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Normative data for the EORTC QLQ-C30 and EORTC-sexuality items in the general Dutch population

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ABSTRACT

Aim: The aim of the present study was to generate Dutch reference data for the EORTC QLQ-C30 and for five sexuality items from the EORTC QL-item bank. Furthermore, to evaluate the relative impact of self-reported health problems on these outcomes and compare the Dutch normative EORTC QLQ-C30 overall QoL with available Scandinavian and German normative data.

Methods: QLQ-C30 and sexual item normative data were obtained from the Health and Health Complaints project from CentERdata. The CentERpanel is an online household panel consisting of more than 2000 Dutch households, representative of the Dutch-speaking population in the Netherlands.

Results: The questionnaire was completed by 1731 (78%) CentERpanel members. For both men and women, functional health (except emotional functioning) decreased with age, and the symptoms pain and fatigue increased with age. Men scored statistically but never clinically significantly better on most functional scales than women. Men reported higher levels of sexual interest and activity than women. All subgroups of participants with health problems reported lower physical and role functioning and overall quality of life (QoL). Those with depression ($n = 79$) reported functioning scores 20–30 points lower than participants without any condition. Dutch men and women reported high levels of overall QoL as compared to previously published Scandinavian and German normative data.

Conclusion: Age, gender and other health problems are important when comparing QoL and sexuality among different cancer cohorts. Normative data on QoL and sexuality are needed to interpret QoL issues among the growing group of (long-term) cancer survivors.

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1. Introduction

Due to earlier diagnosis, improved treatments and an ageing population, the number of cancer survivors is rapidly increasing in the Western world. In 2000, there were about 400,000 cancer survivors in The Netherlands, expected to increase to 700,000 in 2015.[1] The number of people who live in the United States and who have (had) cancer is projected to grow from 11.8 million in 2005 to 18.2 million in 2020.[2] Improving survival is a central goal of cancer treatment. At the same time, with improving survival rates for a number of cancer patient populations, information on the (long-term) sequelae of treatment is essential for understanding the functional and psychosocial health of cancer survivors.

A number of self-report questionnaires have been developed specifically for assessing the cancer survivorship experience. These include the Impact of Cancer (IOC) questionnaire[3,4] and the Quality of Life of Long term Survivors (QoL-CS) questionnaire.[5] These questionnaires focus primarily on important psychosocial issues, such as social relationships, fear of disease recurrence, outlook on life, etc. At the same time, it remains important to monitor the symptom experience and functional health of individuals who have survived cancer, preferably for some years after initial diagnosis and treatment. The Quality of Life Group of the European Organization for Research and Treatment of Cancer (EORTC-QoL) has developed a core self-report questionnaire, the QLQ-C30, for assessing the QoL of patients with cancer.[6] The QLQ-C30 was originally designed for use in cancer clinical trials and other observational studies during the period of active treatment and shortly thereafter. Increasingly, however, the QLQ-C30 is being used in longer term cancer survivorship studies.[7–12]

The QLQ-C30 is often supplemented by a condition-specific questionnaire module. Sexuality is not covered by the core instrument, but incorporated into a number of the EORTC questionnaire modules (e.g. breast, prostate, head-and-neck, ovarian, cervical and colorectal cancer).

Interpretation of QLQ-C30 data in survivorship studies could be facilitated by having normative data from the general population in order to determine the residual functional impairment and symptom burden associated with a particular type of cancer and its treatment. General population normative data for the EORTC QLQ-C30 (version 3 or previous versions) have been generated in Norway,[13,14] Denmark,[15] Sweden[16] and Germany,[17] 10–15 years ago. No normative data have been published for the EORTC-sexuality items or for the Dutch population.

The aim of the present study was to generate Dutch normative data for the EORTC QLQ-C30, version 3 and for 5 sexuality items from the EORTC item bank that are included in six different EORTC questionnaire modules. Our secondary objectives were to evaluate the relative impact of self-reported health problems on these outcomes and compare the Dutch normative EORTC QLQ-C30 overall QoL with available Scandinavian and German normative data.

2. Materials and methods

2.1. Study population

QLQ-C30 and sexual item normative data were obtained from the Health and Health Complaints project from CentERdata. CentERdata is a Dutch research institute at Tilburg University, specialised in online survey research (www.centerdata.nl). The CentERpanel is an online household panel consisting of more than 2000 Dutch households. The panel is designed to be representative of the Dutch-speaking population in the Netherlands, including those without Internet access. Those households that do not have access to Internet at the time of study recruitment are provided with a so-called ‘Net.Box’, enabling connection via a telephone line and a television set. If the household does not have a television, CentERdata provides that as well.

The recruitment of panel members is performed in three stages. In the first stage, a random sample of potential panel members is interviewed by telephone. The interview ends with the question whether the person would like to participate in survey research projects. If so, the household is included in a database of potential panel members. If a participating household drops out of the panel, a new household is selected from the database of potential panel members. This is done on the basis of demographic characteristics, such that the panel remains representative of the adult, Dutch-speaking population (see www.centerdata.nl/en/CentERpanel for details). Sociodemographic data that are collected include age, gender, living situation (with partner and/or children), education, income, work situation and degree of urbanisation of residence.

2.2. Questionnaires

The EORTC QLQ-C30 (version 3.0) is a 30-item questionnaire assessing the functional health, symptom experience and QoL of cancer patients, in general. It includes five scales on physical, role, cognitive, emotional and social functioning, a global health status/QoL scale (Global QoL), three symptoms scales on fatigue, nausea and vomiting, and pain, and six single items assessing dyspnoea, insomnia, loss of appetite, constipation, diarrhoea and financial impact. The time frame of the questions is the previous week, and each item is scored on a 4 point response scale ranging from 1, ‘not at all’ to 4, ‘very much,’ with the exception of the global QoL scale, which is scored on a 7-point modified linear analogue scale ranging from 1, ‘very poor’ to 7, ‘excellent.’

Five sexual items derived by the EORTC QL Group item bank were also administered. These included three items appropriate for both men and women: (1) To what extent were you interested in sex?; (2) To what extent were you sexually active (with or without intercourse)?; and (3) To what extent was sex enjoyable for you? We also asked men who reported being sexually active: (4) Did you have difficulty getting or maintaining an erection? Women who reported having had sexual intercourse were asked: (4) Did you have a dry vagina during sexual activity? and (5) Have you had pain during sexual intercourse? To be consistent with the questionnaire modules from which these items were obtained, all sexual questions were posed with a 4 week time frame.

Following EORTC scoring instructions, all scales and single items are linearly transformed to a ‘0–100’ scale.[18] A higher score on the functional scales, global QoL, sexual interest, activity and enjoyment means better functioning and QoL, whereas a higher score on the symptom scales mean more complaints.

Self-reported health problems were categorised according to an adapted version of the Self-administered Comorbidity Questionnaire (SCQ),[19] and included: stroke, hypertension, asthma/COPD, diabetes, heart disease, stomach-, kidney- or liver-disease, thyroid condition, depression, joint diseases (rheumatoid arthritis and osteoarthritis) and cancer. In the adapted SCQ we left out cancer burden, and included stroke and thyroid conditions. We also expanded the lung disease category to include COPD and asthma. We asked patients whether they currently had any of these conditions or had had them in the past 12 months, whether they had received treatment for the condition, and whether the condition had limited them in their daily activities.

The questionnaire was administered online, and all questions of the EORTC QLQ-C30 and the SCQ had to be completed (i.e. there was no skip option). In contrast, because of the potentially sensitive nature of the topic, respondents were given the choice to opt out of the questions on sexuality.

2.3. *Statistics*

Routinely collected data from the CentERpanel on panel characteristics enabled us to compare the group of non-respondents with respondents, using *t*-tests for continuous variables and chi-square analyses for categorical variables. These tests were also used to compare participant characteristics according to gender or missing sexuality items.

Internal consistency reliability (Cronbach’s coefficient alpha) was calculated for the multi-item scales of the EORTC QLQ-C30.[20] Mean scores and standard deviations were calculated on transformed EORTC QLQ-C30 items and scales. For purposes of comparison with previously published normative data from other countries, mean scores are reported for the same 10-year age groups as those used in those reports.[13,15–17] However, because, as in all previous studies, the distribution of scores was skewed, we follow the approach taken by Schwarz[17] and also present the scale scores as frequency distributions (across 10 levels of the 0–100 scales).

In addition to means by age group and gender, we also report means according to self-reported health problems, adjusted for age and gender differences. Differences between subgroups were analysed using *t*-tests for continuous variables and chi-square analyses for categorical variables. All statistical analyses were performed using SAS (version 9.1 for Windows, SAS institute Inc., Cary, NC). Statistical significance was defined as a two-sided p *value* $\leqslant 0.05$. Differences in scale scores of 10 points or more were considered clinically significant.[21]

3. Results

3.1. *Patient characteristics*

In November 2009, the CentERpanel consisted of 2232 individuals who were all invited to participate in this study, of whom 1731 (78%) agreed to participate. Compared to respondents, the 406 non-respondents were younger (44.6 versus 52.9 years, $p < 0.0001$), were more often working (64% versus 51%, $p < 0.0001$) and more often reported a monthly family income $\geqslant$ € 2600 (53% versus 46%, $p = 0.02$). No significant differences were found between respondents and non-respondents with regard to gender, education, having a partner or degree of urbanisation.

The study population consisted of 935 men and 796 women, with men being, on average, somewhat older (54.7) than women (50.8, $p < 0.0001$) (Table 1). Most of the participants (77%) were living with a partner, with or without children. Men more often lived with a partner, but without children, compared to women ($p < 0.0001$). Male participants were more highly educated ($p = 0.001$), were more often working or retired ($p < 0.0001$) and reported higher net family income ($p < 0.0001$) than women. The degree of urbanisation was similar for men and women ($p = 0.93$).

Six hundred and fifty one respondents (38%) reported that they did not have any chronic health problem. One hundred and twenty eight respondents (7%) had *ever* been diagnosed with cancer. Men reported having heart disease more often than women (11% versus 4%, $p < 0.0001$). A greater percentage of women than men reported having asthma/COPD (12% versus 8%, $p = 0.01$), depression (6% versus 4%, $p = 0.045$) and joint conditions (23% versus 14%, $p < 0.0001$). Diabetes, hypertension and cancer were equally prevalent among men and women ($p > 0.05$). Less than 2% of the respondents reported stomach-, kidney- or liver-disease and 3% reported thyroid condition (data not shown).

3.2. *Score distributions and missing items*

The questionnaire was administered to individuals drawn from the general population, the majority of who were in fairly good health. This resulted in highly skewed score distributions for both the functional scales and the symptom scales/items (Tables 2a and b).

One hundred and ninety seven respondents (11%) chose not to respond to the questions on sexual interest and activity. These individuals were more often female (14% versus 9% male; $p = 0.002$) and, on average, younger ($p < 0.0001$), less well educated ($p < 0.0001$), and reported a lower net family-income ($p < 0.0001$) than those who completed these questions (data not shown). Interestingly, the highest levels of missing data on sexuality items (32%) were observed for the youngest age group (16–29 years), for both men and women, as compared to all other age groups (6–11% missing). There was no statistically significant association observed between missing responses on the sexuality questions and either living situation or degree of urbanisation.

Table 1 – Socio demographic characteristics of the sample.

Variables	Men (*n* = 935)	Women (*n* = 796)	Total (*n* = 1731)
Mean age (years)	54.7 ± 15.7	50.8 ± 15.5	52.9 ± 15.7
	N (%)	N (%)	N (%)
Age category			
16–29	58 (6)	58 (7)	116 (7)
30–39	127 (14)	166 (21)	293 (17)
40–49	147 (16)	134 (17)	281 (16)
50–59	215 (23)	182 (23)	397 (23)
60–69	216 (23)	153 (19)	369 (21)
70–94	172 (18)	103 (13)	275 (16)
Living situation			
Single	158 (17)	161 (20)	319 (18)
Living with partner, without children	439 (47)	296 (37)	735 (42)
Living with partner and children	309 (33)	289 (36)	598 (35)
Single with children	17 (2)	37 (5)	54 (3)
Other	12 (1)	13 (2)	25 (1)
Education			
Elementary school	46 (5)	52 (7)	98 (6)
High school	335 (36)	341 (43)	676 (39)
Vocational school	182 (19)	136 (17)	318 (18)
University	371 (40)	264 (34)	635 (37)
Missing	1 (–)	3 (–)	4 (–)
Employment			
Working in paying job/self-employed	503 (54)	377 (47)	880 (51)
Retired	317 (34)	122 (15)	439 (25)
Work disabled	39 (4)	43 (5)	82 (5)
Unemployed	38 (4)	218 (27)	256 (15)
Student	35 (4)	28 (3)	63 (4)
Other	3 (–)	8 (1)	11 (1)
Family-income (net per month)			
€ 1150 of minder	34 (4)	74 (9)	108 (6)
€ 1151–€ 1800	163 (17)	161 (20)	324 (19)
€ 1801–€ 2600	283 (30)	226 (28)	509 (29)
⩾€ 2600	455 (49)	335 (42)	790 (46)
Urbanisation home (addresses/km^2)			
Very strong (⩾2500)	133 (14)	113 (14)	246 (14)
Strong (1500–2500)	247 (26)	193 (24)	440 (25)
Moderate (1000–1500)	201 (22)	182 (23)	383 (22)
Little (500–1000)	200 (21)	174 (22)	374 (22)
Not (<500)	150 (16)	131 (16)	281 (16)
Missing	4 (–)	3 (–)	7 (–)
Ever been diagnosed with cancer	68 (7)	60 (8)	128 (7)
Self-reported health problems in past 12 months			
No health problems	356 (38)	295 (37)	651 (38)
Heart disease	106 (11)	33 (4)	139 (8)
Hypertension	221 (24)	163 (20)	384 (22)
Asthma/COPD	76 (8)	93 (12)	169 (10)
Diabetes	62 (7)	44 (6)	106 (6)
Depression	34 (4)	45 (6)	79 (5)
Joint disease	131 (14)	183 (23)	314 (18)

3.3. *Reliability*

Cronbach's coefficient alphas for the multi-item scales were: 0.82 (PF), 0.90 (RF), 0.64 (CF), 0.86 (EF), 0.88 (SF), 0.87 (global health status/QoL), 0.84 (fatigue), 0.87 (pain) and 0.71 (nausea and vomiting).

3.4. *EORTC QLQ-C30 and sexuality item scores*

Compared to women, men scored statistically significantly better on the PF, RF, EF, SF, global QoL scales, and reported significantly less fatigue, nausea/vomiting, pain, sleep disturbance, appetite loss and constipation (Table 3). However,

Table 2a – Distribution of QLQ-C30 scale values (%), no missing values.

Scale	0–10	11–20	21–30	31–40	41–50	51–60	61–70	71–80	81–90	91–100
Functioning scales										
Physical	0	0	1	1	1	4	4	9	11	68
Role	1	1	0	4	3	0	13	0	8	71
Emotional	1	0	0	1	2	2	5	8	11	69
Cognitive	0	0	0	1	2	0	7	0	17	72
Social	1	0	0	1	2	0	6	0	6	84
Global quality of life	0	1	1	2	7	5	11	13	34	25
Symptom scales										
Fatigue	39	21	17	10	5	4	2	1	1	0
Nausea/vomiting	90	7	0	2	1	0	0	0	0	0
Pain	59	15	0	14	6	0	3	0	2	1

A higher score on the functioning scales, global QoL means better functioning and QoL, whereas a higher score on the symptom scales mean more complaints.

Table 2b – Distribution of responses for QLQ-C30 and sexuality single items.

	Missing N (%)	Not at all (%)	A little (%)	Quite a bit (%)	Very much (%)
Single items					
Dyspnoea	–	83	14	3	1
Insomnia	–	69	22	7	2
Appetite loss	–	92	6	2	0
Constipation	–	88	9	2	1
Diarrhoea	–	91	7	2	0
Financial difficulties	–	93	4	2	0
Sexuality					
Interest	190 (11)	16	32	32	9
Active	187 (11)	26	35	25	4
If sexually active *men and women* ($n = 1094$)					
Enjoyable	9 (1)	2	15	48	34
If sexually active *men* ($n = 671$)					
Erection difficult	1 (–)	70	18	8	4
If sexual intercourse *women* ($n = 335$)					
Dry vagina	2 (1)	77	20	2	1
Pain at intercourse	2 (1)	85	14	1	0

none of these differences reached clinically significant levels.[21] For both men and women, functional health (with the exception of emotional functioning) decreased with age, and symptoms (pain and fatigue) increased with age.

In all age groups, men reported statistically significantly higher levels of sexual interest (20–30 points higher) and activity (10–20 points higher) than women. For both men and women, sexual interest and activity were fairly constant in the age groups 16–59 years, but decreased after the age of 60 years. Regarding sexual enjoyment, men and women reported comparable levels, except for women aged 50–59 and 60–69, who reported almost lower levels. With increasing age, men reported more difficulty getting an erection, whereas women more often reported a dry vagina during sexual intercourse. Respondents without any self-reported health problems in the past 12 months were significantly younger than those who reported any health problem (Table 4). Compared to those without health problems, all subgroups of those with health problems had significantly lower mean scores on the PF and the RF scales after correction for age and gender differences. The subgroup of respondents with depression reported the worst scores on all functioning scales, with mean scores 20–30 points lower than those without any health problems.

3.5. *International comparison of global quality of life scores in the general population*

Dutch men and women reported high levels of overall QoL as compared to previously published Scandinavian and German normative data (Figs. 1a and b). In all age groups they reported highest or second highest scores.

4. Discussion

The response rate in this study (78%) was quite high. This was not unexpected because the pool of potential respondents had already consented to participate in the CentERpanel.

Table 3 – Mean scores (standard deviations) of QLQ-C30 and sexuality scales and items by sex and age groups (NB: scores or standard deviations ⩾ 10 are rounded).

Age (years)	Men							Women							Total
	All	16–29	30–39	40–49	50–59	60–69	70–94	All	16–29	30–39	40–49	50–59	60–69	70–94	
Functioning scales															
Physical	92 (14)	98	97	95	93	93	84	89 (17)	94	94	93	88	85	78	90 (15)
Role	90 (20)	96	94	92	89	92	84	87 (22)	93	91	92	85	84	81	89 (21)
Emotional	91 (15)	94	89	87	92	91	92	88 (17)	90	87	86	89	88	87	89 (16)
Cognitive	93 (14)	95	96	93	96	92	86	92 (16)	97	93	94	89	91	91	92 (15)
Social	95 (14)	99	97	94	96	96	93	93 (18)	97	94	96	90	93	90	94 (16)
Global quality of life	78 (17)	82	80	76	77	81	76	77 (18)	78	77	80	77	77	73	78 (17)
Symptom scales															
Fatigue	15 (19)	8.6	14	18	15	12	19	20 (21)	16	21	18	20	19	23	17 (20)
Nausea/ vomiting	1.7 (6.9)	1.1	2.9	2.4	1.2	1.5	1.1	3.9 (13)	5.2	4.7	3.7	3.1	2.1	6.1	2.7 (10)
Pain	12 (20)	4	7.3	12	14	11	17	18 (24)	12	13	13	18	25	25	15 (22)
Single items															
Dyspnoea	6.6 (17)	1.1	3.1	6.1	6	7.1	12	7.6 (18)	4.6	6.2	6.2	7.3	7.8	14	7.1 (17)
Insomnia	11 (20)	7.5	8.7	13	10	11	13	17 (26)	9.8	13	15	19	20	23	14 (23)
Appetite loss	2.3 (10)	1.1	2.6	2.9	1.9	2.2	2.7	4.4 (14)	4	5	2.2	4.8	3.9	6.5	3.3 (12)
Constipation	3.3 (12)	2.3	1.6	2.5	1.7	3.4	7.4	6.5 (17)	6.9	4	4.7	6.6	8.1	10	4.8 (14)
Diarrhoea	4.1 (13)	2.9	2.9	5.4	5.4	2.5	4.7	3.8 (14)	2.9	3.8	4	3.7	3.7	4.2	3.9 (14)
Financial difficulties	2.7 (12)	0.6	2.4	3.6	3.3	2.9	1.7	3.6 (13)	2.2	3.4	1.5	5.3	2.6	5.5	3.1 (13)
Sexuality															
Interest	56 (28)	66	69	64	62	51	37	33 (27)	37	42	43	35	25	13	46 (30)
Active	41 (28)	48	49	49	47	37	24	29 (28)	33	38	39	29	23	8.6	36 (28)
Enjoyable	73 (24)	84	82	73	76	73	58	70 (26)	82	77	72	63	64	55	72 (25)
Men															
Erection difficult	16 (27)	2.4	4.8	6.8	10	23	41	–	–	–	–	–	–	–	16 (27)
Women															
Dry vagina	–	–	–	–	–	–	–	8.8 (18)	3.2	4.4	4.5	14	19	19	8.8 (18)
Pain at intercourse	–	–	–	–	–	–	–	5.0 (13)	7.9	5.1	1.6	6.3	6.7	9.5	5.0 (13)

Due to the web-based method of data-collection we had no missing items for the EORTC QLQ-C30 or the SCQ. Consistent with previous studies, we found that QoL outcomes were strongly associated with gender and age.[13–17] Women reported lower scores on functional scales and higher scores on symptoms than men, even though they were, on average, 4 years younger. We also found that lower functional scores (except for emotional functioning) and higher levels of symptoms (pain and fatigue) were reported with increasing age. Gender and age differences in QLQ-C30 scores were never clinically significant. In contrast to the findings based on the Danish[15] and Swedish[16] normative data, we did not observe that emotional functioning improved with age, but rather it remained relatively stable across age subgroups, as was the case in the German[17] and Norwegian[13,14] samples.

Although the EORTC QLQ-C30 was developed specifically for cancer patients, our results support the ability of this questionnaire to discriminate clearly (both statistically and clinically) between those with and without other health problems. The ability of the EORTC QLQ-C30 to detect differences in functional health and symptom burden due to health problems is particularly important when evaluating the QoL of long-term cancer survivors. Cancer survivorship studies often include individuals who are 65 years of age or older, of whom approximately 60% percent is known to suffer from at least one other serious disease.[22] These health problems might affect self-reported functioning more strongly than any residual effects from cancer or its treatment.[23,24] Similarly, symptom reporting and sexuality can be confounded by other health problems. For example, in the current study, dyspnoea was highly prevalent among respondents with heart disease or asthma/COPD, fatigue and insomnia were prevalent among individuals with self-reported depression, and high pain scores were reported by those with joint diseases. Erectile dysfunction and vaginal dryness were reported frequently by men and women with health problems affecting the vascular system (i.e. heart disease and diabetes).

The impact of other health problems on patient-reported outcomes among cancer survivors has received limited attention.[25] Depending on the research question, other health problems, e.g. comorbidity, can be an important variable to include in the evaluation of QoL.[24] Ideally, comorbidity data

Table 4 – Mean scores (standard deviations) of QLQ-C30 and sexuality scales and items by self-reported health problems (NB: scores or standard deviations ⩾ 10 are rounded).

			Current disease or in past 12 months						
	Total	People reporting no health problems	Heart disease	Hyper-tension	Asthma/ COPD	Diabetes	Depression	Joint disease	**Ever diagnosed with cancer**
N (%)	1731	651	139 (11)	384 (24)	169 (8)	106 (7)	79 (4)	314 (14)	128 (7)
Mean age (SD)	53 (16)	46 (15)	66 (12)	62 (12)	53 (15)	62 (12)	54 (15)	63 (12)	64 (12)
Male (%)	935 (54)	356 (55)	106 (76)	221 (57)	76 (45)	62 (58)	34 (43)	131 (42)	68 (53)
Functioning scales									
Physical	90 (15)	98 (6.3)	78 (24)	85 (18)	82 (21)	81 (23)	78 (22)	77 (19)	86 (18)
Role	89 (21)	97 (11)	79 (27)	85 (23)	80 (27)	82 (26)	72 (24)	74 (25)	83 (24)
Emotional	89 (16)	93 (12)	86 (20)	88 (16)	85 (21)	89 (18)	62 (28)	86 (19)	88 (17)
Cognitive	92 (15)	97 (9.0)	85 (20)	91 (17)	87 (22)	86 (20)	72 (27)	87 (19)	87 (19)
Social	94 (16)	99 (6.0)	89 (23)	92 (18)	88 (23)	91 (21)	77 (28)	87 (24)	90 (18)
Global quality of life	78 (17)	84 (14)	71 (19)	75 (19)	68 (21)	71 (20)	60 (20)	69 (19)	73 (21)
Symptom scales									
Fatigue	17 (20)	11 (15)	27 (25)	20 (22)	28 (27)	24 (24)	40 (26)	27 (24)	23 (24)
Nausea/vomiting	2.7 (10)	1.8 (7.5)	4.4 (16)	3.1 (12)	6.9 (19)	4.6 (16)	7.4 (17)	4.9 (16)	3.3 (9.6)
Pain	15 (22)	4.7 (12)	24 (29)	21 (25)	26 (30)	19 (25)	34 (28)	35 (26)	19 (25)
Single items									
Dyspnoea	7.1 (17)	1.8 (8.2)	22 (29)	10 (20)	29 (27)	15 (27)	13 (24)	14 (23)	9.1 (20)
Insomnia	14 (23)	7.4 (16)	22 (30)	18 (26)	23 (29)	15 (27)	29 (30)	24 (29)	18 (27)
Appetite loss	3.3 (12)	1.7 (8.0)	8.2 (20)	4.2 (15)	9.9 (22)	6.9 (19)	11 (23)	7.0 (19)	7.0 (18)
Constipation	4.8 (14)	2.6 (11)	12 (23)	6.3 (16)	8.7 (20)	7.5 (19)	11 (21)	8.9 (20)	9.4 (22)
Diarrhoea	3.9 (14)	2.6 (10)	4.8 (15)	3.7 (13)	6.7 (19)	8.2 (18)	5.9 (17)	5.8 (16)	6.5 (17)
Financial difficulties	3.1 (13)	0.4 (4.1)	8.2 (20)	4.3 (15)	7.9 (21)	6.0 (18)	17 (30)	5.6 (17)	6.0 (16)
Sexuality									
Interest	46 (30)	54 (28)	38 (31)	41 (29)	41 (30)	35 (31)	35 (28)	32 (27)	35 (27)
Active	36 (28)	43 (28)	26 (25)	31 (28)	28 (27)	27 (29)	25 (28)	23 (24)	24 (24)
Enjoyable	72 (25)	75 (23)	67 (27)	69 (26)	70 (26)	73 (22)	61 (32)	66 (26)	65 (30)
Men									
Erection difficult	16 (27)	8.9 (21)	43 (37)	27 (32)	24 (34)	21 (24)	14 (25)	29 (34)	39 (39)
Women									
Dry vagina	8.8 (18)	6.8 (15)	27 (28)	16 (26)	7.8 (17)	17 (25)	14 (30)	12 (24)	12 (20)
Pain at intercourse	5.0 (13)	3.3 (10)	20 (30)	10 (18)	5.6 (13)	8.3 (15)	8.3 (15)	6.2 (15)	12 (16)

should be obtained by means of a combination of health history taking and clinical examination. In many situations, however, it may only be possible to collect such data via self-report.

Sexuality items are not included in the EORTC QLQ-C30, but are incorporated in the EORTC questionnaire modules for breast, prostate, head and neck, ovarian, cervix and colorectal cancer. A recent overview indicates that the incidence of sexual problems among cancer survivors is high, that they are often chronic in nature, and can have a significant impact on the QoL of both cancer survivors and their partners.[26] Our results provide useful information for comparison of sexuality among cancer survivors as compared to the general adult population. This is important because reported sexual problems may be due to natural ageing rather than (or in addition to) long-term effects of cancer and its treatment. Our data show a decline in sexual interest and activity in men and women after the age of 60 years. Men in our normative population reported to be less sexually interested and active than men in a recent Dutch study among randomly selected participants of a prostate cancer screening trial.[27] However, as suggested by these investigators, selection bias may have influenced the findings of the latter study, as screened participants usually have above average social economic and health status.[28] Erectile problems were quite common among men 70 years and older in our normative population but again more frequently reported than among participants of the prostate cancer screening trial.[27] Women in our normative population also reported to be less sexually active compared to a Norwegian normative sample.[29] Again, selective response may explain these differences.

Concern is often voiced about asking about sexual life and functioning in QoL questionnaires. Our data indicate that the problem of missing data on sexual questions is relatively low (11%). An unanticipated finding was that that missing data on sexuality were highest among the youngest age group (18–29 years). It is possible they more often do not have a partner and are reluctant to complete these questions, or perhaps they found the items referring to problems with erection and dry vagina irrelevant for their age. Reasons for this need to be explored in future qualitative studies.

Fayers previously compared Scandinavian and German EORTC QLQ-C30 normative data.[30] He discussed observed differences in the age-related decline in QoL between Germany

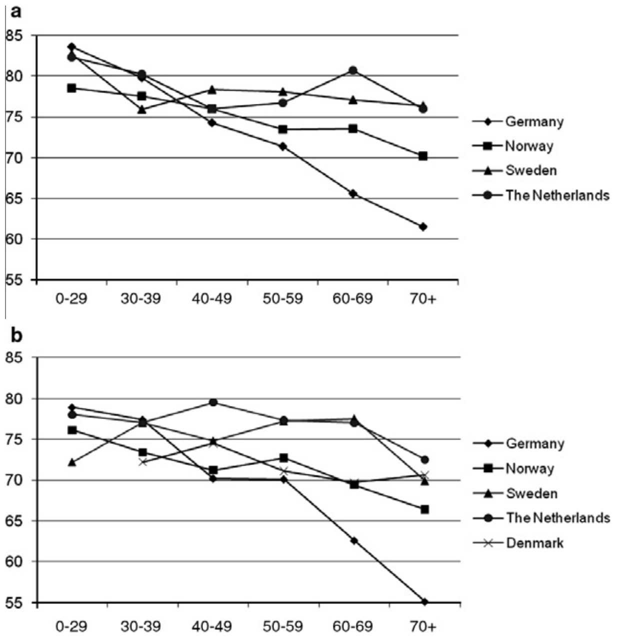

Fig. 1 – Mean EORTC QLQ-C30 global quality of life score (QL) for males (a) and females (b) according to age, for Germany, Norway, Sweden, Denmark (only females) and the Netherlands.

and the other countries in terms of possible translation errors, selection bias, actual health differences and cultural differences between countries. In the present study, we found higher levels of global QoL as compared to data from other countries. This may, at least in part, be due to a cohort effect, in that we compared our recent data to those from studies conducted 10 to 15 years ago. If such a cohort effect is indeed present, then this suggests the need to update normative data with some regularity. Additionally, if the international differences in self-reported QoL are real, than it is all the more important that normative data be generated at the national level so that meaningful comparison can be made with cancer survivor cohorts.

Although the CentERpanel is designed to be representative for the Dutch population, due to selective response on our questionnaire we have included a somewhat older population. Nevertheless, the influence of this minor response bias is limited when used for comparison with cancer survivorship cohorts as these normative data will be freely publicly available upon request in a raw data format including confounding factors. The web based administration of the questionnaire probably results in a higher completion rate than paper and pencil administration would generally do, as previous studies have shown.[31,32] As the panel members are initially contacted by telephone and also include people without Internet access, our population does not represent a selective internet active population.

In conclusion, our data provide valuable normative data that once again confirm the importance of including gender and age when comparing QoL among different cohorts. In addition, we have shown that it is of even greater importance to take other health problems into account, particularly when evaluating the QoL of an ageing cancer survivor population. Normative data on sexual interest, activity and problems will become increasingly important given the growing attention paid to sexuality issues in (long-term) cancer survivors.[26]

Conflict of interest statement

None declared.

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