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ORIGINAL ARTICLE

Patient-reported outcomes 1 year after oesophageal cancer surgery

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ABSTRACT

Purpose: To improve survivorship in patients who have undergone curatively intended treatment for oesophageal cancer, we aimed to identify key targets for future patient-reported outcomes research.

Methods: This nationwide Swedish prospective cohort study enrolled patients between 2014 and 2019 who had undergone surgical resection for oesophageal cancer 1 year earlier. Eight well-validated patient-reported outcome measures, including health-related quality of life, psychological status and sleep, were presented as proportions and mean scores (MS) with 95% confidence intervals (CIs).

Results: Among 281 participants, approximately half of the patients reported problems associated with food intake such as eating restrictions (49%) and food aversion (47%). Other common problems were sleep (51%), fatigue (41%) and anxiety (36%). Fewer patients suffered from financial difficulties (9%), trouble swallowing saliva (4%) and hair loss (7%). However, these problems were perceived as highly burdensome on an individual level.

Conclusions: This nationwide, population-based study indicates that symptom burden is high in oesophageal cancer survivors 1 year after surgery. The most common problems are associated with food intake, sleep, fatigue and anxiety. However, less frequent symptoms were sometimes more debilitating for the individual patient.

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Introduction

Worldwide, around 500,000 people are diagnosed with oesophageal cancer per year [1]. Approximately, 30–40% of these patients are eligible for curatively intended treatment [2], which typically includes a combination of surgery (oesophagectomy), chemotherapy and/or radiotherapy [3]. Oesophagectomy is an extensive procedure where most of the oesophagus with its tumour and the upper part of the stomach are removed and replaced by a substitute, usually the remaining stomach which is reconstructed into a tube [3]. The treatment is associated with a high risk of severe complications [4,5] and poor health-related quality of life (HRQL) [6–8]. The trajectory of HRQL recovery after oesophagectomy for cancer varies largely. Some patients report full recovery while others deteriorate over time [9,10]. Clinical or patient-related factors cannot fully explain the variation and morbidity. Therefore, the purpose of this study was to investigate the prevalence of less explored patient-reported outcomes and to suggest key areas for future survivorship research in these patients, by using data from a recent nationwide and prospective cohort including a large variety of patient-reported outcome measures.

Methods

Study design

The Oesophageal Surgery on Cancer patients – Adaptation and Recovery study (OSCAR) is an ongoing nationwide and prospective cohort study in Sweden. It was initiated in 2013 and designed to provide knowledge that can help improve the survivorship in oesophageal cancer patients who have undergone curatively intended treatment, including surgery. All Swedish-speaking patients with no cognitive dysfunction who underwent curatively intended surgery for oesophageal cancer in Sweden and their closest family members were included 1 year postoperatively. Patients and their closest family members were further followed up 1½, 2, 2½, 3, 4 and 5 years after surgery. For the purpose of this study, 1-year postoperative data from patients operated on from 1 January 2013 to 30 April 2018 were collected in 2014–2019. A research partnership group consisting of patients operated on for oesophageal cancer helped with guidance and prioritisation of research questions connected to the OSCAR study. The project was approved by the Regional Ethical Review Board in Stockholm (diary number 2013/844-31/1), Sweden and all participants gave written informed consent.

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Data collection

Eligible patients were identified through collaboration with all eight pathology departments in Sweden from hospitals where these operations were conducted. A project coordinator distributed the invitations to all potential study participants by post followed by a phone call. The project coordinator informed the patients about the study including the average length of the interview and if they wanted to participate, a visit by a research nurse was booked. A questionnaire including questions about socio-demographic aspects was sent by post to be filled in before the appointment.

At the appointment, a research nurse visited the patients in their homes to collect the present paper questionnaires and guide them through further and more comprehensive self-reported computer-based questionnaires to collect patient-reported outcomes. The visits lasted between 60 and 120 min. Patients were informed that they could discontinue the interview or take a break at any point if they wanted.

Data on clinical details were collected from medical records and included tumour histology, site and stage (histopathology reports), treatment (examination results, interventions provided, operation charts) and post-surgery status, treatments and care. Each medical record was reviewed by two researchers according to a predefined study protocol to ensure consistency and uniformity of the data collection. Cross-validation of randomly selected protocols was performed by an independent person.

Data on patient characteristics were collected by linking the personal identity number assigned to each Swedish resident to national health data registries. Socio-demographic information was obtained via linkage to the Longitudinal Integration Database for Health Insurance and Labour Market, which holds registration since 1990 and is updated yearly [11]. For information on comorbidities, the patients were linked to the Swedish Patient Registry [12] and the Swedish Cancer Registry [13]. Comorbidities were classified according to the well-validated Charlson Comorbidity Index score [14,15]. The Swedish Register of the Total Population was used to retrieve survival data. All these registries hold nearly 100% complete nationwide information [12,16].

Outcomes

HRQL

HRQL was assessed by the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ) Core 30 (QLQ-C30) [17] including the modules for gastroesophageal symptoms (QLQ-OG25) [18], cancer cachexia (QLQ-CAX24) [19] and cancer-related fatigue (QLQ-FA13) [20]. The 30-item core questionnaire (QLQ-C30) measures HRQL aspects with five multi-item functional scales (physical, role, cognitive, emotional and social); one global quality of life scale; three symptom scales (fatigue, pain and nausea/vomiting) and six single-items measuring symptoms common among patients with cancer in general (dyspnoea, insomnia, appetite, constipation and diarrhoea) and financial impact. Oesophageal cancer specific symptoms were measured with the QLQ-OG25, comprising six symptom scales (dysphagia, eating restrictions, reflux, odynophagia, pain and discomfort, and anxiety) and 10 single items (eating in front of others, dry mouth, trouble with taste, body image, trouble swallowing saliva, choking when swallowing, trouble with coughing, trouble talking, weight loss and hair loss). The QLQ-CAX24 captures problems pertaining to weight loss in cancer patients. It has four multi item scales (food aversion, eating and weight worry, eating difficulties, loss of control and physical decline) and four single items (dry mouth, indigestion/heart burn, forcing self to eat and inadequate information). Fatigue was assessed with the QLQ-FA12 questionnaire, which assigns three dimensions of fatigue (emotional, physical and cognitive fatigue).

In all these questionnaires, there are four response alternatives: 'not at all', 'a little', 'quite a bit' and 'very much'. Responses were further dichotomised to no or 'minor problems' versus 'problems' according to previous research [21,22]. Patients who had at least one response of (3) 'quite a bit' or (4) 'very much' to any item within a scale or to a single item were categorised as having 'problems', otherwise patients were categorised as having 'minor problems'. In the global quality of life scale in the QLQ-C30, which has a seven-graded rating, ranging from 1 ('very poor') to 7 ('excellent'), a response of 1 (very poor) and 2 (poor) in either of the items was rated as poor global quality of life, otherwise patients were rated as having good global quality of life. Regarding the information item in the QLQ-CAX24, 'Has the information you have been given about your weight loss been adequate?' a response of 'not at all' corresponded to inadequate provision of information. The HRQL scores were transformed into a scale ranging from 0 to 100 where higher scores correspond to better HRQL, while higher scores for symptoms represent more problems.

Psychological status

Psychological status was measured with the Assessment of Survivor Concerns [23], the Hospital Anxiety and Depression Scale (HADS) [24] and the Impact of Event Scale-Revised (IES-R) [25]. The questionnaire Assessment of Survivor Concerns is a five-item questionnaire that measures fear of recurrence and general health worry in cancer survivors on a four-graded scale ranging from 1 (not at all) to 4 (very much). Responses were dichotomised into patients who reported problems (3='quite a bit' or 4='very much') and were compared to patients who reported no or minor problems (1='not at all' and 2='a little').

The HADS consists of two subscales assessing anxiety and depression, respectively. The subscales include seven questions each to be rated on a four-graded Likert-type scale. Both scales render a score from 0 to 21 with a cut-off of $\geq$8 for clinically significant problems. The IES-R is a 22-item measure with the purpose to assess post-traumatic stress symptoms, divided into intrusion, avoidance and hyperarousal subscales. The items were rated on a five-point scale ranging from 0 (not at all) to 4 (extremely), with a maximum total score of 88. A higher score corresponds to a higher

symptom burden where a score above 24 indicated symptoms of post-traumatic stress.

Sleep

Sleep and sleepiness were measured with the 18-item Karolinska Sleep Questionnaire (KSQ) which includes aspects of sleep quality, snoring and nightmares [26]. Responses on how frequently these problems occur were rated on a six-graded Likert-type scale with the following response alternatives: never, seldom, sometimes, often, mostly or always. Patients were regarded as having sleep problems if the responses 'often', 'mostly' or 'always' were used.

Statistical analysis

Descriptive statistics were presented as counts (n), proportions (%) and mean scores (MS) with 95% confidence intervals (CIs). All data management and statistical analyses were conducted by a senior biostatistician (Asif Johar) with expertise in analyses of patient-reported outcome measures. The statistical analyses were performed using SAS version 9.4 (Cary, NC, USA).

Results

Patient characteristics

Between January 2013 and April 2018, 675 patients underwent oesophageal cancer surgery in Sweden. Of these, 511 (76%) survived for at least 1 year, 85 were not reachable, two excluded because of cognitive impairment, leaving 424 patients eligible for inclusion in OSCAR. Of these, 281 (66%) completed the 1-year assessment and clinical data were available for 281 (100%) patients. The main reason for non-participation was that they did not want/have the energy to participate ($n = 90$), followed by being too ill ($n = 32$) and suffered from cancer recurrence ($n = 20$). Characteristics of the 281 participating patients with complete data are presented in Table 1. The median age was 68 years, 231 patients (82%) were men and 163 patients (58%) had comorbidity (Charlson score $\geq$1). Most patients ($n = 235$; 85%) had adenocarcinoma or high-grade dysplasia, 247 patients (89%) had the tumour located in the lower oesophagus or cardia and 223 (79%) received neoadjuvant therapy.

Health-related quality of life

Global quality of life was low (MS: 19, 95% CI: 14–24) for 10% of the patients. Poor physical function and role function were reported by 40% ($n = 113$) (MS: 65, 95% CI: 62–68) and 27% ($n = 75$) (MS: 31, 95% CI: 27–36), respectively (Table 2). Fatigue was the most commonly reported general cancer-related symptom seen in 41% ($n = 114$) of patients (MS: 57, 95% CI: 54–60). Fewer patients reported problems of dyspnoea 24% ($n = 68$) (MS: 74, 95% CI: 70–77), insomnia 20% ($n = 56$) (MS: 78, 95% CI: 74–82), appetite loss 19% ($n = 53$) (MS: 74, 95% CI: 70–77), constipation 6% ($n = 17$) (MS: 73, 95% CI: 66–79), diarrhoea 13% ($n = 36$) (MS: 75, 95% CI: 70–80) and financial impact 9% ($n = 25$) (MS: 81, 95% CI: 74–88).

Regarding gastroesophageal cancer symptoms, eating restrictions were reported by 49% ($n = 138$) of the patients (MS: 44, 95% CI: 41–48), anxiety by 36% ($n = 100$) (MS: 68, 95% CI: 65–72), coughing by 27% ($n = 76$) (MS: 75, 95% CI: 71–78) and reflux by 26% ($n = 72$) (MS: 64, 95% CI: 60–69). Other symptoms such as eating with others, dry mouth, taste problems, trouble swallowing saliva, choking, coughing, speech difficulties, weight loss and hair loss were perceived as troublesome on an individual level (MS $>$ 70) (Table 2).

Food aversion was a major concern for 47% ($n = 131$) of the patients (MS: 38, 95% CI: 35–42), 29% ($n = 82$) suffered from loss of control (MS: 37, 95% CI: 33–41, 28% ($n = 78$) had worries about eating and weight loss (MS: 65, 95% CI: 61–69), and 26% ($n = 72$) suffered from eating difficulties (MS: 46, 95% CI: 41–50). Dry mouth and forcing self to eat were not as frequently reported problems but had higher symptom burden. Thirty-one percent ($n = 88$) of the patients perceived they had received an inadequate amount of information about their weight loss (MS: 16, 95% CI: 12–19).

Physical fatigue was the most common type of fatigue found in 41% ($n = 119$) of the patients (MS: 50, 95% CI: 46–53). However, tiredness interfering with daily activities and tiredness that was not understood were found to be more problematic (MS $>$ 70).

Table 1. Patient- and clinical characteristics of ($n = 281$) patients in total and categorised by sex.

Characteristics	Categorisation	All patients Number (%)	Men Number (%)	Women Number (%)
Total		281 (100)	231 (82)	50 (18)
Age at surgery	<70 years	178 (64)	147 (63)	31 (62)
	≥70 years	103 (36)	84 (36)	19 (38)
Comorbidity	0	118 (42)	97 (42)	21 (42)
	≥1	163 (58)	134 (58)	29 (58)
Tumour histology	Squamous cell carcinoma	43 (15)	21 (9)	22 (44)
	Adenocarcinoma or dysplasia	235 (85)	207 (91)	28 (56)
Tumour location	Upper or middle oesophagus	31 (11)	19 (8)	12 (24)
	Lower oesophagus or cardia	247 (89)	210 (92)	37 (76)
Tumour stage[a]	0–I	83 (32)	76 (92)	7 (8)
	II	82 (32)	68 (83)	14 (17)
	III–IV	83 (32)	70 (84)	13 (16)
Neoadjuvant therapy	Yes	223 (79)	183 (79)	40 (80)
	No	58 (21)	48 (21)	10 (20)

[a]Missing data for 33 patients.

Table 2. Health-related quality of life (HRQL) limitations at 1 year after oesophageal cancer surgery are presented as numbers, proportions, mean scores and 95% confidence intervals (CIs).

	Poor HRQL		Good HRQL	
	Numbers (%)	Mean scores (95% CI)	Numbers (%)	Mean scores (95% CI)
EORTC QLQ-C30[a]				
Global quality of life	27 (10)	19 (14–24)	254 (90)	69 (67–71)
Functional scales				
Physical	113 (40)	65 (62–68)	168 (60)	94 (93–95)
Role	75 (27)	31 (27–36)	206 (73)	91 (90–93)
Emotional	60 (21)	54 (49–59)	221 (79)	90 (89–91)
Cognitive	44 (16)	49 (43–54)	237 (84)	90 (89–91)
Social	65 (23)	40 (35–44)	216 (77)	91 (90–93)
Symptom scales				
Fatigue	114 (41)	57 (54–60)	167 (59)	18 (16–20)
Nausea/vomiting	47 (17)	52 (47–57)	234 (83)	9 (7–10)
Pain	63 (22)	61 (57–67)	218 (78)	9 (8–11)
Symptom items				
Dyspnoea	68 (24)	74 (70–77)	213 (76)	17 (14–19)
Insomnia	56 (20)	78 (74–82)	225 (80)	9 (8–11)
Appetite loss	53 (19)	74 (70–77)	228 (81)	10 (8–12)
Constipation	17 (6)	73 (66–79)	264 (94)	4 (3–5)
Diarrhoea	36 (13)	75 (70–80)	245 (87)	12 (10–14)
Financial difficulties	25 (9)	81 (74–88)	256 (91)	4 (2–5)
EORTC QLQ-OG25[b]				
Functional scales				
Body image	40 (14)	26 (21–30)	241 (86)	94 (93–96)
Symptom scales				
Dysphagia	43 (15)	36 (31–41)	238 (85)	5 (4–6)
Eating restrictions	138 (49)	44 (41–48)	143 (51)	13 (12–15)
Reflux	72 (26)	64 (60–69)	209 (74)	11 (9–12)
Odynophagia	32 (11)	53 (46–60)	249 (79)	9 (7–10)
Pain and discomfort	56 (20)	63 (58–68)	225 (80)	14 (12–16)
Anxiety	100 (36)	68 (65–72)	181 (64)	19 (17–21)
Symptom items				
Eating with others	20 (7)	75 (68–82)	261 (93)	3 (2–5)
Dry mouth	66 (23)	77 (73–81)	215 (77)	13 (11–15)
Problems with taste	38 (14)	76 (71–81)	243 (86)	9 (7–10)
Trouble swallowing saliva	12 (4)	81 (70–91)	269 (96)	4 (2–5)
Choking	20 (7)	70 (65–75)	261 (93)	9 (7–11)
Coughing	76 (27)	75 (71–78)	205 (73)	20 (18–22)
Speech difficulties	15 (5)	82 (73–92)	266 (95)	4 (3–6)
Weight loss	62 (22)	80 (75–84)	219 (78)	10 (8–12)
Hair loss	21 (7)	81 (73–89)	260 (93)	7 (4–10)
EORTC QLQ-CAX24[c]				
Multi-item scales				
Food aversion	131 (47)	38 (35–42)	152 (53)	9 (8–11)
Eating and weight loss worry	78 (28)	65 (61–69)	205 (72)	13 (11–16)
Eating difficulties	72 (26)	46 (41–50)	211 (74)	11 (6–8)
Loss of control	82 (29)	37 (33–41)	201 (71)	7 (6–8)
Physical decline	34 (12)	44 (37–51)	249 (88)	4 (3–5)
Single items				
Dry mouth	42 (15)	75 (71–80)	241 (85)	13 (11–16)
Heartburn	63 (22)	76 (72–80)	220 (88)	16 (13–19)
Forcing self to eat	47 (17)	71 (68–74)	236 (83)	12 (9–15)
Inadequate information	88 (31)	16 (12–19)	195 (69)	86 (83–90)
EORTC QLQ-FA13[d]				
Physical fatigue	116 (41)	50 (46–53)	167 (59)	13 (12–15)
Emotional fatigue	52 (19)	52 (46–59)	231 (81)	7 (6–8)
Cognitive fatigue	15 (5)	60 (49–71)	268 (95)	5 (4–6)
Single items				
Tiredness interfered with daily activities	36 (13)	73 (69–78)	247 (87)	13 (11–15)
Tiredness not understood	9 (3)	93 (81–104)	274 (97)	4 (3–5)

The health-related quality of life (HRQL) scores were transformed into a scale ranging from 0 to 100 where higher scores corresponded to better HRQL, while higher scores for symptoms represented more problems. Poor HRQL was considered present if the patients reported 'quite a bit' or 'very much' to any item within a scale or to a single item. Good HRQL was considered present if the patients reported 'not at all' or 'a little' to all items within a scale or to a single item.

[a]QLQ-C30: Quality of Life Questionnaire Core 30.

[b]QLQ-OG25: Quality of Life Questionnaire Oesophago-Gastric module 25.

[c]QLQ-CAX24: Quality of Life Questionnaire cancer Cachexia module 24.

[d]QLQ-FA13: Quality of Life Questionnaire Cancer-related Fatigue 13.

Table 3. Psychological symptoms 1 year after oesophageal cancer surgery are presented as numbers, proportions, mean scores and 95% confidence intervals (CIs).

	Patients with psychological symptoms of concern		Patients with less psychological symptoms	
	Numbers (%)	Mean scores (95% CI)	Numbers (%)	Mean scores (95% CI)
ASC[a]				
Cancer worry	80 (28)	2.6 (2.5–2.7)	201 (72)	1.4 (1.3–1.5)
General health worry	62 (22)	2.7 (2.5–2.8)	219 (78)	1.4 (1.3–1.5)
HADS[b]				
Anxiety	31 (11)	10.8 (9.9–11.8)	250 (89)	2.0 (1.7–2.3)
Depression	33 (12)	9 (9–10)	248 (88)	2.2 (2.0–2.5)
IES-R[c]				
Post-traumatic stress[c]	48 (17)	36 (33–39)	233 (83)	7.6 (6.9–8.4)

[a]ASC: Assessment of Survivor Concerns where a score above 2 corresponds to perceived fear of recurrence and general health worry.
[b]HADS: Hospital Anxiety and Depression scale where ≥8 was used as a cut-off for clinically significant symptoms of anxiety or depression.
[c]IES-R: Impact of Events-Revised where ≥24 is of clinical concern of posttraumatic stress.

Table 4. Proportion of patients with sleep problems 1 year after oesophageal cancer surgery are presented as numbers and proportions ($n = 281$).

Karolinska Sleep Questionnaire	Numbers (%)
Sleep problems	144 (51)
Insomnia	115 (41)
Awakening	61 (22)
Apnoea/snoring	30 (11)
Sleepiness	51 (18)
Poor overall sleep quality	29 (10)

Patients who stated that the sleep-related disturbances occurred 'often', 'mostly' or 'always' were regarded as having sleep problems.

Psychological outcomes

Among the included patients, 29% ($n = 79$) reported worries about cancer recurrence (MS: 2.6, 95% CI: 2.5–2.7), and 22% ($n = 62$) were worried about their general health (MS: 2.7, 95% CI: 2.5–2.8) 1 year after surgery. For depression and anxiety, 12% ($n = 33$) (MS: 9, 95% CI: 9–10) and 11% ($n = 31$) (MS: 11, 95% CI: 10–12) reported clinically relevant problems, respectively. Symptoms of posttraumatic stress were found in 17% ($n = 48$) (MS: 36, 95% CI: 33–39) of the patients (Table 3).

Sleep

Half of the patients had sleep problems ($n = 144$, 51%). The most common sleep-related problem was insomnia, which was reported by 41% ($n = 115$) of the patients (Table 4).

Discussion

This study is based on, to the best of our knowledge, one of the most comprehensive data collections on less explored patient-reported outcomes in oesophageal cancer patients using a population-based design. Food intake, sleep, fatigue and anxiety were the most commonly reported problems 1 year after treatment. For patients with poor HRQL, many symptom scores were high. Some symptoms were less frequently reported, yet highly debilitating for the individual patient.

Methodological strengths of this study are the prospective, population-based and nationwide design, which counteracts information bias, selection bias and facilitates generalisability. Thanks to well-organised project coordination and personal contacts with participants prior to the inclusion the sample size is large and the questionnaire response rate is high which increased the precision and internal validity. All outcome measures were assessed with well-validated questionnaires, which reduced the risk of information bias. All patient-reported outcomes were collected on a computer with a research nurse at hand which reduced the risk of missing forms and responses. The major limitation of the study was the lack of a pre-operative assessment of patient-reported outcomes. However, using pre-operative data to measure recovery in HRQL entails inherent flaws because before treatment, patients' HRQL is typically seriously influenced by the disease and associated psychological factors. Another limitation is the number of patients who chose to decline participation. It might have been that participants were less ill than non-participants. In that case, a potential underestimation of reported problems could be the case. With the population-based design, the results should be fairly generalisable to similar populations in the Nordic countries at least.

Previous studies have shown that HRQL is deeply affected after oesophageal cancer [6,27], which is in line with results in the present study. New-onset problems associated with the respiratory system or alimentary tract following surgery as well as psychological sequelae after being exposed to a life-threatening disease are part of everyday life for many of these patients. For some, these problems may be long-lasting [9,10,28]. Some of the symptom scores in this study were alarmingly high, which implies a need for further investigation with clinical implications. Comorbidity, advanced tumour stage, tumour location and postoperative complications have been shown to predict worse HRQL, particularly in terms of dyspnoea, fatigue and eating restrictions [21,29,30]. Assumingly, patients with poorer HRQL could be those with worse prognosis. Especially, since fatigue has been found to be associated with poor survival in oesophageal cancer patients [31]. However, a recent study comparing HRQL in patients with malign versus benign oesophageal resection, found few differences in long-term HRQL outcomes. Surprisingly enough, patients with malign diseases reported better quality of life and fewer eating problems [32], which could possibly be a result of response shift [33].

Food intake is central in most peoples' lives and the surgery alters preconditions for eating and eating habits. Patients have to adapt to the new situation which may impact their HRQL. Nutritional problems are main concerns

for these patients and are most likely associated with prolonged recovery. To date, few studies have explored the relationship between nutritional status and functional outcomes for these patients and whether potential negative outcomes can be prevented. Nutritional problems may also lead to long-lasting cancer-related fatigue, a common symptom among cancer patients in general which entails physical and psychological morbidity [34,35]. Exercise has been shown to be effective in reducing this debilitating condition [36–38]. However, the endurance and frequency of exercise as well as timing in relation to therapy still needs to be determined. Another concern is regurgitation of stomach content, which may lead to nightly coughing and sleep disturbances. An association between gastro-oesophageal reflux and sleep problems has previously been shown for patients who suffer from gastro-oesophageal reflux disease [39,40]. However, if this pattern is similar for patients who have undergone oesophagectomy remains to be clarified and interventions to relieve the symptoms needs to be identified. We anticipate that data from this current cohort will prompt and guide research that may lead to strategies to improve the survivorship among surgically treated oesophageal cancer patients.

The findings of this study were discussed with our patient research partnership group which consists of oesophageal cancer survivors with a mixed background and at different stages post-operatively. They found the results promising and somewhat surprising. Although all patients had obtained a 'new' oesophagus less than half of them did not suffer from problems related to food intake. Yet, from their perspective, eating problems received a high priority for survivorship research. Moreover, fatigue and anxiety, other common symptoms reported by oesophageal cancer survivors in the current study, were also identified by them as key areas for future research. The partnership group also pointed out that more than one third of the patients found information provision insufficient, which should demand for a change in clinical practice. To include patients' perspectives on research findings enhances the clinical meaningfulness of the study. Still, it is important to bear in mind that the members of the group may not be fully representative of the whole patient cohort.

Today, personalised cancer medicine plays an increasingly important role with individualised, molecularly targeted therapies showing increased efficacy and reduced toxicity. Similar personalised treatment to improve functional recovery and minimise symptom severity would probably be beneficial for the individual patients post-surgery. Previous studies have shown that by using patient-reported outcomes with predefined cut-offs for symptom interventions in clinical practice, patients' survival and HRQL increased significantly [41–43]. A broader and deeper knowledge about the patients' outcome can guide personalised care, which in turn might enable tailored interventions in a timely way. This would have a strong and clear clinical significance for the patients, their closest family members, and health care providers.

In conclusion, this prospective and population-based Swedish cohort study with comprehensive data on a wide variety of patient-reported outcomes indicates that oesophageal cancer resection has significant negative impact on HRQL 1 year after surgery, and the most common problems are associated with food intake, fatigue, anxiety and sleep. However, less frequent symptoms are also debilitating for the individual patient. There is a need for further in-depth research on associations between nutritional aspects and other patient-reported outcomes in order to improve oesophageal cancer survivorship.

Author contributions

Conception and design: Anna Schandl, Asif Johar and Pernilla Lagergren. Collection and assembly of data: Kalle Mälberg, Karin Vikström, Poorna Anandavadivelan and Pernilla Lagergren. Data analysis: Asif Johar. Interpretation of results and manuscript writing: all authors. Final approval of manuscript: all authors

Disclosure statement

No potential conflict of interest was reported by the author(s).

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