0%	19.4%
50–59	19.7%	16.3%	17.9%
60–69	11.2%	18.0%	14.7%
> 70	13.9%	13.8%	13.8%
Marital status			
Single	16.3%	12.3%	14.3%
Married/with partner	57.5%	78.3%	68.3%
Divorced	11.0%	5.6%	8.2%
Widowed	15.2%	3.8%	9.3%
Children			
Yes	72.6%	77.0%	74.9%
No	27.4%	23.0%	25.1%
Housing situation			
Alone	25.6%	17.3%	21.5%
With partner/family	68.2	74.5%	71.3%
Origin family	3.9%	5.5%	4.7%
Housing community	1.4%	1.5%	1.5%
Residence	0.9%	1.1%	1.0%
Education (highest achieved level)			
Elementary school	20.8%	15.0%	17.8%
Completed apprenticeship	49.2%	54.9%	52.2%
High school, university	30.0%	30.1%	30.0%
Occupational status			
Full-time	29.3%	54.5%	42.3%
Part-time	15.9%	2.7%	9.1%
Housewife	19.9%	.2%	9.7%
Student	1.6%	1.9%	1.7%
Unemployed	7%	1.5%	1.1%
Retired	27.1%	32.4%	29.8%
Others	5.6%	6.9%	6.3%
Health status			
Healthy	81.4%	78.7%	80.0%
Mild chronic disease	10.7%	13.4%	12.1%
Severe chronic disease	7.8%	7.9%	7.9%

RESULTS

Sociodemographic characteristics and an overview of QOL data (FACT-G)

Of the 2 000 questionnaires posted, 74 (3.7%) could not be delivered because the participants had changed their address or had died. Of the remaining 1 926 questionnaires, 968 were returned giving an overall response rate of 50.3% (723 questionnaires were returned within 3 weeks, the remaining 245 were sent back after a reminder). This response rate is consistent with other recent surveys conducted in Austria (18). Forty-two respondents were excluded because they did not make a statement concerning their age or their gender, leaving 926 participants in the final data set (female 48.3%, age 49.3 ± 16.8).

A detailed description of the sociodemographic characteristics of the sample is presented in Table 1.

Data from the Central Office of Statistics also enabled us to compare our sample with the total population of Austria. No statistically significant differences were found between

Table 2a

Quality of life values of men and women in the general population, as measured by the FACT-G subscales (mean, SD) and percentiles of FACT-G total

	Range		Women							Men							Total sample
			18–29 n = 56	30–39 n = 107	40–49 n = 84	50–59 n = 88	60–69 n = 50	> 70 n = 62	All n = 447	18–29 n = 50	30–39 n = 103	40–49 n = 96	50–59 n = 78	60–69 n = 86	> 70 n = 66	All n = 479	n = 926
FACT-G subscales^{+}																	
Physical well-being	0–28	Mean	25.6	24.4	25.5	23.9	24.4	23.4	24.5	25.9	25.9	25.3	25.3	25.1	24.4	25.3	24.9
		SD	(2.8)	(4.6)	(3.1)	(5.6)	(4.0)	(4.7)	(4.4)	(2.1)	(3.0)	(3.2)	(3.9)	(4.3)	(4.9)	(3.7)	(4.1)
Emotional well-being	0–28	Mean	19.7	19.7	19.0	18.9	18.0	17.9	19.0	21.3	20.6	19.5	19.5	20.1	19.7	20.1	19.5
		SD	(4.3)	(4.5)	(4.6)	(5.3)	(5.7)	(5.3)	(4.9)	(3.2)	(3.5)	(4.1)	(4.5)	(3.9)	(4.9)	(4.0)	(4.5)
Functional well-being	0–24	Mean	22.4	22.3	22.1	20.9	20.2	18.3	21.2	22.3	22.3	21.6	21.6	21.7	20.1	21.6	21.4
		SD	(4.4)	(5.6)	(5.5)	(5.6)	(6.3)	(5.9)	(5.7)	(6.1)	(4.9)	(5.1)	(4.2)	(5.6)	(6.4)	(5.3)	(5.5)
Social well-being	0–28	Mean	22.6	21.6	21.0	19.8	18.8	17.1	20.4	21.8	21.2	19.9	20.2	19.1	18.7	20.1	20.2
		SD	(4.6)	(5.1)	(5.0)	(6.7)	(6.6)	(6.5)	(5.9)	(4.3)	(5.5)	(5.2)	(5.6)	(6.4)	(6.2)	(5.7)	(5.8)
Total	0–108	Mean	90.4	88.3	88.0	83.3	81.8	76.9	85.5	91.5	89.9	86.3	86.7	86.4	83.3	87.3	86.5
		SD	(13.1)	(15.2)	(12.9)	(18.8)	(18.7)	(17.2)	(16.4)	(11.5)	(12.8)	(13.7)	(15.0)	(13.1)	(17.3)	(14.1)	(15.2)
Percentiles (Fact-G total)$^{+}$																	
10%			69.1	69.2	70.8	54.5	50.7	52.3	61.6	73.9	69.6	65.5	64.3	65.7	62.8	67.0	65.5
25%			84.7	81.5	83.9	73.3	69.1	63.0	78.0	84.0	82.9	79.6	78.8	78.1	76.2	79.8	78.9
50%			93.5	91.9	89.5	90.1	86.1	77.6	89.9	95.2	92.6	88.4	90.3	89.4	87.6	90.4	90.1
75%			99.5	98.5	96.3	98.0	95.9	91.6	97.7	101.0	98.4	96.4	96.7	96.5	94.0	97.2	97.5
90%			104.5	102.3	102.5	102.2	100.6	100.2	102.2	104.0	105.1	104.0	103.8	102.4	99.7	103.3	102.5

$^{+}$Higher scores indicate better quality of life.

our sample and the official national data regarding sex, age, marital status and education level.

An overview of the FACT-G subscales with regard to sex and age is presented in Table 2a. For the FACT-G total score, percentiles were calculated independently from mean values, to give more detailed information on the distribution of the scores.

Reliability analysis

The internal consistency of the FACT-G subscales was measured using Cronbach's alpha. It was found that for all the subscales, a was greater than 0.70 (physical well-being, $\alpha = 0.82$, 6 items; social well-being, $\alpha = 0.75$, 5 items; emotional well-being, $\alpha = 0.72$, 4 items; functional well-being $\alpha = 0.84$, 6 items). These results indicate a satisfactory degree of internal reliability for all of the FACT-G subscales.

Impact of age on the FACT-G subscales

The results of a series of ANCOVAs investigating differences in the FACT-G subscales between the six age groups are displayed in Table 2b, post-hoc analyses were carried out using the Tukey method.

The mean values of the FACT-G subscales usually declined with increasing age, although mainly without reaching statistical significance. However, the oldest age group (> 70 years) had significantly lower QOL values than most of the other subgroups.

Table 2b

Quality of life values in the general population, as measured by the FACT-G subscales, including significant differences between age groups

	Range	18–29 n = 106	30–39 n = 210	40–49 n = 180	50–59 n = 166	60–69 n = 136	> 70 n = 128	Significant group differences ($p < 0.05$ Tukey post-hoc method)*
FACT-G subscales$^{\#}$								
Physical well-being	0–28	25.7	25.1	25.4	24.6	24.8	23.9	70^{+} < 18–29, 30–39, 40–49
Emotional well-being	0–28	20.5	20.1	19.3	19.2	19.3	18.9	70^{+} < 18–29, 30–39
Functional well-being	0–24	22.4	22.3	21.8	21.2	21.2	19.3	70^{+} < all other groups
Social well-being	0–28	22.3	21.4	20.4	20.0	19.0	17.9	70^{+} < all other groups (except 60–69); 18–29 > 40–49, 50–59, 60–69
Total	0–108	90.9	89.1	87.1	84.9	84.7	80.5	70^{+} < all other groups; 18–29, 30–39 > 50–59, 60–69

$^{\#}$Higher scores indicate better quality of life.
*ANCOVA with adjustment for gender and education.
Abbreviation: FACT–G = Functional Assessment of Cancer Therapy-General.

Table 3

Impact of sociodemographic variables on the QOL of the general population, as measured by the FACT-G subscales

p-values	Health status	Gender	Marital status	Education	Occupational status
FACT-G subscales					
Physical well-being	< 0.001 Chronic disease ↓	0.009 Female ↓	n.s.	< 0.001 Higher education ↑	n.s.
Emotional well-being	< 0.001 Chronic disease ↓	0.001 Female ↓	n.s.	0.033 Higher education ↑	n.s
Functional well-being	< 0.001 Chronic disease ↓	n.s.	0.002 Divorced/widowed ↓	0.003 Higher education ↑	n.s
Social well-being	< 0.001 Chronic disease ↓	n.s.	< 0.001 Divorced/widowed ↓	< 0.001 Higher education ↑	n.s.
Total score	< 0.001 Chronic disease ↓	n.s.	< 0.001 Divorced/widowed ↓	< 0.001 Higher education ↑	n.s.

↑ Indicates higher QOL values; ↓ indicates lower QOL values.
Abbreviation: FACT-G = Functional Assessment of Cancer Therapy-General.

Impact of other sociodemographic and health-related variables on the FACT-G subscales

The results concerning the impact of other sociodemographic and health-related variables on the FACT-G subscales are displayed in Table 3.

Compared with healthy subjects, participants suffering from chronic illnesses reported lower QOL on all subscales of the questionnaire. The mean values for the age-adjusted FACT total score were 89.0, 78.6 and 67.6 for the healthy, the mildly chronically ill and the severely chronically ill subgroups, respectively.

Women reported significantly lower QOL values than men in the areas of physical (♀ 24.5 vs. ♂ 25.3) and emotional well-being (19.0 vs. 20.1) and subjects with a higher level of education reported higher QOL values on all FACT-G subscales. The mean values for the age-adjusted FACT total score were 79.9, 86.3 and 89.0 for persons with low, intermediate and high levels of education, respectively.

With regard to marital status, divorced and widowed persons had significantly lower QOL scores than married and single subjects in the FACT subscales functional well-being, social well-being and in the FACT total score (age-adjusted FACT total score: married/with partner 87.9, single 84.4, divorced 79.7, widowed 80.4).

The subjects' occupational status did not have a statistically significant effect on any of the FACT subscales.

Comparison between population-based norms and QOL data of various groups of cancer patients

The results of the comparisons between the normative data and the groups of cancer survivors are summarized in Table 4.

Survivors of BMT had significantly lower QOL scores than subjects drawn from the general population (matched with the patient group for sex and age by appropriate weighting) on all FACT subscales with the exception of

Table 4

Comparison of various group of cancer patients vs. normative data

FACT-G subscales^{+}	Range	BMT (n = 56) Mean	Norms Mean	Effect size	Breast cancer (n = 87) Mean	Norms Mean	Effect size	Hodgkin's disease (n = 126) Mean	Norms Mean	Effect size
Physical well-being	0–28	21.1***	25.5	– 1.33	25.1	24.4	0.13	25.5	25.1	0.12
Emotional well-being	0–28	15.6***	20.2	– 1.21	18.8	18.8	0.00	20.3	19.6	0.18
Functional well-being	0–24	20.5*	22.2	– 0.32	21.7	21.0	0.13	23.1**	21.7	0.26
Social well-being	0–28	20.2	21.3	– 0.22	18.3**	19.9	– 0.24	22.2**	20.6	0.29
Total	0–108	77.8***	89.3	– 0.83	83.9	84.2	– 0.02	90.9**	87.3	0.26

*p < 0.05; **p < 0.01; ***p < 0.001.

$^{+}$Age- and gender-adjusted mean values.

social well-being. Effect sizes (EF) ranged from -0.22 (FACT social well-being) to -1.33 (FACT physical well-being).

In contrast, the breast cancer survivors' group showed almost the same QOL scores as the population-based sample, adjusted for age and sex as above, with only scores in the social domain ($EF = -0.24$) being significantly lower than those of the controls.

Patients with Hodgkin's disease reported a higher QOL than the age- and sex-adjusted control group for the areas of functional ($EF = 0.26$) and social well-being ($EF = 0.29$) and for the total score ($EF = 0.26$).

DISCUSSION

Quality of life assessment using self-administered questionnaires has now become standard practice in oncological research and is steadily gaining importance as an evaluation instrument in clinical decision-making (19).

Although QOL data for cancer patients are useful in their own right, for example in direct comparisons between different treatment regimens, they assume even more importance if they can be interpreted in the light of population-based normative data. Such data would not only provide a benchmark for comparison in terms of average perceived quality of life for that population, but would also allow patient data to be compared with demographically matched controls to provide more detailed insights into the quality of life of cancer survivors. The collection of normative data also has an additional use in facilitating comparisons of the health status of different populations or countries (20). In relation to this latter point, data reported by Fayers (10) and Gandeck et al. (11) have shown that QOL scores vary greatly across countries, suggesting that there is a need for a wide range of QOL norms to be collected.

Having said this, it needs to be acknowledged that our results may specifically reflect the situation of a German-speaking population in Europe (Austria). On the other hand, the more general conclusions derived from this study, such as the fact that one needs to base interpretation of QOL studies on age and gender-related norms, can apply in a broader international context.

The present study had two major objectives. The first aim was to derive population-based norms for FACT-G and then to examine the impact of sociodemographic variables on QOL scores. The second aim was to compare the normative values obtained with the QOL data of cancer patients found in previous studies of our group. The latter issue mainly serves as an example for the use of population-based normative values.

In order to prove the representativeness of the collected sample, we compared the gained data with data from the total population of Austria provided by the Central Office of Statistics. As no relevant differences were found regarding the distribution of sociodemographic parameters, the sample was considered as representative of the population of Austria as a whole. Of course, there is still a risk of selection bias owing to the sampling procedure (telephone directory). However, this potential bias is reduced by the fact that the percentage of the Austrian adult population listed in the telephone directory is very high.

Comparing the presented reference data with those of a US sample of subjects with no specified illness recently published by Cella et al. (12), the mean values in the various FACT-G subscales could be found as almost identical (physical well-being 24.9 vs. 24.8 (US), emotional well-being 19.5 vs. 19.8 (US), functional well-being 21.4 vs. 21.5 (US), social well-being 20.2 vs 20.3 (US), total 86.5 vs. 86.9 (US)). This result underlines the cross-cultural applicability of the FACT-G.

Examining the impact of sociodemographic variables on the FACT-G scores it was found that with regard to the effect of health status on QOL, the population-based mean scores showed the expected profile of results, with healthy people reporting a better quality of life than those with mild chronic disease, who in turn stated that they had a better quality of life than those with severe chronic diseases. The observed differences in the mean values, which in some cases were quite marked, underline the sensitivity of the FACT-G. Similar findings for the EORTC QLQ-C30 were reported by Hjermstad et al. (8) and Michelson et al. (9).

Women were found to have a QOL than men in two of the four FACT-G domains, namely physical and emotional well-being. This finding corresponds with earlier studies and provides some evidence that male patients are less inclined to admit their impaired QOL than women (7, 21). No significant gender difference was observed for the FACT total score. It is noted that other investigations using the EORTC QLQ-C30 have generally shown more distinct gender differences (7–9). The discrepancies between previous studies and our own could be explained by differences between the FACT-G and the EORTC QLQ-C30. As shown in a study by Kemmler et al. (22) the latter instrument has a stronger focus on the physical aspects of QOL, which applies not only to the physical but also to the social- and role-functioning subscales.

As with other studies that derive population-based normative values, the present study found that age had a considerable impact on the perceived QOL. Generally, a decline in QOL scores was observed with increasing age. Schwarz et al. (7) and Hjermstad et al. (8) have reported similar results. The most marked decline was found between the 60–69 years age group and the over 70-year-olds. One important factor for this decline appears to be increasing health problems in subjects above the age of 70.

As a further result of the present study, it was found that both lower educational status and divorce/widowhood generally result in a lower QOL. More highly educated people are likely to have more satisfying work situations and generally to have more privileged lifestyles. Concerning marital status, it can be assumed that people who lost their partners are in an emotionally and socially less stable situation because of a decline in instrumental and socio-emotional support. These findings are in agreement with previous research (8, 9, 23, 24).

With regard to the second aim of the study, a comparison between population-based norms and different groups of cancer survivors, several interesting findings were obtained. As expected BMT survivors showed significantly lower QOL values than a sample of the general population matched with the patient group for sex and age by appropriate weighting. It is assumed that the marked differences in the physical and emotional domains are a reflection of the long-lasting effects of aggressive anticancer treatment, as described by Neitzert et al. (25).

The group of breast cancer survivors, on the other hand, differed from the reference group only in the area of social well-being, and showed significantly lower values in this domain. Dow et al. (26) and Holzner et al. (15) have also reported long-lasting impairments to social support and sexuality in this group of patients.

When comparing the reference data with survivors of Hodgkin's disease, we found that the latter group reported higher QOL scores than the general population. This applied especially to the areas of functional and social well-being, although the effect sizes were small compared with the differences between BMT patients and healthy subjects.

These unanticipated findings may be explained by response shift phenomena (27), where patients develop new personal standards because of the experience of constant distress when undergoing prolonged anticancer treatment. Sprangers et al. (28) have suggested that this phenomenon could be quantified using the then-test, which could be employed in further investigations using normative values. An alternative explanation is adaptation to illness reflecting true benefit to survivors in these areas.

Of course response shift phenomena are likely to occur also in the two other groups of patients (breast cancer, BMT). However, especially for the BMT patients, the late effects of high toxicity treatment probably outweigh this effect.

In two recent studies investigating the QOL of patients with Hodgkin's disease, Loge et al. (29) and Ganz et al. (30) reported a less favourable outcome. While this seems to contradict our findings, it has to be noted that, in comparison to the sample investigated by Loge et al. (29) and Ganz et al. (30), the time since diagnosis (treatment) was much longer in our sample. Therefore the negative effects of the anticancer treatment would have worn off, resulting in better physical condition and emotional well-being. Moreover, in the studies mentioned above, a different QOL instrument, namely the SF-36, was used. This questionnaire is focused more on physical issues than the FACT-G, which may also be a reason for the divergent results.

In summary, our findings show that QOL data in cancer survivors require careful interpretation, beyond a mere evaluation of scores on a rating scale. There are a number of issues that do not come to light unless patient data are considered in the light of normative values (9). In producing normative values for the FACT-G, the present study has confirmed that there are a large number of demographic variables that mediate QOL including gender, marital status education and health. The study has also shown that unless patient data are compared with normative values, phenomena such as adaptation and response shift may be missed or misinterpreted.

It is therefore emphasized that the use of normative data is important in the correct interpretation of QOL data in oncological studies and that the aim of further research should be to produce norms for different populations and guidelines for more precise interpretation of clinical QOL data.

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