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ORIGINAL ARTICLE

Health-related quality of life among family caregivers of oesophageal cancer survivors one year after curative intended treatment – a nationwide population-based study

Cecilia Ringborg[a], Asif Johar[a] and Pernilla Lagergren[a,b]

[a]Surgical Care Science, Department of Molecular Medicine and Surgery, Karolinska Institutet, Karolinska University Hospital, Stockholm, Sweden; [b]Department of Surgery and Cancer, Imperial College London, London, UK

ABSTRACT

Background: To investigate factors that might influence the quality of life of the family caregivers of oesophageal cancer patients.

Material and methods: A cross-sectional study within a prospective, population-based nationwide cohort study including family caregivers to oesophageal cancer patients was conducted. The exposures were family caregivers' age, sex, education level and patients' tumour stage, postoperative complications, weight loss and comorbidities. The outcome was health-related quality of life (HRQL) one year after the patient's cancer surgery measured by the RAND-36. Multivariable linear regression analysis provided mean score differences (MSD) with 95% confidence intervals (CI).

Results: In total 257 family caregivers were included. Family caregivers $\geq$65 years displayed lower physical function (MSD=-8.5; $p = 0.001$) but a higher level of energy (MSD = 9.2; $p = 0.002$). Those with a higher education level had less pain (MSD = 11.2; $p = 0.01$) and better physical function (MSD = 9.1; $p = 0.006$).

Results: Among the patient related exposures, postoperative complications were associated with family caregivers' physical function (MSD= −6.0; $p = 0.01$) and pain (MSD= −7.9; $p = 0.01$). Tumour stage and comorbidities were not associated with the HRQL of the family caregiver.

Conclusion: The study suggests that patients' complications and age and education level of the family caregivers are associated with family caregivers HRQL. This information provides guidance in the process of creating support for family caregivers of oesophageal cancer patients.

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Cancer survivorship; cancer treatment; surgical complications; RAND-36; family caregivers

Background

A diagnosis of cancer does not only influence the patient, but it also influences the life of the patient's family caregivers. A family caregiver has been defined as 'any relative, partner, friend or neighbour who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition' [1]. Family caregivers of oesophageal cancer patients might be negatively impacted partly because of the poor oesophageal cancer prognosis (overall survival 10–20%) [2] but also because of the complicated and complex treatment and recovery.

Curatively intended treatment for oesophageal cancer includes extensive surgery often in combination with neoadjuvant chemo-radiotherapy and sometimes adjuvant treatment after surgery. The 5-year survival rate after curatively intended surgery is 30–55% [3] but only 25–30% of patients diagnosed with oesophageal cancer are eligible for such surgery. In addition, the treatment often entails a number of complications and side effects. Common complications due to surgery are pulmonary complications [4], anastomotic leaks [5] and malnutrition [3]. It has been suggested that complications and side-effects influence patients' health-related quality of life (HRQL) both in the short and the long term perspective [6–8].

There are observations that family caregivers may have a higher risk of psychological distress in terms of anxiety and depression when caring for a patient with oesophageal cancer [9]. The levels of psychological distress were comparable to the levels for family caregivers of palliative patients. The caregiver burden may have a negative influence on HRQL of family caregivers of patients with cancer [10]. One-third of family caregivers in a previous study reported moderate or high caregiver burden 3 years after oesophageal cancer patients' curative treatment [11].

Furthermore, there is a need to explore factors that negatively influence the HRQL of family caregivers of oesophageal cancer patients and their need for healthcare support. If it is possible to identify family caregivers at risk of a poor HRQL, supportive actions can be given in a timely way to avoid the

CONTACT Pernilla Lagergren ✉ pernilla.lagergren@ki.se Surgical Care Science, Department of Molecular Medicine and Surgery, Karolinska Institutet, Retzius väg 13a, Solna 171 77, Sweden

negative impact among family caregivers. Family caregivers with a good quality of life or with their own support may remain a more reliable support to oesophageal cancer patients. Associations of HRQL and characteristics show that women and those with a lower education have a lower overall HRQL. In addition, a higher age is associated with a decreased physical health but better in some mental health's dimensions [12].

The aim of this study, therefore, was to investigate how age, sex and education level of a close family caregiver as well the tumour stage, surgical complications, weight loss and comorbidities of the patient may influence the HRQL of the family caregiver.

Methods

Study design and data collection

Data for the current cross-sectional study were collected from an ongoing prospective, population-based nationwide cohort study entitled Oesophageal Surgery on Cancer patients – Adaptation and Recovery (OSCAR). The cohort for the present study includes patients operated on for oesophageal or gastroesophageal junction cancer in Sweden since 2013. The patients were included at 1 year postoperatively. Eligible patients were identified through an on-going collaboration with all pathology departments in Sweden. In addition, one family caregiver per patient was included. The patient was asked to invite one family caregiver to participate in the study. The patient suggested which family caregiver he/she thought was most appropriate to be included in the cohort. The project coordinator sent out a written consent to the family caregiver that could chose to participate or not. Both the patients and their closest family caregivers that chose to participate were included in the present study 1 year after the patient's surgery. Thereafter they are followed up at 1.5, 2, 2.5, 3, 4 and 5 years postoperatively. The data collection started in 2014 (i.e., 1 year after surgery).

All family caregivers participating in OSCAR are required to fill in a self-report questionnaire-package containing several well-validated measurements together with some study specific questions (e.g., marital status, relationship to the patient, working or retired, etc.). For the purpose of this study, family caregivers of patients operated on between 2013 and 2018 were included. About 76% of all patients who received curative intended treatment during this time period survived 1 year after surgery and 66% of them agreed to participate in OSCAR [13]. Of these patients, 86% had family caregivers who were included in the cohort.

Exposures

Family caregiver-related exposures

The exposures related to family caregivers were age (<65 and ≥65), sex (female and male) and education level (≤9 year and >9 year). Information about the family caregivers was self-reported except for education level which was collected from the Swedish national register; longitudinal integrated database for health insurance and labour market studies – LISA. The information about education level was collected by the time of the first year data collection one year after the patients' surgery.

Patient-related exposures

Exposures related to patients were patients' tumour stage (TNM I-II and TNM III-IV), 24 different postoperative complications (including for example pulmonary and coronary complications, infections and anastomotic leakages) (0 and ≥1), weight loss ($<10\%$ and $\geq10\%$) and comorbidities included in the Charlson comorbidity index [14] (0 and ≥1). The clinical information was collected from patients' medical records based on a predefined study protocol.

Outcome

The outcome was HRQL among family caregivers 1 year after the patients' operation measured by the RAND-36 [15]. The RAND-36 contains 36 items that are distributed across eight subscales: physical function, role functioning – physical, role functioning – emotional, social functioning, emotional well-being, energy/fatigue, pain and general health. The responses to the items are scored 0–100. A low score indicates lower HRQL and higher score indicates a higher HRQL [15].

Statistical analysis

Multivariable linear regression models were used to assess the associations between exposures (family caregivers' age, sex, education level and patients' tumour stage, complications, weight loss and comorbidity) and the outcome (HRQL). Mean score difference (MSD) with 95% confidence intervals (CI) were calculated. Adjustments were made for the following covariates: (age: continuous; sex: male and female; education level: ≤9 year and >9 year; the patient's tumour stage: TNM I-II and III-IV; surgical complications: (0 or ≥1); weight loss: ($<10\%$ or $\geq10\%$); and comorbidities (0 or ≥1)), where the individual studied exposure variable, under analysis, was excluded from that regression model as a covariate and was included as an exposure.

In addition to the eight subscales of the RAND-36, two summary scores for *physical health* and *mental health* were calculated by standardising RAND-36 scales by a *z*-score transformation (using means and standard deviations (SD) from the general US population) followed by aggregating these *z*-scores by multiplying each RAND-36 *z*-score by respective factor score coefficient and adding these to create aggregate scores [16]. Followed by transforming these aggregated scores by multiplying by 10 and adding 50, respectively, to create physical health and mental health summary scores [16]. The *physical health* concerns physical function, role functioning – physical, pain and general health and the *mental health* includes social functioning, role functioning – emotional, emotional well-being and general health [17]. Based on previous research, clinical relevance was considered when a mean score difference was ≥5 [17,18]. To reduce the risk of multiple testing, a statistical significance was tested (two sided) only when there was a clinically relevant difference between comparison groups. A statistical significance was considered when $p < 0.05$. There were very low number of missing (<3%) so a complete case analysis approach was used.

A sensitivity analysis was conducted on partners only following the same modelling approach as the main analysis.

All data management and all the analysis were conducted by a senior biostatistician (AJ) using SAS® version 9.4 (SAS Institute, Cary, NC).

Results

Participants

By the time of analysis, 322 patients (participation rate 69%) were included in OSCAR study and asked to invite a family caregiver. In total, 257 (80%) family caregivers were suggested by the patients and deemed eligible to be invited to participate. All invited family caregivers accepted participation. Characteristics between patients who invited a family caregiver and those who did not were similar except for sex with a males/female distribution of 87%/13% and 96%/4%, respectively. Characteristics of the participants are presented in Table 1. The mean age of the group was 63 years. The majority the family caregivers were women (84%) and had more than 9 years of education (86%). Most of the family caregivers were partners of the patients (81%), 9% were children and about 10% were either a friend or neighbour to the patient.

Table 1. Characteristics of the 257 family caregivers of oesophageal cancer patients.

Characteristics	Number (%)
Age	
Mean age (SD; range)	63 (13; 26–87)
<65	123 (48)
≥65	134 (52)
Sex	
Male	41 (16)
Female	216 (84)
Education level	
≤9 year	37 (14)
>9 year	220 (86)
Relation	
Partner	208 (81)
Children	22 (9)
Others	27 (10)

Family caregivers' characteristics and influence on their HRQL

Table 2 shows the results of the family caregiver related exposures effect on the family caregivers' HRQL. Family caregivers older than 65 years reported a clinically relevant and statistically significant lower physical function compared to younger family caregivers (MSD=−8.4; $p = 0.001$). However, they reported a higher energy level compared to the younger age group (MSD = 9.2; $p = 0.002$). The older age group also reported a clinically relevant higher level of role functioning – emotional (MSD = 6.3) but this difference did not reach the level of statistical significance (Table 2).

The female family caregivers scored a clinically relevant higher (i.e., better) level of role functioning – emotional compared to male family caregivers (MSD = 5.6). However, the clinically relevant differences did not reach the level of statistical significance (Table 2).

Regarding education level, family caregivers with a lower education level reported clinically relevant and statistically significantly more pain (MSD = 11.2; $p = 0.01$) compared to

Table 2. Results of the family caregivers' exposures impact on family caregivers' health-related quality of life of patients treated for oesophageal cancer using the RAND-36 questionnaire.

	Age^{b}		Sex^{b}		Education Level^{b}	
Quality of life aspects	Mean score (95% CI)	Mean score difference (95% CI)	Mean score (95% CI)	Mean score difference (95% CI)	Mean score (95% CI)	Mean score difference (95% CI)
	<65 (reference)	≥65	Male (reference)	Female	≤9 year (reference)	>9 year
Physical function	80.9 (75.7 to 86.1)	−8.4$^{\#}$ (−13.4 to −3.4)^{a}	77.9 (71.7 to 84.2)	−2.0 (−8.1 to 4.2)	72.4 (65.9 to 78.9)	9.1$^{\#}$ (2.6 to 15.7)^{a}
Role functioning – physical	70.1 (59.8 to 80.4)	−4.3 (−14.0 to 5.3)	67.1 (54.4 to 79.9)	2.4 (−9.9 to 14.8)	65.5 (52.3 to 78.8)	5.6$^{\#}$ (−7.5 to 18.7)
Role functioning – emotional	68.4 (57.5 to 79.4)	6.3$^{\#}$ (−4.0 to 16.7)	69.0 (55.2 to 82.7)	5.6$^{\#}$ (−7.8 to 18.9)	72.4 (58.1 to 86.7)	−1.3 (−15.4 to 12.9)
Social functioning	79.2 (72.5 to 86.0)	0.7 (−5.6 to 7.1)	79.7 (71.2 to 88.3)	0.3 (−8.0 to 8.5)	78.9 (70.1 to 87.7)	1.9 (−6.8 to 10.6)
Emotional well-being	75.8 (70.2 to 81.3)	2.1 (−3.0 to 7.3)	78.9 (72.0 to 85.9)	−4.2 (−11.0 to 2.6)	78.0 (70.9 to 85.2)	−2.4 (−9.6 to 9.6)
Energy	59.0 (53.1 to 65.0)	9.2$^{\#}$ (3.5 to 14.9)^{a}	64.7 (57.3 to 72.2)	−1.9 (−9.2 to 5.4)	62.6 (55.0 to 70.3)	−2.2 (−9.9 to 5.4)
Pain	62.4 (54.8 to 70.0)	−1.4 (−7.9 to 5.2)	63.6 (55.0 to 72.3)	−1.2 (−6.4 to 12.4)	57.4 (48.4 to 65.8)	11.2$^{\#}$ (2.3 to 20.1)^{a}
General Health	63.1 (57.9 to 68.3)	2.0 (−2.9 to 6.9)	63.3 (56.8 to 69.9)	1.6 (−4.8 to 8.0)	62.1 (55.3 to 68.9)	4.1 (−2.6 to 10.8)
Physical Component Scale	46.5 (44.0 to 48.8)	−2.3 (−4.6 to −0.1)	45.7 (42.6 to 48.8)	−0.6 (−3.6 to 2.4)	43.1 (39.9 to 46.3)	4.7 (1.5 to 7.8)
Mental Component Scale	48.7 (45.3 to 52.2)	3.6 (0.3 to 6.8)	50.5 (46.2 to 54.9)	−0.0 (−4.3 to 4.2)	51.3 (46.7 to 55.8)	−1.5 (−5.9 to 3.0)

[a] Statistically significant: $p < 0.05$. CI: confidence interval. # = clinically relevant. [b] The model is adjusted for: age: continuous; sex: male and female; education level: ≤ 9 year and >9 year; the patient's tumour stage: TNM I–II and III–IV; surgical complications: (0 or ≥1); weight loss: (<10% or ≥10%); and comorbidities (0 or ≥1).

those with a higher education level. Also, the group of higher educated family caregivers had a clinically relevant and statistically significant better physical function (MSD = 9.1; $p = 0.006$) and a clinically relevant better role functioning – physical (MSD = 5.6) (Table 2).

Patient factors related to HRQL of the family caregiver

In Table 3, the results of patient related exposures and their association on family caregivers' HRQL are presented. The tumour stage of the oesophageal cancer patient was not associated with the HRQL of the family caregivers; no clinically relevant differences between tumour stage groups were found.

If the patient experienced at least one surgical complication family caregivers' HRQL was clinically relevant and statistically significant poorer regarding physical function (MSD = −6.0; $p = 0.01$) and pain (MSD = −7.9; $p = 0.01$) compared to family caregivers with patients not experiencing complications. Complications were also found to have a clinically relevant negative impact in family caregivers' role functioning – physical (MSD = −6.0) and social function (MSD = −5.9) compared to family caregivers whose patients had no complications, but the differences did not reach the level of statistical significance (Table 3).

Family caregivers of patients who lost ≥10% of their preoperative weight reported more pain (MSD = −5.0) than those caring for patients with less weight loss. However, the clinically relevant difference did not reach the level of statistical significance.

Whether the patients had comorbidities or not was not associated with family caregivers' HRQL, no clinically relevant difference was found.

Sensitivity analysis

The sensitivity analysis on the subgroups of partners only showed similar results to the results from the main analysis, except for education level losing statistical significance for physical function (MSD = 9.1, $p > 0.05$) and pain (MSD = 8.8, $p > 0.05$) and clinical relevance for role function – physical (MSD = 2.7, $p > 0.05$). Complications became more clinically relevant for all previous clinically relevant findings and also statistically significant for role functioning – physical ($p < 0.05$).

Discussion

This population-based nationwide study on family caregivers of oesophageal cancer patients showed that family caregivers' age, sex and education level as well as patients' complications and patients' weight loss were associated with their HRQL where patients' complications was the single exposure that had the strongest association with the family caregivers' HRQL. Neither patients' tumour stage nor comorbidities were associated with family caregivers' HRQL.

The population-based design is the strength of the study. All patients operated on for oesophageal cancer in Sweden were asked to participate and to invite their closest family caregiver, resulting in a large cohort with a high participation rate and good power (90%). The data were collected by using well-validated self-report questionnaires. The validated Swedish version of the generic RAND-36 questionnaire was used to measure family caregivers' HRQL [15,19]. The RAND-36 is designed to be used in any context by anyone and is the most common and frequently-used questionnaire to assess HRQL [20]. The use of such a comprehensive HRQL

Table 3. Results of the patient-related exposures' impact on family caregivers' health-related quality of life of patients treated for oesophageal cancer using the RAND-36 questionnaire.

	Tumour stage^{b}		Complications^{b}		Weight loss^{b}		Comorbidity^{b}	
Quality of life aspects	Mean score (95% CI) I–II (reference)	Mean score difference (95% CI) III–V	Mean score (95% CI) 0 (reference)	Mean score difference (95% CI) ≥1	Mean score (95% CI) <10% (reference)	Mean score difference (95% CI) ≥10%	Mean Score (95% CI) 0 (reference)	Mean Score Difference (95% CI) ≥1
Physical function	75.2 (70.6 to 79.8)	3.5 (−1.2 to 8.2)	80.0 (74.8 to 85.1)	−6.0$^{\#}$ (−10.7 to −1.4)^{a}	76.5 (77.0 to 81.9)	0.9 (−3.9 to 5.8)	77.2 (72.1 to 82.2)	−0.4 (−5.0 to 4.2)
Role functioning – physical	68.1 (58.8 to 77.3)	−0.6 (−10.0 to 8.8)	71.4 (61.0 to 81.7)	−6.0$^{\#}$ (−15.3 to 3.3)	70.5 (59.5 to 81.6)	−4.1 (−14.1 to 5.3)	68.9 (58.6 to 79.1)	−1.0 (−10.2 to 8.1)
Role functioning – emotional	70.2 (60.2 to 80.2)	3.2 (−7.0 to 13.3)	73.5 (62.4 to 84.7)	−3.6 (−15.9 to 5.9)	70.9 (59.0 to 82.9)	1.6 (−8.8 to 12.0)	70.9 (59.8 to 81.9)	1.8 (−8.1 to 11.6)
Social functioning	79.6 (73.4 to 85.8)	0.5 (−5.7 to 6.7)	82.8 (75.9 to 89.7)	−5.9$^{\#}$ (−12.0 to 0.3)	80.1 (72.7 to 87.5)	−0.4 (−6.9 to 6.0)	80.1 (73.3 to 86.9)	−0.4 (−6.3 to 6.6)
Emotional well-being	77.9 (72.8 to 83.0)	−2.1 (−7.2 to 3.0)	78.4 (72.8 to 84.1)	−3.2 (−8.3 to 1.9)	76.8 (70.7 to 82.8)	0.2 (−5.2 to 5.5)	76.8 (71.3 to 82.4)	0.0 (−5.0 to 5.1)
Energy	64.0 (58.6 to 69.5)	−0.6 (−6.1 to 5.0)	66.0 (60.0 to 72.1)	−4.6 (−10.1 to 0.9)	64.7 (58.3 to 71.2)	−2.0 (−7.7 to 3.7)	62.5 (56.6 to 68.5)	2.4 (−3.0 to 7.8)
Pain	61.7 (55.4 to 68.0)	2.6 (−3.8 to 9.0)	67.0 (60.0 to 74.0)	−7.9$^{\#}$ (−14.2 to −1.6)^{a}	65.5 (58.0 to 73.0)	−5.0$^{\#}$ (−11.6 to 1.6)	63.2 (56.2 to 70.1)	−0.3 (−6.5 to 5.9)
General Health	64.8 (60.1 to 69.6)	−1.4 (−6.2 to 3.3)	65.7 (60.4 to 71.0)	−3.1 (−9.4 to 0.8)	64.4 (58.7 to 70.1)	−0.6 (−5.5 to 4.4)	65.0 (59.8 to 70.3)	−1.8 (−6.5 to 2.9)
Physical Component Scale	45.0 (42.8 to 47.2)	0.8 (−1.4 to 3.1)	46.8 (44.3 to 49.3)	−2.7 (−5.0 to −0.5)	46.2 (43.5 to 48.8)	−1.5 (−3.8 to 0.9)	45.6 (43.1 to 48.0)	−0.3 (−2.5 to 1.9)
Mental Component Scale	50.9 (47.8 to 54.1)	−0.9 (−4.0 to 2.3)	51.2 (47.7 to 54.7)	−1.3 (−4.5 to 1.8)	50.2 (46.5 to 53.0)	0.6 (−2.7 to 3.9)	50.2 (46.7 to 53.7)	0.6 (−2.5 to 3.7)

[a] Statistically significant: $p < 0.05$. CI: confidence interval. # = clinically relevant. [b] The model is adjusted for: age: continuous; sex: male and female; education level: ≤ 9 year and >9 year; the patient's tumour stage: TNM I–II and III–IV; surgical complications: (0 or ≥1); weight loss: (<10% or ≥10%); and comorbidities (0 or ≥1).

instrument makes the study results more detailed and gives the opportunity to investigate the impact in every specific dimension of the family caregivers HRQL that, from our knowledge, not been studied previously. This will make it easier to understand the future need for research and what information that is required to further improve the situations of the family caregivers.

Although there are many strengths of the study, there are also some limitations. For example, the risk of selection bias, even though the inclusion rate is relatively high. There could be a risk that the patients who are most negatively affected by the disease and the treatment chose to decline participation. In that way, also, information from these patients' family caregivers is lost. However, we believe that such selection bias could only dilute the association and would not change the conclusions. The inclusion rate of patients in OSCAR is approximately 69%. The high inclusion rate of family caregivers (80%) makes it reasonable to generalise our results for family caregivers of patients treated for oesophageal cancer in Sweden.

Although the use of well-validated questionnaires is an advantage, there may be a risk of response bias. However, because of the questionnaires were sent to the family caregivers' homes, without any contact with the researcher, the risk of the researcher affecting the responses in the questionnaires is minimised. The use of a generic questionnaire to measure HRQL may have missed to capture specific caregiver related HRQL aspects.

The lack of baseline data is another limitation when trying to describe the health change for family caregivers. However, although it is an advantage to have baseline data for patients and family caregivers, the HRQL will probably be affected negatively by the time of patients' diagnosis.

Surgery for oesophageal cancer is a major procedure and is followed by a high risk of postoperative complications, which has been shown to be the strongest risk factor for poor HRQL and recovery among patients [6,8,13,21]. Some patients also suffer from side-effects and poor HRQL up to 10 years after surgery [7]. A previous study has found that cancer patients with symptoms of side-effects with a negative impact on patients' functions promote a higher burden on the family caregivers [11]. In the current study, complications were found to be the most prominent factor affecting family caregivers' HRQL negatively. Two out of eight subscales were both clinically relevant and statistically significant negatively impacted (physical function and pain) and in addition, two subscales were clinically relevant negatively impacted (role functioning – physical and social functioning). These results were more pronounced in the sensitivity analysis of partners only. A reason for the negative impact of patients' complications could be the more complex caring that these patients need. The complications make the treatment process and the recovery time for the patients longer and the burden of the family caregivers might increase. However, the RAND-36 does not capture caregiver burden and specific caregiver HRQL and studies with such more detailed outcomes are warranted. Because of the long-term effect in HRQL among patients due to complications, it would be highly advisable to investigate family caregivers' burden and specific HRQL for a longer time period than 1 year to see whether complications associate with family caregivers' HRQL in the long term.

The older age group in the current study reported a more poor physical function but a higher level of energy compared to the younger family caregivers. A reasonable explanation could be the cut-off in the age groups. In Sweden, the average retirement age is 65 years meaning the younger age group is still actively working and at the same time caring for the patient which may impact their energy level. Caring for a patient and being employed has been studied previously. An American study showed that family caregivers are often late to work or leave early to be able to care for the patient as much as possible [22]. This could be a stressful situation for caregivers and could be the reason of the lack of energy compared to retired family caregivers.

In the current study, the results indicate that family caregivers with a lower education level have more pain and the reason behind this can be discussed. The family caregivers with a higher education level had a better physical function which is correlated with less pain. The correlation of physical activity and less pain and well-being have been demonstrated previously [23,24]. Therefore, one explanation why family caregivers with a lower education level reported more pain in the current study could be that family caregivers with a higher education level are more physically active and therefore experience less pain. Well-educated family caregivers to cancer patients have been observed to have a higher level of stress in a previous study [25] but a high education level was not associated with family caregivers' HRQL in the current study.

Compared to norm-based reference data, our studied population scored lower in several subscales of RAND-36 [12]. The most prominent differences were for physical function, energy and pain. Furthermore, energy and pain differed for all studied characteristics of the family caregivers which point towards that family caregivers of oesophageal patients may be in need for support during the cancer trajectory.

Surprisingly, the patients' tumour stage was not associated with family caregivers' HRQL in the current study. There is reason to believe that the more advanced cancer stages would impact the patient's family caregivers in a negative manner. However, in the current study, all patients were treated with a curative intent despite tumour stage which may influence the results. Another explanation could be that patients and family caregivers are not well informed about the patient's tumour stage and the consequences of an advanced stage despite treatment with a curative intent. A study investigating family caregivers to advanced lung cancer patients found that patients' HRQL had a larger impact on the family caregivers' HRQL compared to the impact of the patients' tumour stage [26]. This indicates that it is not the severity of the tumour that has an impact on family caregivers, but the patients' well-being. In addition, potential comorbidities did not have an impact on family caregivers' HRQL in this study. However, it has been found in previous research that cancer patients with comorbidities have poorer

HRQL compared to patients without comorbidities [27,28]. This is, however, not in line with the recent discussed literature regarding the impact of patients' HRQL and the impact among family caregivers. Therefore, further investigations on the impact of oesophageal cancer patients' HRQL on family caregivers' HRQL are warranted.

To make the picture more complete, studies comparing family caregivers to oesophageal cancer patients with a background population are suggested, however, the current study aimed to identify family caregivers in potential need for extra support within the group of oesophageal cancer family caregivers. Even though the current study in this context can be considered as large with good power it had some borderline results regarding education level and complications. A larger study sample might show more findings of clinical relevance and statistical significance. In addition, it is also important to further investigate the effects on the family caregivers' life situation to understand how they can be helped and supported in the clinical context. Moreover, it is important to investigate other consequences such as psychosocial and economic consequences for a complete understanding of the family caregivers' perspective.

In the current study, the family caregivers caring for patients with complications probably are the most distinctive regarding having a poorer HRQL. Physical activity has been found to have positive impact on cancer survivors' HRQL [29]. Especially it had good effect on the survivors' physical function, social function and mental health. Support by arranging a better rehabilitation of the patients with physical activity could reduce the burden for the family caregivers at home.

In conclusion, this study indicates that, substantially, patients' complications, the age of the family caregivers and education level are associated with the HRQL of family caregivers of patients treated for oesophageal cancer. More research is needed to better understand the situation of family caregivers of patients treated for oesophageal cancer to be able to define their needs and how they can be helped. Such information can further be of use to improve the survivorship concept of cancer patients and their family caregivers.

Disclosure statement

There are no conflicts of interest.

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Data availability statement

The data that support the findings of this study are available from the corresponding author, [PL], upon reasonable request.

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