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The impact of curative cancer treatment on sexual health – clinical results from the EORTC QLQ-SH22 validation study

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Abstract

Background The European Organization of Research and Treatment of Cancer (EORTC) has recently developed and validated a patient-reported outcome measure (PROM) for sexual health (SH) in cancer patients. Here, we present results from a secondary analysis of the EORTC QLQ-SH22 validation study. The objective was to investigate the impact of cancer treatment on SH over the disease trajectory into survivorship in patients who underwent curative treatment.

Methods Participants completed the EORTC QLQ-SH22 and the EORTC QLQ-C30 assessing SH and Quality of Life. We analyzed differences in SH of patients on active cancer treatment compared to patients off-treatment (cross sectional group comparison) as well as changes in SH during the course of treatment (from pre-treatment to follow-up).

Results Our sample consisted of $n = 394$ (66.2% females) curatively treated cancer patients with 34% of patients being on-treatment and 66% of patients being in their follow-up after primary treatment (off-treatment group). Compared to patients off- treatment, patients on active cancer treatment experienced less sexual satisfaction ($p = .021$, *Cohen's* $d = .36$) and libido ($p < .001$, $d = .60$) and had higher levels of fatigue ($p < .001$, $d = .50$). Importance of sexual activity, masculinity and femininity did not differ between groups. Treatment effects on sexual activity decreased with treatment completion ($p < .001$, $d = .50$). Patients undergoing intensified treatment (chemotherapy, radiation, or endocrine treatment) reported more treatment effects (subscale EORTC QLQ-SH22) compared to patients undergoing surgery only.

Conclusion Our results highlight the negative impact of oncological treatment on SH and how increasing treatment intensity further impair SH. Sexual satisfaction and libido improve after treatment completion while other aspects (e.g. masculinity/femininity) do not change during survivorship. We suggest monitoring of SH from the start of cancer treatment on and beyond into survivorship using PROMs as part of routine cancer care. Routine monitoring allows

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systematic identification of patient's SH problems and may improve awareness as well as target intervention for those in need of care.

Keywords Sexual health, Cancer, Quality of Life, EORTC QLG

Background

Sexual health (SH) is an integral component of quality of life (QoL) [1, 2]. Cancer disease can have a detrimental effect on SH due to disease-related symptoms, treatment side-effects as well as related psychosocial impairments. About 66% of female cancer patients [3] and up to 90% of male patients [4] (depending on cancer site), experience sexual difficulties. Observed SH impairments include a lack or reduction of sexual desire, orgasmic problems, pain during intercourse, and gender-dependent problems such as vaginal dryness and erectile dysfunction [5]. Body perception, feeling of attractiveness, emotional stability and other psychosexual issues can be affected by cancer [6–8]. Moreover, SH and reproductive issues not only concern patients, but also affect their partners and intimate relationships [9]. These SH problems, particularly psychosexual problems, have been reported to persist beyond the active treatment phase long into survivorship [10–12]. A thorough understanding of the extent of sexual adverse events and their character considering the disease- and treatment stages are therefore crucial for tailoring supportive care efforts during active treatment and in survivorship care.

To assess SH of cancer patients in clinical trials as well as in daily clinical routine, the European Organization of Research and Treatment of Cancer (EORTC) Quality of Life Group (QLG) has developed and psychometrically validated a cross-cultural patient reported outcome measure (PROM) – the EORTC QLQ-SH22 [1] (development completed).The QLQ-SH22 is conceptualized as a generic PRO-measure for assessing SH beyond sexual (dys-)function considering physical, psychological, and social aspects of SH in male and female cancer patients and in patients with a history of cancer disease. To the best of our knowledge, the multidimensionality, the instrument's broad cross-cultural applicability and validation across cancer entities along the entire disease and treatment trajectory is unique.

To supplement the EORTC QLQ-SH22 cross-cultural validation study by taking up a clinical perspective, we performed a secondary analysis investigating the impact of cancer treatment on SH in male and female cancer patients. The aim was to analyze changes in SH during curative treatment and to compare SH in patients undergoing active cancer treatment with curative intent (on-treatment group) with patients with a history of cancer, who already completed their curative treatment at the time of assessment (off-treatment group). In addition, we aimed to improve our understanding of factors determining sexual satisfaction after cancer treatment. In detail, we determined the following research questions:

1. To what degree does curative cancer treatment impact on sexual health compared to an off-treatment situation?
2. How does SH change along the curative cancer treatment trajectory?
3. Which sociodemographic and clinical factors predict sexual satisfaction after curative cancer treatment completion?

In this study we provide comprehensive information on SH in a large multinational population of male and female patients with varying cancer sites, treatment types, and treatment stages [10, 13, 14].

Patients and methods

Sample

Original validation study sample

The original sample from the EORTC QLQ-SH22 international validation study (phase IV)1 consisted of $n=444$ male and female patients undergoing curative or palliative treatment for different cancer types as well as patients who had completed their treatment [1]. Eligible patients were recruited at 18 collaborating centers; the sample was well distributed across 13 European countries and Taiwan. Patients were consecutively included and allocated to study groups according to protocol (group A-D, see appendix 1 in the supplemental material). Group A and B were newly diagnosed patients on-treatment (A = surgery only, B = intensified treatment). For these groups two assessment time points were available: Baseline (before start of treatment) and a follow-up time point (2–6 months after treatment start). The latter assessment depended on the type of treatment which differs across cancer groups and treatment plan (e.g. chemotherapy and/or radiation). Group D consisted of patients with no evidence of disease having completed first line treatment. Group D was assessed cross-sectionally but had a second time point assessment one week after the assessment for test–retest analysis. Group C was a palliative sample which we excluded from this analysis (see Appendix 1 for more details).

Present study sample

For the purpose of this analysis, we derived data from adult cancer patients treated with curative intent ($n=335$) from the overall EORTC QLQ-SH22 validation study sample [1] described in the previous section. The inclusion criteria for the present analysis were as follows: study participation in EORTC QLQ-SH22 validation study and curative treatment intent (on- or off treatment). In addition, data of a sample of 59 breast cancer patients treated with curative intent at the Medical University of Innsbruck were included. These patients had originally been recruited for the validation study but were not included in the original final analysis as logistical problems prevented the collection of second assessment data. A second assessment was mandatory for the psychometric analysis according to the study protocol group distribution. Hence, the total sample analyzed herein comprised 394 patients.

The "on-treatment group" includes data of patients newly diagnosed receiving treatment at the time of assessment (group B) and from the additional sample of breast cancer patients. The "off-treatment group" consisted of patients from group A (second assessment) and D (data from the cross-sectional assessment time-point were used) and from the additional sample of breast cancer patients (please see Fig. 1).

Data collection

Data collection in the original validation study

The study has been approved by the ethical committees of all participating centers, the principal investigators application has been approved by the Ethical Committee of the Medical University of Graz, Austria. After consenting to study participation, eligible patients completed the EORTC QLQ-SH22 alongside the EORTC QLQ-C30 during an in-patient stay or an after-care visit. Medical and sociodemographic patient data were retrieved from the medical records or reported by patients. For patients undergoing active treatment QoL data were assessed before treatment start (baseline) and 2–6 months after treatment start (including surgery/ chemotherapy/ radiation/ endocrine therapy). Details on the data collection procedure have been reported earlier [1].

Data collection of additional breast cancer patient sample

A sample of 59 breast cancer patients treated with curative intent was additionally recruited at the Medical University of Innsbruck. The sample fulfilled eligibility criteria according to EORTC QLQ-SH22 study protocol. These patients had originally been recruited for the validation study following the phase IV protocol and recruitment procedure (i.e. completion of EORTC QLQ-SH22 alongside the EORTC QLQ-C30 during an in-patient stay or an after-care visit as described above). As indicated above, no second time point assessment (i.e. follow-up assessment or retest) had been performed due to logistic reasons so that data could not be included in the final analysis.

PROMs

EORTC QLQ-C30 (Version 3.0)

The EORTC QLQ-C30 [2] is a generic PROM that has been developed to assess QoL in cancer patients. It has been translated and validated in various languages and is

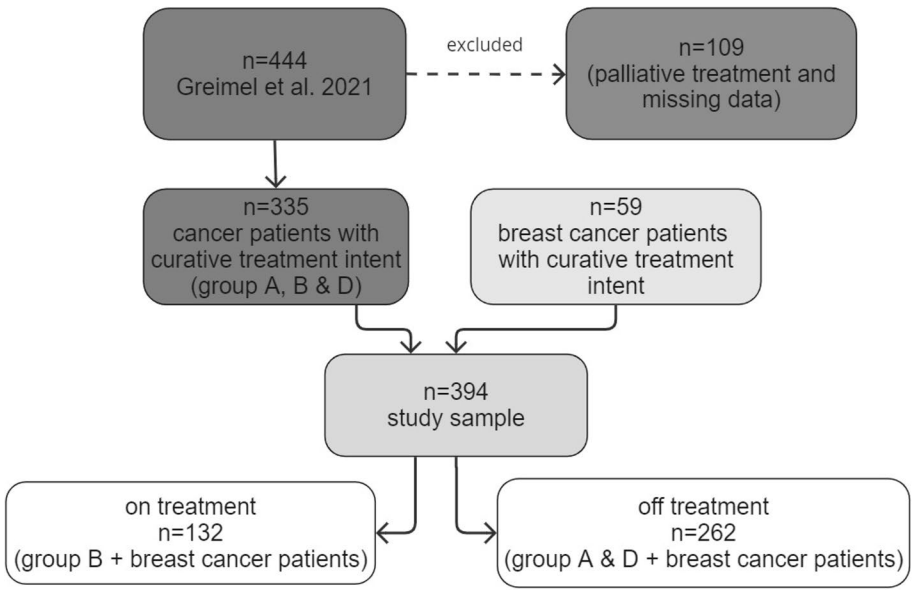

Fig. 1 Flowchart of the sample composition

commonly used in studies as well as routinely in the clinic. The QLQ-C30 consists of 30 items that are summarized into a global health status/QoL scale, five functional scales and nine symptom scales/items with scores ranging from 0–100. Higher scores on the function scales indicate better QoL, whereas for the symptom scales/items, a higher score indicates more symptom burden. The time frame refers to the previous week except for physical functioning which is assessed without time frame. Responses are given on a four-point Likert scale ranging from "not at all" to "very much". The QLQ-C30 can be complemented with modules assessing more specific aspects of QoL for different tumor sites, treatment modalities, or patient groups.

EORTC QLQ-SH22 (fully validated PROM

The EORTC QLQ-SH22 [1] is a 22-item short valid and reliable PROM (phase IV) assessing SH in male and female cancer patients and survivors. The conceptualized SH domains comprise sexual satisfaction, sexual pain, importance of sexual activity, decreased libido, effect of treatment on SH, communication with professionals, security with partner, femininity/ masculinity, vaginal dryness, confidence in erection, fatigue, and worry about incontinence. The time frame referred to and response format correspond to the EORTC QLQ-C30: the past week and a 4-point Likert scale. The QLQ-SH22 has been cross-culturally validated and is currently available in 10 languages.

Statistical analysis

Sociodemographic and clinical sample characteristics are given as means, medians, standard deviations, and frequencies. First, we compared SH outcome in patients undergoing active cancer treatment (on- treatment) with those who had finalized their treatment (off-treatment) using a t-test for independent samples. Second, we investigated changes of SH outcome over time in relation to treatment intensity i.e. patients with surgery only were compared to patients who underwent intensified treatment including chemotherapy, radiation, targeted treatments and/or endocrine treatment. The SH outcome from the first assessment (pre-treatment) was compared to the follow-up assessment for these groups using analysis of variance. Third, we performed a linear regression analysis (backward elimination procedure) to investigate clinical and socio-demographic predictors of SH in patients who were off-treatment. According to clinical considerations, the following variables were considered potentially predictive of sexual satisfaction in the off-treatment sample: sex, age, having or not having a sexual partner, time since diagnosis, treatments received (including chemotherapy, radiation, endocrine treatment, targeted treatment), tumor site and overall quality of life (EORTC QLQ-C30 scales). Based on a significant correlation (Pearson correlation coefficient), these variables were included in a backward stepwise regression (Pearson correlation coefficient) with the outcome variable sexual satisfaction. R2 was reported as a measure of model determination; β was employed as a measure of effect size in the regression analyses. Effect sizes were interpreted according to Cohen. For all analysis performed, α-level was set to 0.05. All analyses were conducted in the software SPSS 29.0.

Results

Clinical and sociodemographic patient characteristics

The total sample constituted 394 cancer patients who underwent curative treatment and comprised about two thirds female and one third male patients aged median 56 years. Breast, gynecological and prostate cancer were the most prevalent cancer sites. About 34% of the patients underwent active treatment at the time of the assessment (including surgery and/or oncological treatment). Most patients (85.6%) reported having a sexual partner. Details on clinical and sociodemographic sample characteristics are presented in Table 1.

Impact of curative cancer treatment: comparison of SH in patients on- vs. off curative cancer treatment

Patients undergoing active cancer treatment at the time of the assessment reported significantly less sexual satisfaction (mean 37.44 vs. 46.66, $p=0.021$), lower libido (mean 37.93 vs. 55.05, $p<0.001$), more fatigue (mean 53.81 vs. 35.45, $p<0.001$) and a higher treatment effect on sexuality (mean 34.49 vs. 53.30, $p<0.001$) compared to patients in the off-treatment group. We found no differences for the other EORTC QLQ-SH22 scales. Results of the t-test are displayed in Fig. 2; results related to single items are given in Table 2.

Changes in SH across the treatment trajectory

At follow-up assessment, all patients reported that cancer treatment had a negative effect on their sexuality over the treatment trajectory ($p<0.001$), regardless of treatment intensity.

The intensified treatment group reported significantly lower sexual satisfaction ($p=0.018$), higher levels of fatigue ($p=0.048$), more vaginal dryness ($p=0.030$) and lower femininity scores ($p=0.004$) over the treatment trajectory compared to the surgery only group. Moreover, the importance of sexuality during treatment significantly decreased ($p=0.043$) over the treatment trajectory in the intensified treatment group whereas it was stable in the surgery only group.

While libido decreased in patients in the intensified treatment group ($p=0.004$), it increased in the surgery only group after treatment. Male patients of both groups experienced a decline in their confidence in erection ($p=0.010$). Interesting to note, both groups reported a small but significant increase in communication about

Table 1 Clinical and sociodemographic sample characteristics

	All	**On active treatment**	**Off treatment**
	N **= 394**	***N*** **= 132 (33.6%)**	***N*** **= 262 (66.5%)**
	Frequency (%)		
Sex			
Female	261 (66.2%)	85 (64.4%)	176 (67.4%)
Male	133 (33.8%)	47 (35.6%)	88 (32.6%)
Age (in years)			
Mean (SD)	56 (11.91)	56 (9.95)	55.73 (12.82)
Median	56	56	56
Range	23–84 y	25–79	23–84
Tumor site			
Lung cancer	20 (6.1%)	19 (19.4%)	1 (0.4%)
Colorectal cancer	18 (5.5%)	4 (4.1%)	14 (6.1%)
Breast cancer	99 (30.0%)	30 (30.6%)	69 (29.9%)
Gynaecological cancer	73 (22.1%)	15 (15.3%)	58 (25.1%)
Head and Neck	35 (10.6%)	11 (11.2%)	24 (10.4%)
Prostate cancer	51 (15.5%)	13 (13.3%)	38 (16.4%)
Genito-urinary cancer	14 (4.2%)	2 (2.0%)	12 (5.2%)
Oesophageal, stomach cancer	5 (1.5%)	3 (3.1%)	2 (0.9%)
Hematologic cancer	10 (3.0%)	1 (1.0%)	9 (3.9%)
Other	5 (1.5%)		5 (2.2%)
Time since diagnosis			
Mean (SD)	33.2 (38.07) months	17.1 (36.24) months	41.81 (36.34) months
Median	22.50 months	4 months	28 months
Range	0–247 months	0–247 months	1–208 months
Treatment[a]			
Surgery	283 (71.8%)	71 (53.8)	212 (80.9%)
Surgery only	61 (23.4%)	-	61 (23.4%)
Chemotherapy	145 (36.8%)	54 (40.9%)	91 (34.9%)
Radiation	153 (38.9%)	56 (42.4%)	97 (37.3%)
Targeted therapy	29 (7.4%)	11 (8.3%)	18 (6.9%)
Endocrine therapy	96 (24.4%)	45 (34.1%)	51 (19.5%)
Living situation			
Living with partner or family	284 (74.2%)	94 (72.3%)	190 (75.1%)
Living alone	51 (13.3%)	21 (16.2%)	30 (11.9%)
Living with others	48 (12.5%)	15 (11.5%)	33 (13.1%)
Sexual partner			
Yes	314 (85.6%)	95 (81.2%)	219 (88.0%)

[a] multiple treatments per patient possible

sexuality with professionals at the second assessment ($p = 0.007$). Detailed results are given in Table 3.

Predictors of sexual satisfaction after cancer treatment completion

The final regression model (see Table 4) explained about 26% of variance of sexual satisfaction in patients off-treatment. Higher social functioning, emotional functioning and QoL, as well as younger age and having a sexual partner predicted higher sexual satisfaction. The variables sex, time since diagnosis, treatments received (chemotherapy, radiation, endocrine treatment, targeted treatment) and tumor entity (cancer of sexual organs vs. other cancers) were eliminated from the model.

Discussion

In our study, any cancer treatment (i.e. surgery only or intensified treatment) was associated with SH impairment as assessed by the EORTC QLQ-SH22.

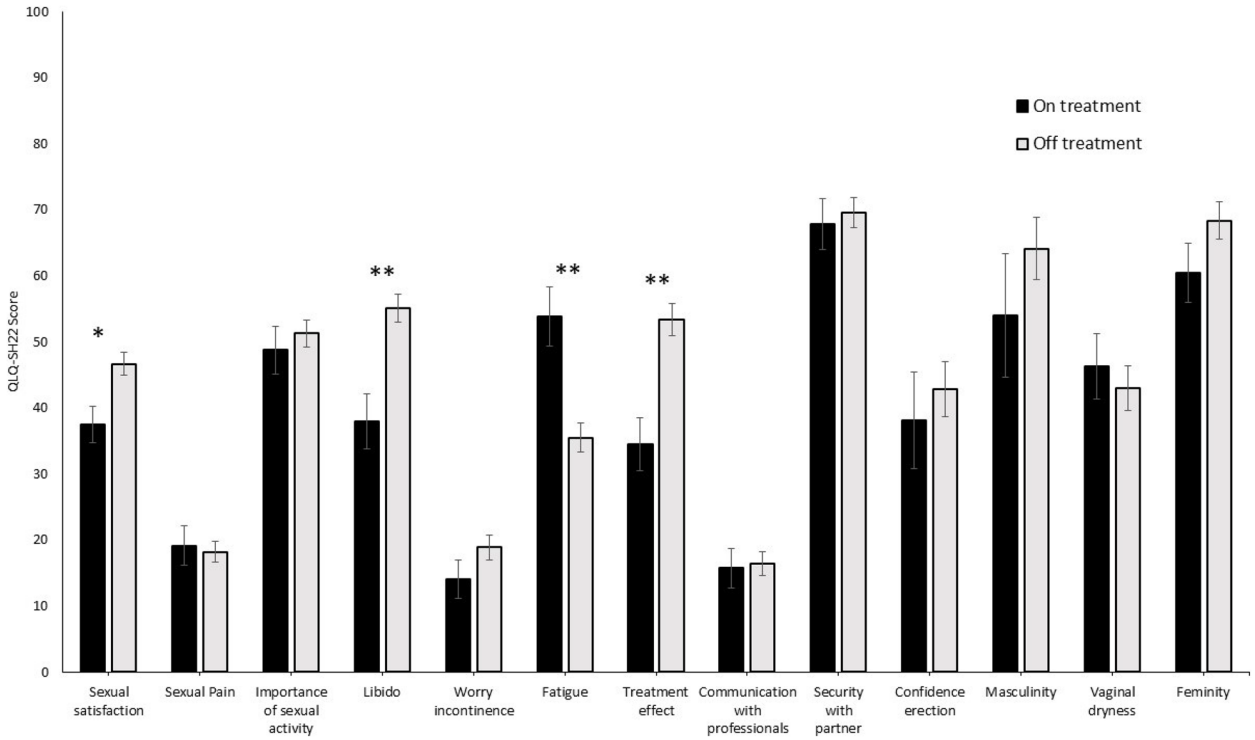

Fig. 2 Differences in the QLQ-SH22 scales between patients on active treatment vs. patients off treatment

Table 2 Differences in the QLQ-SH22 scales by treatment

	On active treatment			Off treatment				
	M ± SD	Median	N	M ± SD	Median	N	P	Cohen's d
Sexual satisfaction[a]	37.44 ± 25.18	32.5	85	46.66 ± 26.84	47.30	241	.021*	.36
Importance of sexual activity[a]	48.72 ± 34.89	49.06	91	51.25 ± 31.34	51.67	247	.563	
Libido[a]	37.93 ± 39.43	30.24	87	55.05 ± 33.90	57.07	244	< .001*	.60
Treatment effect on sexual activity[a]	34.49 ± 37.72	26.66	86	53.30 ± 37.38	54.70	237	< .001*	.50
Communication with professionals[a]	15.75 ± 28.69	10.97	91	16.45 ± 28.06	12.03	237	.840	
Security with partner[a]	67.84 ± 35.05	73.88	85	69.60 ± 34.65	75.90	227	.632	
Confidence erection[a]	38.09 ± 33.80	33.33	21	42.85 ± 36.61	33.33	77	.593	
Masculinity[a]	53.96 ± 42.79	66.6	21	64.10 ± 41.44	66.6	78	.285	
Femininity[a]	60.38 ± 37.17	63.54	69	68.32 ± 35.51	75.14	161	.127	
Sexual pain[b]	19.15 ± 27.88	8.64	85	18.20 ± 24.64	9.15	239	.769	
Worry incontinence[b]	14.01 ± 27.08	9.83	88	18.85 ± 30.38	13.49	244	.189	
Fatigue[b]	53.81 ± 40.60	57.29	83	35.45 ± 33.54	30.70	236	< .001*	.50
Vaginal dryness[b]	46.32 ± 38.16	45.24	59	42.93 ± 37.58	38.981	125	.570	

* significant value $p < 0.05$, according to T-Test

[a] high values indicate high functioning/low symptoms

[b] high values indicate low functioning/high symptoms

The impact of cancer treatment and changes over time: While receiving cancer treatment, patients experienced significantly lower sexual satisfaction, lower libido and higher levels of fatigue than patients who were off-treatment. This observation is in line with established evidence [3–5]. After treatment termination, the effects of treatment on sexual activity seem to decrease while sexual satisfaction increases. This is a promising result in terms of long-term QoL.

Table 3 ANOVA results for QLQ-SH22 scales surgery alone vs. intensified patients over time

Scale	First assessment		Follow-up		Comparison			
	Surgery only	Intensified	Surgery only	Intensified	Group by time		Time	
	M ± SD	M ± SD	M ± SD	M ± SD	p*	η_p^{b}	p*	η_p^{b}
Sexual satisfaction[a]	41.78 ± 28.20	50.93 ± 26.37	45.23 ± 27.12	39.74 ± 26.47	.018	.047	n.s	
Importance of sexual activity[a]	57.03 ± 31.97	57.99 ± 32.99	60.25 ± 31.68	48.82 ± 33.25	.043	.03	n.s	
Libido[a]	34.5 ± 33.31	44.68 ± 35.82	53.84 ± 28.12	38.16 ± 38.03	.004	.071	.003	.04
Treatment effect on sexual activity[a]	75.18 ± 38.99	59.70 ± 40.48	48.29 ± 36.68	33.33 ± 38.34	n.s		.001	.275
Communication with professionals[a]	13.33 ± 26.14	12.38 ± 25.71	22.45 ± 32.19	16.19 ± 29.35	n.s		.007	.062
Security with partner[a]	67.32 ± 35.58	70.86 ± 34.89	62.32 ± 38.23	70.59 ± 32.84	n.s		n.s	
Confidence erection[a]	61.40 ± 33.81	54.67 ± 37.35	45 ± 37.89	37.18 ± 31.73	n.s		.010	.15
Masculinity[a]	53.97 ± 37.23	78.47 ± 34.71	48.33 ± 42.54	61.53 ± 41.83	n.s		n.s	
Femininity[a]	64.52 ± 35.42	73.99 ± 34.35	71.11 ± 32.44	53.33 ± 37.87	.004	.118	n.s	
Sexual pain[b]	20.44 ± 23.91	16.06 ± 25.45	22.78 ± 26.23	17.40 ± 25.12	n.s		n.s	
Worry incontinence[b]	17.58 ± 31.98	15.95 ± 29.89	16.34 ± 27.79	19.40 ± 31.33	n.s		n.s	
Fatigue[b]	39.10 ± 36.59	39.09 ± 37.49	34.66 ± 31.56	54.11 ± 41.26	.048	.035	n.s	
Vaginal dryness[b]	40.23 ± 32.58	35.34 ± 36.19	30.95 ± 28.58	40.00 ± 38.63	.030	.079	n.s	

* *p* value below .05 was considered significant, according to ANOVA

[a] High values indicate high functioning/low symptoms

[b] High values indicate low functioning/high symptoms

Table 4 Predictors of sexual satisfaction

Predictors	Sexual Satisfaction $R^2 = 25.9\%$						
	B	SE B	β	t	p	95% CI	
						LB	UB
Social Functioning	.196	.075	.200	2.611	.010	.048	.344
Emotional Functioning	.222	.075	.217	2.976	.003	.075	.369
Global health status/QoL	.192	.094	.166	2.043	.042	.007	.377
Role Functioning	-.147	.078	-.159	-1.879	.061	-.301	.007
Sexual Partner	20.357	4.546	.245	-4.478	< .001	11.405	29.309
Age	-.435	-.118	-.211	-3.690	< .001	-.668	-.203

Bold numbers indicate significant *p*-values at .05 α-level

LB Lower bound, *UB* Upper bound

As expected, more intensive treatment (including chemotherapy, radiation, and endocrine treatment) aggravates SH impairments. This is not only true for physical symptoms including vaginal dryness and confidence in erection but also for psychosexual symptoms such as sexual satisfaction, libido, and femininity. Previous studies have observed similar effects: For instance, breast cancer patients undergoing chemotherapy before the start of endocrine therapy experienced a significantly decreased libido, femininity and more vaginal dryness compared to breast cancer patients not receiving chemotherapy [6]. Wu and colleagues reported chemotherapy and radiation as significant risk factors for sexual dysfunction in cervical cancer patients [7]. Overall, combined treatments have been observed to have the greatest impact on the development of sexual impairments in cancer patients [8, 9]. As for importance, we observed that patients who underwent more intensive treatment, reported some decline in the importance of sexual activity during treatment. Eker and Acikoz (2011) also reported a decline in sexual importance in patients undergoing chemotherapy [10]. During treatment, patients are confronted with multiple symptoms such as nausea, pain, fatigue, and

paresthesia that is likely to interfere with daily functioning. This may imply that the dominance of treatment related symptoms exceeds the relative importance of sexual activity as part of the symptom cluster in the disease phase – at least temporarily. However, the level of sexual symptom manifestation must be understood independently from its relative importance in order to allow early intervention.

When it comes to partnership, we can demonstrate another encouraging finding based on patient reports of this study: Cancer disease and treatment overall does not seem to change the perception of relationship security, neither during treatment nor thereafter. We found similar levels in patients on- and off-treatment as well as independent from treatment intensity. Though couples face sexual challenges and may experience a reduced quality of their relationship on a multidimensional level [11], their security as a couple seems to remain stable over the disease trajectory [12, 15]. For clinical care, this result can be helpful when providing patients information on social implications of cancer as it can contribute to reduce patients' anxieties about disease consequences for their partnership.

Communication between health care providers and patients is a common subject when it comes to sexuality: In the present on-treatment group, the communication with professionals about SH slightly but significantly improved from the first to the second assessment independent of treatment. This observation may support the previously established evidence, that bringing up a sensitive subject by the health care provider—even if simply for study purposes—can contribute to breaking taboos [13, 16]. This facilitates its discussion for both: patients, and health care providers. However, and in line with previous findings [14], when comparing patients on- and off treatment cross-sectional, we found equally low levels of communication with healthcare professionals.

Changes of SH beyond primary treatment: In regard of long-term SH, we sought to identify factors associated with sexual satisfaction beyond the active treatment phase. Interestingly, we found that predominantly psycho-social variables were associated with sexual satisfaction, rather than treatment-related variables or tumor entity. Hence, having a sexual partner, younger age, a better global health status and a higher social and emotional functioning were identified as predictive for a higher sexual satisfactory after treatment completion. Psycho-social health status is well-known to be associated with sexual functioning in cancer patients as well as in the general population. Depression has been associated with a decrease in sexual interest, arousal [17], and sexual functioning [18, 19]. Similarly, stress and anxiety are common contributors to sexual problems [20]. A decline in sexual desire and activity with higher age and lower health-status has been shown in older people in the US [21], as well as in elderly cancer survivors [22]. One of the most common reasons for sexual inactivity in cancer patients – as well as in healthy individuals—is the lack of a partner and for cancer patients and survivors there are additional barriers to finding a new partner [23]. Bernett et al. reported that female cancer patients expressed concerns about getting involved in new relationships and fearing rejection [24]. Hence, we may have to pay particularly attention to single patients with a low general health status after treatment who report low emotional and social functioning, regarding their risk of deterioration of sexual functioning. This might be an indirect consequence of cancer disease and treatment intensity. Survivor care efforts might be targeted in this direction i.e. on psychosocial care efforts.

While our results contribute with valuable insight into the effects of cancer disease and treatment on SH on a general basis, there are still some limitations. We acknowledge that our results are derived from a heterogeneous study sample, including different types of cancer and with differing treatment strategies applied. Regarding cancer sites there was an imbalance favoring breast cancer and gynecological cancer patients. However, we could not find any influence of tumor entity in our analysis. When intending a more in-depth insight into SH to specific patient groups or treatment regiments, further investigations with more homogenous samples and higher sample numbers are warranted. Further, we cannot make any assertions about SH concerns of individuals in the lesbian, gay, bisexual, transgender, queer/questioning, and otherwise non-cisgender (LGBTQ+) community, as the original study did not assess any information about gender identity or sexual orientation. While the QLQ-SH22 aims to assess SH regardless of gender or sexual orientation, we acknowledge the importance of research focusing on experiences of sexual minorities and we encourage future studies to use the PROM specifically in these populations.

Conclusion

In conclusion, our results line up with established evidence that curative cancer treatment is associated with physical- and psycho-sexual changes, with intensified treatments causing more harm to SH and well-being. While SH impairments seem to be highest during intensified treatments, some stabilization can be expected thereafter at least for sexual satisfaction, libido and fatigue. However, following previous evidence we want to state the obvious: It is advisable to actively acknowledge SH as crucial QoL domain for cancer patients during and beyond active cancer treatment. Sexual

symptoms need to be understood as distinct component of the treatment-related symptom cluster determining individual patient burden. Communication about SH is the key for translating this recommendation into routine cancer care. Still, a lack of communication is common [25, 26] – as reported also in our study. The use of screening tools in routine care is well known to facilitate communication about a taboo topic such as SH besides providing specific individual information on (sexual) health care demands. PRO monitoring can be performed from diagnosis into survivorship care. Well working electronic solutions for PRO data collections are available allowing not only on-site but also at home assessments [27, 28]. The EORTC QLQ-SH22 is fit for use as a short and efficient screening tool across a curative disease trajectory. It not only gives insight into the patient's SH status but also provides information on the quality of the patient-provider communication. It reveals comprehensive information about where the patient stands in terms of SH. Health care providers such as oncologists or cancer nurses can refer to this information which facilitates "breaking the ice" and talking about the patient's SH care demands and tailor supportive care strategies such cancer related sexual health education, enhanced symptom management, transferal to specialists such as a sexual psychologist. For example, some cancer survivors undergo maintenance therapy for years after primary treatment completion such endocrine treatment in breast cancer. These treatments though highly effective for cancer prevention cause continuous QOL-impairments and are often undertreated [29], in particular the taboo SH. This might impact on patient treatment adherence. Longitudinal PRO monitoring across survivorship with the EORTC QLQ-SH22 might help to detect treatment related SH impairments and to identify further treatment needs. Ultimately it can contribute to the improvement of patient QoL, satisfaction and treatment adherence.

Abbreviations

EORTC	European Organization of Research and Treatment of Cancer
LGBTQ +	Lesbian, gay, bisexual, transgender, queer/questioning, and otherwise non-cisgender
PROM	Patient reported outcome measure
QoL	Quality of Life
QLG	Quality of Life Group
SH	Sexual Health

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12885-024-13123-7.

Additional file 1. Contains the patient inclusion matrix used in the original validation study by Greimel et al. 2021 EJC. For the present study only curative patient groups (A, B and D) were used.

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Authors' contributions

EG, AO, VE, and CS contributed significantly to the conceptual formulation. Authors AO and VE have contributed significantly to the analysis, interpretation, and presentation of the data and wrote the first draft of the manuscript with subsequent edits from AN, AL, PJ, and VB. Authors AO, CS, AN, VB, AL, KK, PJ, CC, KZ, SS, JA, EN and EG contributed to data collection and discussion of results. All authors read and approved the final manuscript.

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Data availability

The data that support the findings of this study are available from the EORTC Quality of Life Group but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the corresponding author upon reasonable request and with permission of the EORTC Quality of Life Group.

Declarations

Ethics approval and consent to participate

Due to the secondary character of this analysis, no additional ethical approval was needed. In the original study eligible patients were invited to participate in accordance with the ethical and governance requirements of each centre. The Ethical Committee of the Medical University of Graz, Austria, was responsible for the principal investigator's application and approved the study protocol as per the national requirements. Written informed consent was requested in all countries.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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