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Utilising quality of life outcome trajectories to aid patient decision making in pelvic exenteration $\stackrel{\star}{\sim}$

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ABSTRACT

Background: Shared decision-making in pelvic exenteration is a complex and detailed process, which must balance clinical, oncological and patient-reported outcomes (PROs), whilst addressing and valuing the patient priorities. Communicating patient-centred information on quality of life (QoL) and functional outcomes is an essential component of this. The aim of this systematic review was to understand the impact of pelvic exenteration on QoL PROs over a longitudinal period and to develop QoL trajectories to support decision-making in this context.

Methods: MEDLINE, Embase and Web of Science databases were searched between 1st January 2000 and 20th December 2021 Studies reporting on PROs, including QoL, in adults undergoing pelvic exenteration were included. Risk of bias was assessed using the ROBINS-I assessment tool. Data from studies reporting QoL using the same outcome measure at the same candidate timepoint were extracted and synthesised to develop a longitudinal QoL trajectory.

Results: Fourteen studies consisting of 1370 patients were included in this review. QoL trajectories were constructed in the domains of physical function, psychological function, role function, sexual function, body image and general and specific symptoms. Decision-making was only assessed by one study, with satisfaction with decision-making reported to be high. There is an initial decline in QoL scores in the domains of physical function, role function, sexual function, body image and general health and symptoms deteriorating during the first 3–6 months post-operatively. Psychological function is the only QoL domain that remains stable throughout the post-operative period.

Conclusion: Mapping QoL trajectories provides a visual representation of post-operative progress, highlighting the enduring impact of pelvic exenteration on patients and can be used to inform pre-operative shared decision-making.

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1. Introduction

Pelvic exenteration is a life-changing operative procedure reserved for locally advanced and recurrent pelvic malignancy.

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https://doi.org/10.1016/j.ejso.2022.08.001 0748-7983/© 2022 Published by Elsevier Ltd. Decision-making in pelvic exenteration is complex as it takes into account technical and oncological considerations alongside patient priorities [1-5]. Patients requiring pelvic exenteration often have to make trade-offs between curative treatment, treatment-related morbidity, survival and quality of life [6,7]. Shared decisionmaking is an essential component of pre-operative decision-making for patients and clinicians, ensuring that the best evidence is applied to clinical decision-making, whilst ensuring the patients intentions, values and preferences are appropriately considered. The clinical and oncological impact of pelvic exenteration across

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the spectrum of advanced and recurrent pelvic malignancy is well documented in the current literature. The current evidence-base in pelvic exenteration is limited by its paucity of high-quality, longi-tudinal data on quality of life (QoL) and patient-reported outcomes [1,2].

Patients with advanced pelvic malignancy equally prioritise survival and OoL [7,8]. It is therefore essential that alongside clinical complexity. longer term implications on OoL and function, that are associated with pelvic exenteration are appropriately communicated to patients and reflected in the decision-making process. Understanding the QoL impact, its trajectory and recovery should be an essential part of the decision-making process for pelvic exenteration. Psychological preparedness and an in-depth understanding of the implications of major, exenterative surgery is associated with improved post-operative outcomes and appropriately manages patients' expectations [9,10]. High-quality, patientcentred information pre-operatively empowers patients to make decisions that reflect their own values and preferences and reduces decisional regret post-operatively [11]. The aim of this systematic review is to understand the impact of pelvic exenteration on QoL and PROs over a longitudinal period of time, through the construction of QoL trajectories, to help inform future surgical decision-making.

2. Material and methods

This systematic review was conducted according to a prespecified protocol based on guidance from the Centre for Reviews and Dissemination [12] and the Cochrane Handbook [13] and is reported in line with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement [14]. Our protocol was registered with the international, prospective register of systematic reviews, PROSPERO (CRD42022321244).

2.1. Eligibility criteria

All studies reporting on patient reported outcomes, including quality of life, in adults (>18 years old) undergoing pelvic exenteration with curative intent were eligible for inclusion. Studies were only included if they measured PROs over a longitudinal period of time, with more than one PRO assessment reported at a candidate timepoint. Studies reporting on multiple operative approaches were only included if the PRO data pertaining to pelvic exenteration was individually available. Systematic reviews, case reports and letters were excluded.

2.2. Search Strategy

The OVID SP versions of MEDLINE, Embase and Web of Science (1st January 2000–20th December 2021) were searched using the following search terms 'pelvic exenteration', 'quality of life', 'patient reported outcome measures' and 'shared decision-making' separated by the Boolean operator 'AND'. Reference lists of included articles were hand-searched to identify any additional studies. All citations were collated within EndNote X7.8®, USA and duplicates were removed. All relevant titles and abstracts were screened by two reviewers (DH and BG). The full text versions of potentially eligible abstracts were retrieved in full. Only studies that fulfilled all eligibility criteria were included. Any conflicts were resolved through discussion.

2.3. Data extraction

Data were extracted across three key areas: study design, clinical and QoL/PRO data. Data on study design included year of

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publication, years included, study design, QoL/PRO measure used, baseline QoL/PRO assessment and subsequent timings. Clinical data included patient demographics, type of pelvic malignancy, operative details including type and radicality of pelvic exenteration. QoL/PRO data extracted included summary scores from each PRO assessment at all time points.

2.4. Study quality

Methodological quality assessment of studies included in this review was undertaken using the 'Risk of Bias In Non-Randomised Studies of Intervention' (ROBINS-I) assessment tool [15] for nonrandomised studies and the Cochrane risk of bias tool for randomised controlled trials (RCTs).

2.5. Data analysis

The frequency of generic and disease-specific QOL instruments was reported. Due to the significant heterogeneity in QOL instruments, outcome time points and study characteristics, QOL outcomes were presented descriptively. Studies reporting QoL using the same outcome measure were synthesised to develop a longitudinal QoL trajectory by extracting collective QoL assessment scores at each candidate timepoint.

3. Results

Fourteen studies were included in this systematic review (Fig. 1) [16–29]: 11 prospective cohort studies. 1 prospective pilot cohort study and 3 retrospective cohort studies were identified. A total of 1370 patients were included across all studies, including, 263 (19.1%) patients with locally advanced rectal cancer, 358 (26.1%) with locally recurrent rectal cancer, 139 (10.1%) patients with gynaecological malignancy and 9 (0.6%) with urological malignancy. Two hundred and sixteen (15.7%) patients were labelled as primary or recurrent pelvic malignancy and 34 (2.4%) patients had rare advanced pelvic malignancies. The underlying diagnosis was unreported in 351 (25.6%) patients. QoL outcome data available was in 1017 (74.2%) patients. Four studies did not report any relevant clinical data, five studies reported clinical data for the total cohort of patients with no extractable data for patients with PRO data and 6 studies reported clinical and QoL data together. The primary outcome in 7 studies was QoL, PROs in 2 studies, physical activity in 1 study, sexual function in 1 study, clinical outcomes in 2 studies and survival combined with QoL in 1 study. Table 1 highlights relevant study detail and clinical data.

The risk of bias was high overall, with twelve studies identified as seriously or critically biased. The domains which demonstrated the highest degree of bias were confounding, missing data and participant selection (Supplementary material).

3.1. Outcome assessment

A total of 20 questionnaires were used across 14 studies to assess QoL and decision-making, with a combination of generic and disease-specific questionnaires (Supplementary material). Generic questionnaires assessing overall QoL included the EORTC QLQ-C30, Short Form-36 (SF36), Short Form12 (SF12), Short Form Six Dimension (SF6D) and Assessment of Quality of Life (AQoL). Questionnaires specifically assessing psychological function included the Distress Thermometer Score and Centre for Epidemiologic Studies - Depression Scale. Sexual function was assessed using the validated Sexual Activity Questionnaire and a studyspecific sexual activity questionnaire. Pain was assessed using the validated Brief Pain Inventory and three study-specific pain

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Fig. 1. Search strategy.

questionnaires. The EORTC QLQ-OV28 was used to assess symptoms in patients with gynaecological malignancy and the FACT-C questionnaire was used to assess symptoms in patients with locally advanced and recurrent rectal cancer. Generic symptoms were assessed using the MD Anderson Symptom Inventory. Body image was assessed using the validated Body Image Scale. Stomarelated QoL of was assessed using the Stoma-QoL questionnaire. Social support was assessed using the Duke-UNC Functional Social Support questionnaire. Decision-making was assessed using the Satisfaction with Decision Scale and a study-specific patient decision-making questionnaire.

Thirteen studies collected baseline QoL scores, with only one study collecting longitudinal post-operative QoL data without baseline pre-operative data. There was some variation in the collection of early post-operative data, with one study reporting outcomes at 2 weeks post-operatively, 3 studies reporting outcomes at 1 month and 1 study reporting outcomes at 6 weeks. Short-term outcomes were collected at 3 months by 6 studies, at 6 months by 10 studies, at 9 months by 2 studies and at 12 months by 11 studies. Longer-term QoL data is limited with only three studies reporting QoL outcomes beyond two years.

3.2. Decision-making

Ambruster et al., were the only authors, to report on decisionmaking using the Satisfaction with Decision Scale and a studyspecific questionnaire in 28 female patients undergoing pelvic exenteration for locally advanced gynaecological malignancy [18]. Patients reported high scores of satisfaction on the Satisfaction with Decision Scale with the decision to undergo pelvic exenteration, with stable scores observed at 6 and 12 months post-operatively. The study-specific questionnaire assessed decisional regret and reported only 1 out of a total cohort of 33 patients regretted their decision of undergoing a pelvic exenteration.

3.3. QoL outcomes

Several QoL domains were used to report longitudinal trajectories in patients undergoing pelvic exenteration. These domains were summarised into the following categories; physical function (physical, physical functioning, physical function, physical component summary), psychological function (mental health, mental component score, distress, psychological, emotional functioning), role function (role function, social support, social functioning, role functioning), sexual function (sexual pleasure, discomfort and habit, influence of surgery on sexual life, influence of surgery on relationship with partners), body image, pain, general health and symptoms (general health, general health and global QoL, general and specific symptoms i.e. fatigue, insomnia, constipation, diarrhoea, abdominal complaints, nausea/vomiting, loss of appetite, dyspnoea, peripheral neuropathy). QoL outcomes across all studies are extracted and presented in the supplementary material.

3.3.1. Physical function

Physical function is defined as 'the ability to carry out various activities that require physical capability, ranging from self-care, including basic activities of daily living, to more vigorous activities that require increasing degrees of mobility, strength or endurance' [30]. Physical function was reported using the SF-36 physical function domain in 727 patients across 8 studies [16,18,20,21,24,25,31,32] and the EORTC QLQ-C30 physical functioning domain in 187 patients across 4 studies [26–29] (Fig. 2a and 2b). All studies demonstrated a general decline in physical function post-operatively for a period of up to 6 months, followed by gradual recovery. The magnitude of decline in physical function is clinically significant, irrespective of the questionnaire used. Generally, function did not return to baseline, pre-operative activity across all studies. Physical function scores stabilise by 12 months post-operatively and were maintained at this level.

3.3.2. Psychological function

Psychological Functioning is defined as 'the ability to achieve his or her goals within him or herself and the external environment. It includes an individual's behaviour, emotion, social skills, and overall mental health' [33]. Psychological function was reported using the SF36 Mental Component summary in 727 patients across 8 studies [16,18–21,24,25,31] (Fig. 3a). The majority of studies using this measure demonstrated stability of psychological function

Table 1

4

Patient and clinical characteristics.

Author	Year Years Included	d Country	Study Design	No of Patients	No of Patients with QoI Data	Primary outcome	Disease Group	Gender M:F	Median Age	Neoadjuvant Treatment	Operative Details
van Ramshorst	^a 2020 2003–2016	Australia	Prospective Cohort	87	58	Flap related morbidity	Primary Rectal Cancer –24 Recurrent Rectal Cancer –30 Recurrent SCC - 26 Prostate - 3 Sarcoma 1 Basal Cell	49:38	60	Chemotherapy - 37 Radiotherapy - 35	Neovaginal reconstruction - 13/38 Ileal conduit 53/87
Steffens	2019 2016-2017	Australia	Prospective Pilot	16	16	Physical	Primary and recurrent	10:6	54	_	_
Armbruster ^a	2018 2009–2017	USA	Prospective Cohort	54	43	Activity	Cervical cancer - 22 Uterine - 12 Vaginal – 9 Vulval – 9 Ovarian - 1	0: 54	56	_	Total Exenteration -41 Anterior Exenteration -6 Posterior Exenteration -4 Neovaginal Reconstruction -34
Young	2014 2008–2011	Australia	Prospective Cohort	148	148	QoL	Primary rectal cancer - 36 Recurrent rectal cancer - 75 Other primary pelvic malignancy - 11 Other recurrent pelvic malignancy - 26	93: 55	60	_	_
Coker	2020 2008-2011	Australia	Prospective Cohort	42	42	PROs	Primary cancer - 28 Recurrent - 14	26: 16	60	-	-
Choy ^a	2015 2008–2013	Australia	Prospective Cohort	93	77	QoL	Recurrent Rectal Cancer - 77	61:16	61	_	Pelvic exenteration + en bloc bony resection -62 Pelvic exenteration + excision major sacral nerve 40
Quyn ^a	2016 1994–2014	Australia	Prospective Cohort	104	64	Survival and QoL	Primary Rectal Cancer- 64	_	_	-	- 39 Ileal conduit - 41 Bony resection - 35
Esnaola**	2002 1999–2000	USA	Prospective Cohort	30	30	QoL	Recurrent Rectal Cancer - 30	11:19	61	-	Anterior Exenteration - 22 Total Pelvic Exenteration - 8
Brown ^a	2021 1994–2018	Australia	Prospective Cohort	68	40	Clinical	Primary Rectal Cancer - 5, Recurrent rectal cancer - 27 Re-recurrent rectal cancer - 6 Other primary pelvic malignancy - 11 Recurrent pelvic malignancy - 19	Male 35 Female 33	56	Radiotherapy - 21	Pelvic exenteration + en bloc bony resection -38 Pelvic exenteration + excision major sacral nerve - 68 Ileal conduit -19
Steffens**	2018 1994–2016	Australia	Prospective Cohort	515		Survival and QoL	Primary Rectal Cancer – 77 Recurrent Colorectal Cancer- 119 Advanced Primary – 41 Recurrent other - 50	176:111	59	Radiotherapy — 15 Chemotherapy — 23 Chemoradiotherapy - 128	Total Pelvic Exenteration - 145 Partial Exenteration - 139

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Anterior Pelvic Exenteration – 31 Posterior Pelvic Exenteration – 5 Total Pelvic Exenteration – 25 Neovagina reconstruction - 17	I	I		1		
1	Regime unknown - 23	Radiotherapy – 7		I		
60	64	62		60		QoL data.
1, 97	19:37	2:7	L	y 0:25		itients with
Vaginal/cervical cancer - 5 Uterine cancer – 9 Other gynaecological malignancy - 1	Primary Rectal Cancer	Cervical cancer – 6	Primary rectal cancer 1 GIS - 2	Gynaecological malignanc	– 19 Bladder cancer - 6	**Clinical data reported for pa
QoL	QoL	QoL		QoL		porting QoL
	56	8		25		or patients re
Prospective Cohort 97	Prospective Cohort 56	Retrospective Cohort 9		Retrospective Cohort 25	2	extractable clinical data available fi
France	UK	China		The	INELIIEIIIII	ort with no
2018 2008-2009	2015 2011-2012	2014 2002-2013		2004 1989–1999		reported for entire coh
Martinez**	Radwan**	Hsu **		Roos		^a Clinical data

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throughout the post-operative period. Van Ramshorst was the only study to report psychological function according to complication profile; demonstrating higher scores and improved QoL trajectories in those without complications compared to those with complications [16].

Four studies employed the EORTC QLQ-C30, reporting mixed results in 187 patients, with two studies observing higher psychological scores in the post-operative period indicative of improved psychological function (Fig. 3b) [26–29]. Radwan et al. observed an initial decline in post-operative psychological function two weeks post-operatively, with an improvement to scores to baseline and beyond by three months [27]. Roos et al. observed long-term stability in psychological function in 25 women undergoing pelvic exenteration for gynaecological or urological malignancy [29].

Steffens et al. measured distress in 16 patients and reported stability in this domain throughout the early post-operative period [31]. Armbruster et al. measured the prevalence of depression in 54 women undergoing pelvic exenteration for advanced and recurrent gynaecological malignancy using the Centre for Epidemiologic Studies - Depression Scale [18]. This study reported low prevalence of post-operative depression with stable scores observed throughout the first post-operative year.

3.3.3. Role function

Role function is defined 'as involvement in life situations related to family life, partner relationship, household chores, work for pay, studies, social life (including interactions with friends), leisure time activities, community involvement (including volunteer work) and everyday living activities' [34]. Four studies reported this aspect of QoL using the EORTC QLQ-C30 role functioning domain in 187 patients (Fig. 4a) [26–29]. Both Martinez et al. and Radwan et al. observed a clinically significant decrease in role functioning within the first month post-operatively, with gradual recovery towards baseline at 3–6 months [26,27]. Roos et al. reported on longer term outcomes from a baseline of 24 months post-operatively to 120 months; reporting a steady decline in role functioning over this timeframe [29].

Van Ramshorst captured the social aspect of this HrQoL domain using the SF36 social functioning domain in 58 patients, reporting gradual improvement in social functioning scores from baseline of 47.7–72.7 at 18 months post-operatively [35]. Four studies assessed social functioning using the EORTC QLQ-C30 questionnaire in 187 patients [26–29], with Martinez et al. and Radwan et al. reporting an initial decline in social functioning within the first month postoperatively, with gradual recovery of HrQoL scores at 3 months (Fig. 4b). Hsu et al. support this observation, with much higher social functioning HrQoL scores observed at 3 months postoperatively when compared to baseline scores.

Armbruster et al. assessed the social support systems of 43 female patients with advanced gynaecological malignancy using the Duke-UNC Functional Social Support Scale [18]. They reported stable scores and perceptions of support throughout the postoperative period.

3.3.4. Sexual function

Sexual functioning is defined by the 'absence of difficulty moving through the stages of sexual desire, arousal, and orgasm, as well as subjective satisfaction with the frequency and outcome of individual and partnered sexual behaviour' [36]. Armbruster et al. reported sexual function in 43 women undergoing pelvic exenteration [18]. There was a decline in post-operative scores in the domains of sexual pleasure, discomfort and habit. Roos et al. used the EORTC OV28 to assess sexual function in 32 women undergoing pelvic exenteration, reporting a reduction in long-term sexual



a: SF-36 Physical Function QoL Trajectory

Fig. 2a. SF-36 physical function QoL trajectory.



b: EORTC QLQ-C30 Physical Function Domain QoL Trajectory

Fig. 2b. EORTC QLQ-C30 physical function domain QoL trajectory.

activity [29]. The influence of surgery on long-term (>2years postoperatively) sexual activity and on relationships with partners remained static.

3.3.5. Body image

Body image is defined as 'the assessment of both positive and negative emotion for one's own body parts and their characteristics by himself or herself [37]. Body image was assessed by two studies using the Body Image Scale or the EORTC OV28 in 140 patients. Martinez et al. reported an initial worsening in body image scores as measured by the EORTC OV28 in the initial postoperative period (1–3 months) with a gradual return to baseline scores at 6 months in 97 women [26]. In contrast, Armbruster et al. reported significantly poor baseline scores of body image in 43 women undergoing pelvic exenteration for gynaecological malignancy as measured by the Body Image Scale [18]. However, these scores, and overall body image improved significantly at 6 months post-operatively.



a: SF-36 Mental Component QoL Trajectory

Fig. 3a. SF-36 mental component QoL trajectory.



b: EORTC QLQ-C30 Emotional Function QoL Trajectory

Fig. 3b. EORTC QLQ-C30 emotional function QoL trajectory.

3.3.6. Pain

Pain was assessed in 480 patients using a multitude of pain domains across several different PROMS, including three studyspecific measures, the SF-36 Bodily Pain scale, the Brief Pain Inventory and the EORTC QLQ-C30 Pain Scale. Van Ramshorst reported improved pain scores in the first 12 months post-operatively using the SF-36 Bodily Pain subscale [16]. Esnaola et al. reported moderate pain in the first 6 months post-operatively using the Brief Pain Inventory [23]. Four studies reported pain using the EORTC QLQ-C30 pain scale in 187 patients (Fig. 5), with Radwan et al. reporting increased pain scores in the initial post-operative period with a return to baseline scores at 6 months [27]. Martinez et al. reported relatively static pain scores in the first 12 months post-operatively [26]. Hsu et al. reported a reduction in pain scores from baseline at 3 months post-operatively [28].

3.3.7. General health and symptoms

Four studies reported global health perception using the EORTC QLQ-30 in 187 patients, reporting an initial decline in General Health and Global QoL in the immediate post-operative period,

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with a consistent improvement in long-term scores postoperatively (Fig. 6) [26–29]. Van Ramshorst et al. reported higher scores of general health perceptions over a 12-month period using SF36 in patients with a post-operative complication [16]. In contrast, patients who did not experience any post-operative complications reported a decline in general health over the same timeframe.

Armbruster et al. reported general symptoms using the MD Anderson Symptom Inventory in 43 patients undergoing pelvic exenteration for gynaecological malignancy, reporting increased symptom severity and interference at 6 months post-operatively, with some improvement at 12 months [18]. Both physical and psychological symptoms were higher at 6 months than at baseline, with some improvement observed at 12 months.

Generic gastrointestinal symptoms of nausea, loss of appetite, constipation and diarrhoea were reported in 187 patients by four studies using the EORTC QLQ-C30 [26]. The trajectory of scores followed a similar pattern across all studies, with an initial deterioration and higher symptom score in the immediate post-operative followed by improvement over a 12–24-month period. Fatigue generally worsened in the first 3 months post-operatively, with a gradual return to baseline at 12 months. Symptoms of insomnia were heightened at baseline and improved gradually over a 12-month period. Colorectal specific symptoms were reported by seven studies using the FACT-C questionnaire in 611 patients [17,19–21,23–25]. These studies demonstrated an initial decline in symptoms in the first 3 months post-operatively, with recovery of scores by 6 months and an eventual return to baseline (Fig. 7).

4. Discussion

Pelvic exenteration has a wide-ranging impact on patients' overall QoL and recovery. Overall, there is an initial decline in all aspects of QoL, with the domains of physical function, role function, sexual function, body image and general health and symptoms deteriorating during the first 3–6 months post-operatively. Psychological function is the only QoL domain that remains stable throughout the post-operative period. The enduring impact of

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pelvic exenteration on all domains of QoL can be up to 12–24 months.

Mapping QoL trajectories provides a pictorial roadmap of postoperative progress from a patient perspective and can be used to inform pre-operative shared decision-making. Visual representation of OoL is considered to be valuable and relatively easy to interpret from a patient perspective, which enhances its utility [38–40]. Patients undergoing pelvic exenteration often report the need for pre-operative preparedness, with information needs regarding treatment outcomes, recovery and lifestyle adjustment and impact on QoL. Survivors of pelvic exenteration report the persistent physical, psychological and social effects of surgery, with a need to improve pre-operative counselling and patient-level education [9,41]. Our systematic review consolidates the current literature across several disease groups to address these key patient priorities. Providing high quality information which aligns with patient priorities, has the potential to reduce post-operative uncertainty, improves patient satisfaction by addressing their expectations appropriately and aids decision-making.

There is a significant burden of symptoms in patients undergoing pelvic exenteration in the post-operative period, with an increase in symptom severity and interference in the early postoperative period. General health symptoms of fatigue, insomnia and loss of appetite worsen in the post-operative period for up to 12-24 months. System specific symptoms, e.g. colorectal symptoms, also deteriorate in the first 6 months post-operatively. High symptom burden is common in patients undergoing surgery for advanced and recurrent pelvic malignancy, with new or ongoing symptoms reported in up to a third of patients [42]. This is of particular importance given the high post-operative morbidity associated with pelvic exenteration, which will manifest clinically as new post-operative symptoms. The impact of symptoms due to post-operative complications was reported by Van Ramshorst with a significant QoL impact on a number of SF-36 domains, including, role physical, role emotional and mental health component summary, for a period of up to 12 months [16]. Interestingly, general health perception scores improved in patients with major postoperative complications compared to patients without



a: EORTC QLQ-C30 Role Function QoL Trajectory

Fig. 4a. EORTC QLQ-C30 role function QoL trajectory.

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b: EORTC QLQ-C30 Social Function QoL Trajectory

Fig. 4b. EORTC QLQ-C30 social function QoL trajectory.



Fig. 5. EORTC QLQ-C30 pain QoL trajectory.

complications over the first year post-operatively. This is likely to coincide with improvements in symptoms and recovery of post-operative complications. Patients with ongoing or worsening symptoms tend to express decisional regret, with a lack of satisfaction expressed with the treatment decision of undergoing pelvic exenteration [9,43]. It is therefore essential that patients are appropriately counselled in the pre-operative setting with regards to their risk of post-operative morbidity, the development of new symptoms, the impact of this on QoL and the enduring length of time of this impact.

The broad impact of pelvic exenteration on general health,

physical, psychological and role function is well documented. However, there is limited information regarding the impact of pelvic exenteration on sexual function and body image, particularly in male patients. Our review reported the impact of sexual function, including activity and interest declined in the post-operative period in 75 women undergoing pelvic exenteration for gynaecological malignancy. In comparison, body image scores declined in the immediate post-operative period and improved at 6 months postoperatively, following a period of adjustment. The majority of the literature regarding sexual function and body image is restricted to women with advanced or recurrent gynaecological malignancy,



Fig. 6. EORTC QLQ-C30 general health and global QoL trajectory.

which supports our observation of significant decline in sexual function and body image, with the decline correlating with the extent of surgery [44,45]. There is very little evidence of the extent of sexual dysfunction in male patients following exenterative surgery, with the current data limited to cross-sectional studies in small sample sizes [46,47]. Further work is required to understand the impact of pelvic exenteration on sexual function and body image in a larger cohort of men and women, with a range of pelvic malignancies over a longitudinal period.

There is a paucity of high-quality information to aid shared decision-making with patients undergoing pelvic exenteration [48], with the quality of decision-making sparsely reported.

Armbruster et al. was the only study to report satisfaction with decision-making in female patients undergoing pelvic exenteration for locally advanced gynaecological malignancy, reporting high and stable scores of satisfaction over a 12 month period [18]. Qualitative studies in pelvic exenteration survivors report some dissatisfaction with decision-making, due to a lack of psychological preparedness [41]. The process of pre-operative shared-decision-making needs to be well informed and robustly documented with appropriate reporting of satisfaction and decisional regret. Understanding the incidence of decisional regret and its impact on QoL in patients undergoing pelvic exenteration will lead to improved pre-operative counselling with a greater emphasis on shared-decision making



Fig. 7. FACT-C QoL trajectory.

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and improving decisional conflict.

Key limitations of this systematic review include the heterogenous patient population across a range of diseases using a range of outcome measures. The majority of patients included in this review had a diagnosis of locally advanced rectal cancer (n = 263, 19.1%) or locally recurrent rectal cancer (n = 358, 26.1%), with a limited number of patients with a gynaecological (n = 139, 10.1%) or urological malignancy (n = 9, 0.6%). It is uncertain whether all disease groups undergoing pelvic exenteration surgery have similar QoL trajectories, consequently, further work is required in identifying disease specific QoL trajectories in subgroups undergoing pelvic exenteration. Furthermore, the QoL trajectories extracted collated outcomes in a variable number of patients due to the multitude of questionnaires used at variable time points, which may have impacted the synthesis of our QoL trajectories and may lead to an element of reporting bias. To ensure the generalisability of QoL reported for patients requiring pelvic exenteration requires uniform assessment of important patient-centred metrics using the same disease-specific outcome assessment measure across all studies. Consistency in QoL assessment measurement in this cohort of patients is the only way that a meaningful volume of patientcentred data will be collected, akin to the PelvEx collaborative clinical studies [49,50], and will inform and guide shared decisionmaking practices in this complex cohort of patients. Finally, it is important to note that eight cohort studies included all provided QoL data from the same exenterative unit, with potentially overlapping study cohorts and times, and therefore it is possible, that some patients may have their QoL assessment measure duplicated.

5. Conclusion

Decision-making in pelvic exenteration for advanced malignancy is complex and requires a dual focus on survival and quality of life to appropriate reflect patient priorities. Our systematic review synthesises existing QoL data into trajectories to highlight the longer-term impact of pelvic exenteration beyond traditional clinical metrics, which can help guide decision making in this setting.

Declaration of competing interest

The authors have no competing interests to declare, no financial support was required for this study.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejso.2022.08.001.

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