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Reference values for the EORTC QLQ-C30 quality of life questionnaire in a random sample of the Swedish population

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Abstract

Aim. To obtain reference values for health-related quality of life (HRQL) measured with the European Organization for Research and Treatment of Cancer (EORTC) Core Quality of Life Questionnaire (QLQ-C30) in a random sample of the adult Swedish population. *Methods*. A population-based survey of a random sample of 7002 Swedish adults aged 40–79 years, frequency-matched to reflect the age and sex distribution of upper gastrointestinal cancer patients. Scales were scored on a 0–100 metric according to standard procedures. Functions and symptoms were dichotomized into "poor" versus "good" function, and "symptomatic" and "no or minor symptoms", respectively. The results were stratified for age and gender. *Results*. The questionnaire was completed by 4910 (70.5%) of 6969 eligible participants. Missing values were limited. HRQL was found to vary according to age and sex. Generally, men reported better functioning and fewer symptoms than women. The most common symptoms were fatigue, pain, and insomnia. *Conclusion*. The reference values provided can be used as a surrogate baseline measure in HRQL research, and when evaluating the effect of interventions on HRQL in cancer patients.

Health-related quality of life (HRQL) is increasingly recognized as an important outcome measure in clinical cancer research. One of the most widely used cancer-specific HRQL questionnaires is the European Organisation for Research and Treatment of Cancer Core Quality of Life Questionnaire (EORTC QLQ-C30) [1]. This questionnaire has been shown to be valid, reliable and responsive to change [2]. It has been used to assess HRQL, before and after treatment, to identify short- and long-term effects in different cancer types and at different stages of the disease. There are however problems in assessing baseline HRQL in cancer patients, as the assessment is generally carried out after diagnosis is confirmed. By this time, patients are typically already suffering from tumor symptoms and are psychologically affected by the newly diagnosed cancer. Therefore, instead of assessing the baseline HRQL of individual patients, it could be valuable to use HRQL data from a reference population of corresponding age and sex as surrogate or additional baseline measures. Reference values from general populations for the EORTC QLQ-C30 questionnaire have been reported in five studies, from Denmark [3], Norway [4], Germany [5], Netherlands [6], and Sweden [7]. However, most of these reports were conducted more than 10 years ago, and updated reference values reflecting HRQL in the general population are warranted. Moreover, a sample matched to mimic the age and sex distribution of cancer patients is justified. Therefore the aim of this study was to provide reference values for the EORTC QLQ-C30 from a random sample of the Swedish adult population.

Material and methods

Study design

A population-based survey was conducted in Sweden from April to June 2008. A random sample of the Swedish adults aged 40–79 years was drawn from the Swedish Total Population Register, which includes updated, complete information about all births and deaths in Sweden since 1968. The sample was frequency-matched to reflect the age and sex distribution of upper gastrointestinal cancer patients

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according to the Swedish Cancer Register [8]. People who died or emigrated (recorded in the Swedish Total Population Register) during the period between the sampling and before the data collection were excluded. Together with an invitation letter, the EORTC QLQ-C30 written questionnaire, a sociodemographic questionnaire, and a stamped addressed envelope were sent out to the eligible people. Up to two reminder letters were sent to people who did not respond. Variables, such as age and sex were validated using the Swedish Total Population Register.

The EORTC QLQ-C30 version 3 Questionnaire

The EORTC QLQ-C30 (version 3.0) [1] is a questionnaire assessing HRQL during the previous week. It has been developed for general cancer patients and has good reliability and validity [2]. The EORTC QLQ-C30 has 30 items arranged into nine scales and six single items. The scales are divided in five function scales (physical, role, cognitive, emotional, and social function); three symptom scales (fatigue, pain, and nausea or vomiting) and one global health-status/quality of life scale. The six single items address specific symptoms: dyspnea, appetite loss, insomnia, constipation, and diarrhea, and one question addressing the financial impact of the disease. Each item has four response alternatives: 1) “not at all”, 2) “a little”, 3) “quite a bit”, and 4) “very much”, except for the global health-status/quality of life scale, which has response options ranging from 1) “very poor” to 7) “excellent”.

Statistical analyses

The reliability of the questionnaire was assessed with Cronbach’s alpha for all scales consisting of two or more items. This yielded a coefficient greater than 0.8 for all functional scales, except the cognitive scale (alpha 0.6), and all symptoms scales except for nausea and vomiting (alpha 0.6). All questionnaire responses were transformed into scores on a linear 0 to 100 scale according to the EORTC scoring manual [9]. Mean scores with standard deviations (SDs) were calculated. Missing responses were handled according to recommendations by the questionnaire authors [9]. Responses were dichotomized into “good” versus “poor” for function scales, and into “no or minor symptoms” versus “symptomatic”

Table I. Baseline characteristics of a random sample of 4910 persons from the Swedish population and the Swedish population in year 2008.

	Sample n (%)			Swedish population 2008 n (%)		
	Total	Men	Women	Total	Men	Women
Total group	4910 (100.0)	3224 (65.7)	1686 (34.3)	4 224 252 (100.0)	2 099 188 (50.0)	2 125 064 (50.0)
Age groups (years)						
40–49	410 (8.4)	212 (6.6)	198 (11.7)	1 274 449 (30.2)	649 237 (30.9)	625 212 (29.4)
50–59	1073 (21.9)	658 (20.4)	415 (26.6)	1 167 976 (27.6)	587 963 (28.0)	580 013 (27.3)
60–69	1542 (21.9)	1109 (34.4)	415 (24.6)	1 111 680 (26.3)	553 837 (26.4)	557 843 (26.3)
70–79	1903 (38.8)	1245 (38.6)	658 (39.0)	670 147 (15.9)	308 151 (14.7)	361 996 (17.0)
Marital status						
Married	3694 (75.2)	2541 (78.8)	1153 (68.4)	2 370 206 (56.1)	1 206 169 (57.5)	1 164 037 (54.8)
Single	1192 (24.3)	670 (20.8)	522 (31.0)	1 854 046 (43.9)	893 019 (42.5)	961 027 (45.2)
Data missing	24 (0.5)	13 (0.4)	11 (0.6)	–	–	–
Educational level						
Nine-year compulsory school	2369 (48.3)	1545 (47.9)	824 (48.9)	1 044 903 (24.7)	553 521 (26.4)	491 382 (17.8)
2 years high school	620 (12.6)	410 (12.7)	210 (12.5)	1 361 724 (32.2)	648 505 (30.9)	713 219 (33.6)
3–4 years high school	516 (10.5)	397 (12.3)	119 (7.1)	531 203 (12.6)	297 580 (14.2)	233 623 (11.0)
University < 3 years	447 (9.1)	267 (8.3)	180 (10.7)	537 543 (12.7)	251 541 (12.0)	286 002 (13.5)
University > 3 years	800 (16.3)	505 (15.7)	295 (17.5)	703 608 (16.7)	325 244 (15.5)	378 364 (17.8)
Data missing	158 (3.2)	100 (3.1)	58 (3.3)	45 271 (1.0)	22 797 (1.1)	22 474 (1.1)
Occupation						
Employed	1595 (32.5)	979 (30.4)	616 (36.5)			
Self-employed	328 (6.7)	291 (9.0)	37 (2.2)			
Studying	12 (0.2)	3 (0.1)	9 (0.5)			
Retired	2618 (53.3)	1737 (53.9)	881 (52.2)			
On sick leave (> 3 months)	51 (1.0)	24 (0.7)	27 (1.6)			
Unemployed	63 (1.3)	47 (1.5)	16 (1.0)			
Working at home	34 (0.7)	4 (0.1)	30 (1.8)			
Other	70 (1.4)	43 (1.3)	27 (1.6)			
Data missing	139 (2.9)	96 (3.0)	43 (2.6)			

Table II. Results for the EORTC QLQ-C30 scales and items in a random sample of 4910 adults from the Swedish population. Presented with mean score, standard deviation (SD) and frequencies.

		Total (n = 4910)		Male (n = 3224)		Female (n = 1686)	
Functions	Number	Mean score (SD)	Poor quality of life/function*†	Mean score (SD)	Poor quality of life/function*†	Mean score (SD)	Poor quality of life/function*†
Global quality of life scale	4867	76.4 (22.8)	16.1	77.2 (22.3)	14.8	74.9 (23.5)	18.5
Functional scales							
Physical function	4642	88.0 (18.3)	21.5	89.2 (17.8)	19.2	85.6 (19.1)	26.0
Role function	4746	88.2 (23.9)	11.6	89.0 (23.5)	11.0	86.7 (24.7)	12.8
Emotional function	4771	85.8 (18.7)	13.9	87.4 (17.6)	11.8	82.7 (20.3)	18.0
Cognitive function	4796	88.1 (16.9)	9.2	88.0 (16.8)	9.3	88.2 (17.2)	9.0
Social function	4792	91.2 (19.0)	7.6	91.7 (18.4)	7.2	90.2 (20.0)	8.3
Symptoms		Mean score (SD)	Symptomatic¤†	Mean score (SD)	Symptomatic¤†	Mean score (SD)	Symptomatic¤†
Symptom scales							
Fatigue	4684	19.1 (21.7)	18.4	17.9 (21.0)	16.1	21.5 (22.8)	22.7
Nausea and vomiting	4810	2.6 (9.3)	1.9	2.4 (9.1)	1.7	3.0 (9.6)	2.3
Pain	4753	18.9 (25.7)	17.7	16.8 (24.5)	15.3	22.7 (27.4)	22.3
Single items							
Dyspnea	4796	16.3 (24.3)	9.0	17.0 (24.5)	9.4	15.0 (24.0)	8.4
Insomnia	4831	17.5 (25.9)	11.8	15.0 (23.9)	9.3	22.2 (28.8)	16.6
Appetite loss	4818	3.3 (12.8)	1.7	3.1 (12.4)	1.7	3.8 (13.6)	1.7
Constipation	4814	5.4 (6.1)	3.1	4.3 (14.0)	2.2	7.8 (9.3)	4.9
Diarrhea	4796	5.6 (15.9)	2.8	5.4 (15.3)	2.4	6.0 (7.1)	3.7
Financial difficulties	4832	4.4 (16.2)	3.5	4.1 (15.7)	3.3	5.0 (7.1)	3.8

*Poor function = any response of 3 (“quite a bit”) or 4 (“very much”) on an item within a functional scale. Poor quality of life = any response of ≤ 4 on an item within the scale. Otherwise good function or quality of life.

¤Symptomatic = any response of 3 (“quite a bit”) or 4 (“very much”) on an item within a symptom scale or for a single item otherwise no symptoms.

†Values are in percent.

for symptom scales and single items. People who responded 3 “quite a bit” or 4 “very much” on an item within a scale or for a single item were included in the “poor” function or “symptomatic” groups. Otherwise the person was categorized as having “good” function or “no symptoms. This strategy was used to facilitate interpretation of the data and has been used in previous research [10,11]. All statistical analyses were performed using Stata®, version 9.2 (Stata Corporation, College Station, Texas, USA).

Results

Participants

A sample of 7002 individuals was randomly drawn from the Swedish population. After excluding 33 people who had died or emigrated, 6969 were eligible for the study. Of these, 4910 responded to the questionnaire, representing a 70.5% participation rate. Among the non-participants, 2001 (28.7%) people did not respond and 58 (0.8%) had an unknown address or someone other than the invited person responded. The response rate of 54.8% of younger people, aged 40–49 years, was lower than the response rate of 77.0% of people aged 70 years or older. Most non-responders were unmarried (42.4%) or single (34.2%), born outside of Sweden (38.2%), and did not have any salary (61.4%). Response rates were for men and women 69.5% and 72.4%, respectively. The percentage of individual questions answered was high (96.7–98.7%). Sociodemographic characteristics of the participants are shown in Table I. After frequency matching to patients with upper gastrointestinal cancer, the sample was predominantly male (65.7%) with a mean age of 65 years (range 40–79). Most participants were married, and approximately half had finished nine-year compulsory school, while a quarter had education at a university level. Half of the population were retired, while 39.2% were working.

HRQL mean scores

HRQL mean scores for the total group and for males and females are shown in Table II. Men reported better global quality of life, and higher scores on all function scales except for the cognitive functioning scale, compared to women. Women reported more symptoms than men, except for dyspnea. The strongest sex differences were seen for insomnia and pain (mean score difference 7.2 and 5.9, respectively). Mean scores stratified for sex and age are presented

Table IIIa. Results for the EORTC QLQ-C30 scales and items in a random sample of 4910 adults from the Swedish population. Presented with mean scores, standard deviation (SD) and frequencies in different age groups.

	Men (n = 3224)							
	40–49 years		50–59 years		60–69 years		70–79 years	
Functions	Mean score (SD)	Poor quality of life/function[*,†]	Mean score (SD)	Poor quality of life/function[*,†]	Mean score (SD)	Poor quality of life/function[*,†]	Mean score (SD)	Poor quality of life/function[*,†]
Global quality of life scale	74.4 (22.0)	14.2	78.6 (21.7)	12.5	78.2 (22.1)	14.1	76.1 (22.9)	16.7
Functional scales								
Physical function	95.3 (11.7)	9.1	93.7 (14.0)	11.7	90.6 (16.7)	17.2	84.4 (20.2)	27.0
Role function	90.2 (22.1)	9.6	90.8 (22.2)	8.9	90.4 (21.3)	9.6	86.5 (25.9)	13.5
Emotional function	81.8 (18.5)	19.0	84.9 (19.0)	15.1	88.3 (17.1)	9.7	89.0 (16.8)	10.5
Cognitive function	88.2 (17.5)	12.5	89.2 (18.0)	9.8	89.3 (16.2)	6.8	86.2 (16.4)	10.8
Social function	91.2 (18.6)	6.7	92.4 (18.4)	6.9	92.4 (17.8)	6.7	90.7 (18.8)	7.9
Symptoms	Mean score (SD)	Symptomatic[¤,†]	Mean score (SD)	Symptomatic[¤,†]	Mean score (SD)	Symptomatic[¤,†]	Mean score (SD)	Symptomatic[¤,†]
Symptom scales								
Fatigue	17.0 (20.0)	19.7	15.6 (20.4)	16.3	16.0 (19.9)	14.2	21.1 (22.1)	17.2
Nausea and vomiting	3.1 (10.4)	2.4	2.5 (9.7)	2.0	2.2 (8.6)	1.8	2.2 (9.0)	1.4
Pain	16.5 (24.7)	13.9	15.6 (25.1)	15.0	16.4 (24.2)	15.0	17.9 (24.3)	16.1
Single items								
Dyspnea	15.9 (24.4)	9.5	14.7 (23.1)	7.9	14.9 (23.0)	7.5	20.3 (26.1)	11.8
Insomnia	17.5 (26.7)	13.7	14.5 (24.7)	9.7	15.1 (23.6)	9.3	14.8 (23.3)	8.4
Appetite loss	4.6 (15.4)	1.9	3.5 (14.1)	2.4	2.7 (10.7)	1.3	3.0 (12.3)	1.7
Constipation	2.7 (11.2)	1.0	2.8 (11.7)	1.4	3.2 (11.9)	1.6	6.3 (16.8)	3.4
Diarrhea	6.8 (16.3)	1.9	5.5 (15.8)	2.5	5.7 (15.6)	2.8	4.8 (14.6)	2.1
Financial difficulties	5.9 (17.6)	4.7	6.4 (20.1)	5.8	4.5 (15.9)	3.5	2.3 (11.7)	1.5

[*] Poor function = any response of 3 ("quite a bit") or 4 ("very much") on an item within a functional scale. Poor quality of life = any response of ≤ 4 on an item within the scale. Otherwise good function or quality of life.

[¤] Symptomatic = any response of 3 ("quite a bit") or 4 ("very much") on an item within a symptom scale or for a single item otherwise no symptoms.

[†] Values are in percent.

in Table IIIa and b and differences between age groups and sexes are illustrated in Figure 1(a–o). Older respondents of both sexes (70–79 years) scored lower for physical and role function than younger age groups. However, emotional function increased with higher age. Older participants scored higher for fatigue, pain, dyspnea and constipation than younger people. People between 50–59 years of age had more financial difficulties than younger and older age groups, and people in the oldest age group had least financial difficulties.

Dichotomized HRQL measures

Frequencies of poor functions and symptoms are presented in Tables II and III. Approximately one quarter of participants reported poor global quality of life, which was more frequent in women (18.5%) than in men (14.8%). Poor physical function was reported by 21.5% of all participants, with higher prevalence in women (26.0%) than men (19.2%). The most common symptoms were in descending order fatigue, pain, insomnia and dyspnea. Fatigue and pain were more frequent in women (22.7% and 22.3%, respectively) than in men (16.1% and 15.3%, respectively). Insomnia was almost twice as common in women (16.6%) as in men (9.3%). There were some differences in the prevalence of poor functional and symptom scales across age groups. Older women (70–79 years) were more likely to report a poor global quality of life as compared to women in the age category 40–49 years (22.1% and 12.7%, respectively). Men across different age groups had similar prevalence of poor global quality of life. Poor physical function was more prevalent in the oldest age group in both sexes in comparison to the youngest age group (20% vs. 9.1% in men, and 36.7% vs. 12.3% in women). The occurrence of pain increased with age in women, but there was no such trend with age in men.

Discussion

This study offers reference values for the HRQL questionnaire EORTC QLQ-C30 from a random sample of the adult population in Sweden. In general, woman and older people tended to report more symptoms and poorer health than men and younger participants.

Table IIIb. Results for the EORTC QLQ-C30 scales and items in a random sample of 4910 adults from the Swedish population. Presented with mean scores, standard deviation (SD) and frequencies in different age groups.

	Women (n = 1686)							
	40–49 years		50–59 years		60–69 years		70–79 years	
Functions	Mean score (SD)	Poor quality of life/function*†	Mean score (SD)	Poor quality of life/function*†	Mean score (SD)	Poor quality of life/function*†	Mean score (SD)	Poor quality of life/function*†
Global quality of life scale	74.9 (23.5)	12.7	74.4 (23.6)	19.2	77.2 (21.8)	15.1	73.8 (24.3)	22.1
Functional scales								
Physical function	93.6 (13.5)	12.3	90.5 (15.6)	18.0	87.3 (16.8)	24.9	79.0 (21.9)	36.7
Role function	90.0 (21.9)	11.0	86.8 (26.3)	13.0	88.1 (22.5)	10.9	84.7 (25.7)	14.7
Emotional function	78.7 (22.9)	23.4	79.5 (20.8)	20.8	84.4 (19.4)	16.4	85.0 (19.3)	15.4
Cognitive function	87.1 (19.4)	10.3	88.5 (18.3)	8.5	89.0 (16.0)	8.0	87.7 (16.4)	9.7
Social function	91.1 (19.9)	5.6	88.8 (20.8)	10.1	91.1 (18.9)	7.8	90.2 (20.2)	8.4
Symptoms	Mean score (SD)	Symptomatic¤†	Mean score (SD)	Symptomatic¤†	Mean score (SD)	Symptomatic¤†	Mean score (SD)	Symptomatic¤†
Symptom scales								
Fatigue	20.0 (22.5)	25.3	20.7 (22.2)	24.9	19.1(22.3)	20.2	24.1(23.4)	22.0
Nausea and vomiting	2.9 (10.1)	1.5	3.5 (11.4)	3.2	3.6 (9.6)	2.4	2.3 (8.0)	1.9
Pain	15.3 (23.2)	15.5	21.7 (27.9)	18.7	23.2 (27.8)	22.6	25.3 (27.7)	26.6
Single items								
Dyspnea	11.9 (20.7)	5.7	11.9 (21.0)	5.9	12.6 (21.8)	6.1	19.6 (27.2)	12.4
Insomnia	19.2 (28.8)	13.8	22.8 (29.2)	18.2	21.4 (28.1)	15.1	23.3 (29.0)	7.3
Appetite loss	4.6 (16.8)	2.6	3.4 (11.8)	1.2	3.7 (13.8)	1.7	3.9 (13.5)	1.7
Constipation	5.0 (14.1)	1.6	7.2 (18.9)	4.6	6.3 (17.5)	3.2	10.0 (21.6)	7.3
Diarrhea	5.3 (17.0)	3.1	6.8 (17.5)	4.1	6.0 (17.0)	3.7	5.6 (17.0)	3.7
Financial difficulties	6.1 (20.2)	4.6	6.8 (20.9)	5.6	4.6 (15.4)	3.2	3.6 (14.1)	2.8

[*] Poor function = any response of 3 (“quite a bit”) or 4 (“very much”) on an item within a functional scale. Poor quality of life = any response of ≤ 4 on an item within the scale. Otherwise good function or quality of life.

[¤] Symptomatic = any response of 3 (“quite a bit”) or 4 (“very much”) on an item within a symptom scale or for a single item otherwise no symptoms.

[†] Values are in percent.

Some methodological issues deserve attention. The sample was randomly selected using the Swedish Total Population Register, which includes information about all births and deaths in the entire Swedish population virtually without any delay. Therefore there is little risk of selection bias. Selection bias could, however, be introduced as a result of non-participation and missing data, particularly among younger persons where the participation rate was lower. However the high participation rate and low rate of missing data in this study make such bias unlikely. The differences in HRQL values between age groups and sex confirm the ability of the EORTC QLQ-C30 to detect differences in HRQL not only in cancer patients but also in the general population at large. For the purpose of this study responses were also dichotomized. This strategy was used to facilitate interpretation [12], and has previously been used in several studies on HRQL [10,11]. Results are presented by age and sex groups since HRQL scores for scales and single items vary with age and sex and it is recommended that HRQL values are tabulated by such groups [13].

It is known that women are more likely than men to report more problems and poorer HRQL [5,7,14–16]. In a Norwegian study of the EORTC QLQ-C30 [4], women scored lower on global quality of life and physical and emotional function scales than men, and had more problems with pain, fatigue and insomnia. Similarly, in a Swedish population study [7] using the same questionnaire, women of all ages reported more symptoms and poorer health than men. In another study [14] assessing HRQL among overweight and obese people, women reported poorer physical and mental well-being than men. Hence, our finding of regarding sex differences is consistent with some earlier investigations.

Age importantly influenced the responses to scales and single items in this study. The oldest age group rated the lowest values for physical and role function as well as highest values for pain. These results are in line with some earlier studies on reference values in Norwegian and Swedish populations [4,7]. In agreement with previous studies, the oldest respondents rated higher on the emotional function scale. Several theories for this finding have been proposed previously, including the socioemotional selectivity theory, which posits that as we realize that time is limited positive experience is selected over negative

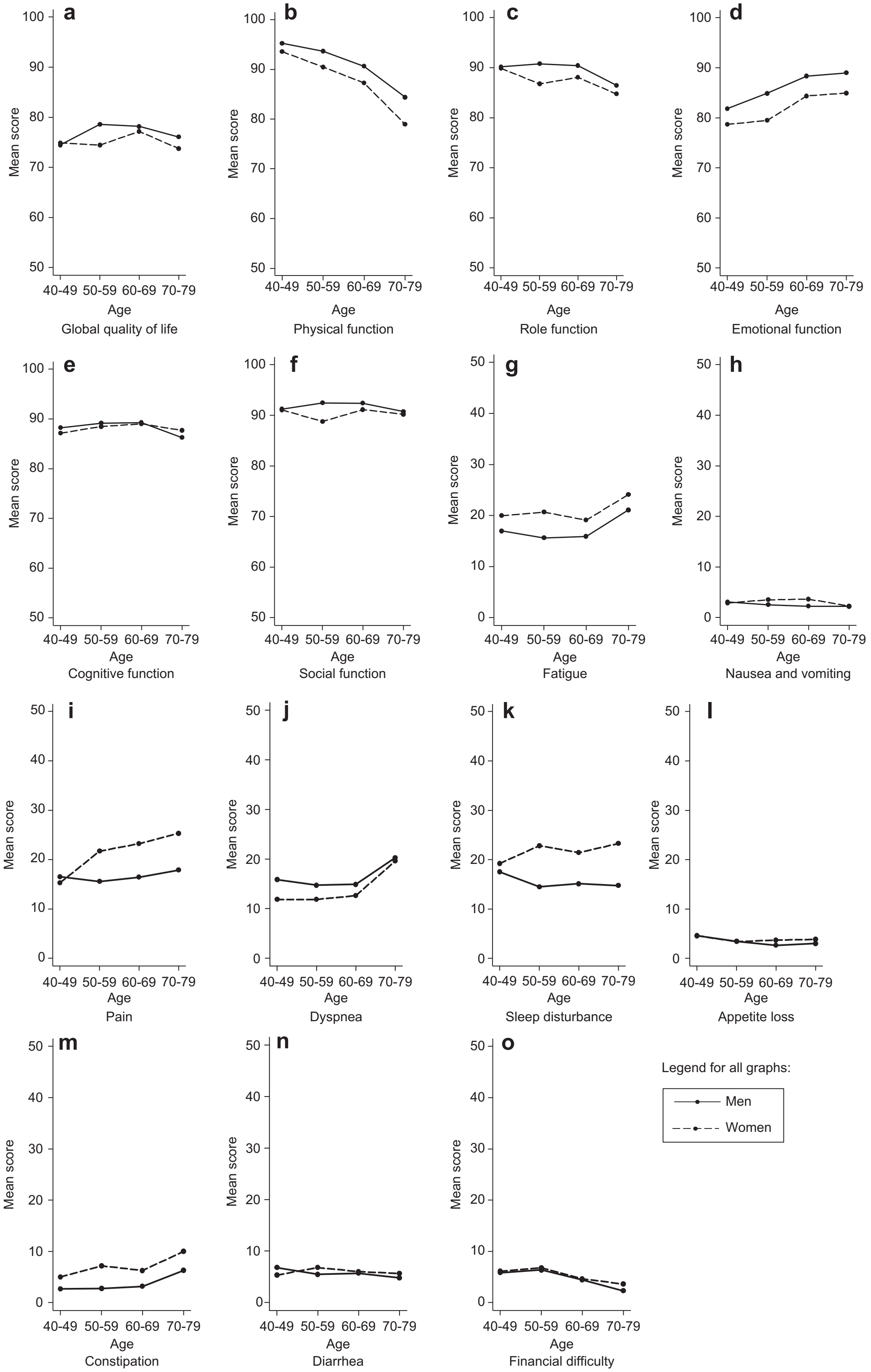

Figure 1. (a–o) Mean scores for functions and symptoms of EORTC QLQ-C30 in a random sample of 4910 Swedish adults, stratified by age and sex.

and greater resources are invested in emotionally meaningful goals and activities [17,18].

Compared to the previous Swedish study [7] conducted over 10 years ago, most HRQL aspects seem virtually unchanged. However, such comparison is not entirely valid since the two cohorts have different age and sex distributions.

When assessing changes over time in HRQL, for example before and after treatment, it is common to use the HRQL measured for the first time in the patients as the baseline level. This value can, however, only be attained after the diagnosis has been made. Since the HRQL is influenced by the tumor, a true baseline is not possible to obtain. In this respect, the use of population-based reference values could act as a surrogate or additional baseline and facilitate the interpretation of data.

In summary, this large population-based study provides updated reference values for the EORTC QLQ-C30 in a random sample of the Swedish adult population. The study results can be used as a baseline for HRQL in future research using this questionnaire.

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