Patient-Reported Bladder, Bowel, and Sexual Function After Cauda Equina Syndrome Secondary to a Herniated Lumbar Intervertebral Disc

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Background: Cauda equina syndrome (CES) is rare neurosurgical emergency requiring emergent surgical decompression to prevent bladder, bowel, and sexual dysfunction that can have significant impact on quality of life. There is a paucity of data relating to the prevalence of these long-term complications. **Objective:** The aim of this observational study was to evaluate the long-term prevalence of CES-related bladder, bowel, and sexual dysfunction and impact on quality of life to inform service provision. **Methods:** Participants were selected through coding of operative records of patients who underwent lumbar decompression for CES secondary to a herniated intervertebral disc at two large UK neurosurgical departments between 2011 and 2015 inclusive. A telephone-based survey including both validated and modified tools was used to collect data pertaining to bladder, bowel, and sexual function and impact on quality of life both before development of CES and at the time of the survey, at least 1 year postoperatively. **Results:** Of 135 patients contacted, 71 (42 male, 29 female) responded. Post-CES compared to pre-CES, there was higher prevalence and significant intrasubject deterioration of bowel dysfunction, bladder dysfunction, perception of bladder function, sexual function, effect of back pain on sex life, and activities of daily living/quality of life ($p < .0001$ for all). Significant differences in individual questions pre-CES versus post-CES were also found. **Conclusion:** We show high prevalence of long-term bowel, bladder, and sexual dysfunction post-CES, with functional and psychosocial consequences. Our results demonstrate the need for preoperative information and subsequent screening and long-term multidisciplinary support for these complications. **Key words:** back pain, cauda equina syndrome, quality of life, sexual function, sphincter dysfunction

Introduction

Cauda equina syndrome (CES) is a clinical diagnosis supported by radiological evidence of compression of the cauda equina causing loss of sensation of the saddle area, bladder and bowel dysfunction, and/or sexual dysfunction. The most common cause of CES in adults under age 50 is a herniated intervertebral disc. Early discectomy with the aim of preserving or preventing deterioration of lower limb and bladder and bowel function is the accepted standard of care for CES. Although debate exists regarding the exact timing and technique of surgery, there is now substantial evidence that decompression within 48 hours yields significantly better outcomes than decompression after 48 hours.¹⁻⁴

Bladder, bowel, and sexual dysfunction are important complications of CES and can have

widespread impact on activities of daily living (ADLs), quality of life, and psychological health. Moreover, the demographics of CES secondary to lumbar disk herniation include a significant population of young, healthy people.⁵ This population is impacted the most by the psychosocio-sexual dysfunction. Young age has been correlated with increased risk of sexual dysfunction.⁶

Other than prevention of deterioration in bladder and bowel function, which is a key indication for surgery, little is known about patient-reported outcomes regarding bladder, bowel, and sexual function following CES. Furthermore, data regarding the long-term effects of CES have important medico-legal and economic implications. The UK National Health Service paid out £2,541,098 in CES-related claims over 5 years.⁷

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Top Spinal Cord Inj Rehabil 2020;26(4):290-303
© 2020 American Spinal Injury Association
www.asia-spinalinjury.org
doi: 10.46292/sci19-00065

Uro-neurology and sexual function services are rarely linked directly with neurosurgery units, but when they are, referral of patients can lead to specialized multidisciplinary input and support in the form of education, support groups, physiotherapy, occupational therapy, and management of symptoms.

The aim of this study was to establish the prevalence and quality of life burden of bladder, bowel, and sexual dysfunction among patients treated for CES. We are not seeking to stratify patients' risk and prognosis based on preoperative status, time to surgery, or other factors but rather to examine the need for joined-up, multidisciplinary services and to inform service development to ensure CES patients are appropriately screened for bladder, bowel, and sexual dysfunction and referred.

Materials and Methods

Patients were identified through coding of electronic operation records of patients who underwent lumbar decompression for CES secondary to a radiologically confirmed herniated intervertebral disc between 2011 and 2015 inclusive at two major academic hospitals in London. The epoch of 2011-2015 was selected to identify 100 to 200 patients at least 1 year postoperatively at the time of the survey. In the case of death, missing or incorrect contact details, age under 18 years, or unwillingness to participate, a patient was considered ineligible. Patients were telephoned a maximum of three times and invited to participate in the service evaluation. Verbal informed consent was obtained from all individual participants included in the study. The study was approved by the local audit committees.

A combination of validated and modified questionnaires were used, including the Modified Wexner Constipation Questionnaire,⁸ Bristol Female Lower Urinary Tract Symptoms Questionnaire (for both genders),⁹ patient perception of bladder condition (PPBC),¹⁰ Modified Pelvic Organ Prolapse/Urinary Incontinence Sexual Questionnaire (mPISQ-12),¹¹ EQ-5D-5L Index,¹² modified International Index of Erectile Function Questionnaire (mIIEF),¹³ and effect of back pain on sex life (see **Appendix A** for full questionnaires). Originals were modified to

prevent asking nonrelevant but sensitive questions that may confuse patients and to include other relevant information. The patients were asked to answer the questions retrospectively with reference to their baseline function in the months preceding their CES and then the same questions again with reference to the present time, which would represent at least 1 year postoperatively.

Data were collected anonymously in Excel 2016 (Microsoft) and analyzed in Prism 7 (GraphPad). The D'Agostino-Pearson test showed non-normality of the data, and differences in pre- and postoperative scores were analyzed with the Wilcoxon matched pairs signed-rank test. The effect of back pain on sex life was analyzed with Fisher's exact test (**Table 1**). Percentages of patients reporting symptoms were also calculated. The EQ-5D-5L Crosswalk Index Value Calculator was used to calculate the EQ-5D-5L Index.¹²

Results

A total of 135 patients were contacted, and 71 (53%) responded; 64 (47%) did not answer the telephone call. All 71 respondents (42 males, 29 females) were willing to participate and were included in the final analysis.

Modified Wexner Constipation Questionnaire

Patients on average reported no bowel problems before CES (pre-CES median total score: 0); post-CES there was a significant increase in average total ($p < .0001$) and all individual ($p < .05$) scores (**Table 1**, **Figure 1a**), especially loss of anal sensation, feeling of incomplete evacuation, duration of evacuation attempts, and use of laxatives, enemas, or digital evacuation ($p < .001$).

The proportion of patients experiencing each symptom increased (**Table 2**), notably fecal incontinence (2.8% pre-CES; 12.7% post-CES) and need for laxatives or digital evacuation (2.8% pre-CES; 29.6% post-CES).

Bristol Female Lower Urinary Tract Symptoms Questionnaire

Patients on average reported no urinary problems before CES (pre-CES median total score: 0); post-CES there was a significant increase in

average total ($p < .0001$) and 18 of the 19 individual ($p < .05$) scores (Table 1, Figure 1b), especially frequency of urgency, frequency of urination, intermittent stream, urge incontinence, incontinence while active, frequency of incontinence, and degree of interference with life ($p < .0001$).

The proportion of patients experiencing each symptom increased (Table 2), notably urinary incontinence (9.9% pre-CES; 38% post-CES) and urgency (14.4% pre-CES; 48.6% post-CES).

Patient perception of bladder condition (PPBC)

The average score worsened from pre-CES (mean: 0.2, median: 0.0) to post-CES (mean: 1.3, median: 1.0) ($p < .0001$) (Figure 1c). The proportion of patients reporting that they had a bladder problem increased from 11.8% pre-CES to 55.8% post-CES.

Modified Pelvic Organ Prolapse/Urinary Incontinence Sexual Questionnaire (mPISQ-12)

Post-CES there was a significant increase in average total ($p < .0001$) and three of the five individual ($p < .05$) scores (Table 1, Figure 1d), including sensory changes, frequency of climax, and pain during intercourse.

The proportion of patients experiencing each symptom increased (Table 2), notably genital sensory changes (4.3% pre-CES; 47.8% post-CES) and pain during sex (8.7% pre-CES; 34.8% post-CES).

Modified International Index of Erectile Function Questionnaire (mIIEF)

Post-CES there was a significant increase in average total ($p < .0001$) and seven of the nine individual ($p < .05$) scores (Table 1, Figure 1e), especially deteriorations in frequency of erections, ability to maintain

Figure 1. (a) Total Modified Wexner Constipation Questionnaire score. Reported bowel dysfunction was statistically higher post cauda equina syndrome (CES) vs pre-CES as measured by the Modified Wexner Constipation Questionnaire ($p < .0001$). (b) Total Bristol Female Lower Urinary Tract Symptoms Questionnaire score (both genders). Reported lower urinary tract symptoms and impact on quality of life was statistically higher post-CES vs pre-CES as measured by the Bristol Female Lower Urinary Tract Symptoms Questionnaire ($p < .0001$). (c) Patient perception of bladder condition (PPBC). Participants reported more “problems” with their bladder post-CES compared to pre-CES as measured by the PPBC ($p < .0001$). (d) Total Modified Pelvic Organ Prolapse/Urinary Incontinence Sexual Questionnaire (PISQ-12) score (females). Reported sexual function and impact on sex life was statistically higher post-CES vs pre-CES as measured by the modified PISQ-12 Questionnaire ($p < .0001$). (e) Modified International Index of Erectile Function Questionnaire (IIEF). Reported sexual function and impact on sex life was statistically higher post-CES vs pre-CES as measured by the modified IIEF score ($p < .0001$). (f) EQ-5D-5L Index. Participants experienced more problems with mobility, self-care, usual activities, pain/discomfort, and anxiety/depression post-CES vs pre-CES indicated by a lower EQ-5D-5L Indices ($p < .0001$).

erections, reduced frequency of intercourse attempts, and satisfaction with sex life ($p < .0005$).

The proportion of patients experiencing each symptom increased (**Table 2**), notably difficulty maintaining erection (10% pre-CES; 47.5% post-CES) and dissatisfaction with their sex life (7.4% pre-CES; 36.6% post-CES).

Effect of back pain on sex life

Six of 60 participants (10%) reported that back pain affected their sex lives pre-CES versus 27 of 60 (45%) post-CES. This difference was statistically significant ($p < .0001$).

EQ-5D-5L Index

The median index decreased (1.0 pre-CES; 0.6 post-CES; $p < .0001$) indicating worse ADLs and quality of life (**Figure 1f**). Proportion of patients reporting problems with walking, washing and dressing, activities, pain, and anxiety or depression increased between 14.3% and 22.9%.

Discussion

A limited number of previous studies have reported a prevalence of micturition, defecation, and sexual dysfunction ranging from 33% to 60%.^{1,6,14-16} A 2013 systematic review of 15 studies suggests that this dysfunction occurs in 45% to 50% of patients, but this is limited by the heterogeneity and small scale of the studies included.¹⁵ A retrospective case notes analysis of micturition, defecation, and sexual function post-CES in 75 patients demonstrated more than 50% with deficits at a mean of 2 months.¹⁶ However, there are scant data on long-term outcome beyond 1 year.

The key finding of our study is a significantly high prevalence of bowel, bladder, and sexual dysfunction, corroborating with previous studies. With patients in our study between 1 year and 6 years post-CES, our data suggest that symptoms persist beyond the limited follow-up time of other studies and current services. We compared patients before and after CES and are able to illustrate the physical, functional, and psychosocial decline of all these individual aspects due to CES, saliently in a typically young, active population.

The communication skill set of neurosurgeons regarding bladder, bowel, and sexual function is an important area to explore as neurosurgeons represent the first point of contact in the postoperative period. A survey of Dutch neurosurgeons assessed that one-third of their patients had spinal-related sexual dysfunction, but almost 75% of surgeons declined to discuss it with the patients despite believing they had a responsibility to do so. Reasons cited included the patients being “too old,” not knowing how to address the topic, patients did not take the initiative to broach the topic themselves, and lack of time. Despite this, half of respondents wished to gain experience in communicating with patients about the topic.¹⁷ Consistent with this, our study demonstrates significant prevalence of sexual dysfunction among patients post-CES across all ages and therefore highlights the importance of such discussion with patients. The lack of preoperative discussion regarding micturition, defecation, and sexual function has also been acknowledged in a study by Korse et al, in which two-thirds of patients wished for more information regarding bladder, bowel, and sexual function to gain a realistic idea of these long-term complications.⁶ The consent process for surgery includes the prevention of bladder and bowel function deterioration as an aim of surgery and typically emphasizes that, despite surgery, dysfunction may progress or fail to improve to baseline. There may be a role for patient information leaflets to explain this further and provide a patient narrative of what one may expect postoperatively.

Screening all patients for bladder, bowel, and sexual dysfunction may be an option given the high prevalence, the communication barriers, and the potential for patients to fall between the cracks in the absence of a united service infrastructure for post-CES dysfunction. Screening using validated structured questionnaires is fast, inexpensive, and reduces the likelihood of clinician or patient embarrassment leading to nonreporting. Our study illustrates how this approach can be used as a simple tool to detect bladder, bowel, and sexual dysfunction and its impact on CES patients. Factors that informed the use of questionnaires in our study were published validation, intersubject reliability, inclusion of questions pertaining to impact on

Table 1. Mean, median, and differences in scores pre and post cauda equina syndrome (CES)

Variables analyzed	Test	n	Mean		Median		p value	Significance
			Pre	Post	Pre	Post		
Modified Wexner Questionnaire								
Frequency of bowel movements	Wilcoxon matched pairs	71	0.155	0.296	0.0	0.0	.0150	*
Pain perievacuation	Wilcoxon matched pairs	71	0.127	0.662	0.0	0.0	.0034	**
Feeling of incomplete evacuation	Wilcoxon matched pairs	71	0.329	1.129	0.0	0.0	.0002	***
Abdominal pain	Wilcoxon matched pairs	71	0.254	0.718	0.0	0.0	.0010	**
Duration spent on lavatory	Wilcoxon matched pairs	71	0.282	0.859	0.0	0.0	.0008	***
Evacuation assistance	Wilcoxon matched pairs	71	0.042	0.437	0.0	0.0	< .0001	***
Lavatory revisits	Wilcoxon matched pairs	71	0.099	0.409	0.0	0.0	.0010	***
Loss of anal sensation	Wilcoxon matched pairs	71	0.113	0.789	0.0	0.0	.0006	***
Leaking of stool	Wilcoxon matched pairs	71	0.056	0.310	0.0	0.0	.0348	*
Total Modified Wexner Score (out of 34)	Wilcoxon matched pairs	71	1.471	5.329	0.0	3.5	< .0001	***
Bristol Questionnaire								
Nocturnal urination	Wilcoxon matched pairs	71	0.704	1.254	0.0	1.0	.0003	***
Urgency	Wilcoxon matched pairs	70	0.300	1.100	0.0	1.0	< .0001	***
Bladder pain	Wilcoxon matched pairs	71	0.056	0.437	0.0	0.0	.0024	**
Frequency	Wilcoxon matched pairs	71	0.549	1.127	0.0	1.0	< .0001	***
Hesitancy	Wilcoxon matched pairs	71	0.296	0.930	0.0	0.0	.0004	***
Straining	Wilcoxon matched pairs	71	0.254	0.803	0.0	0.0	.0015	**
Intermittent stream	Wilcoxon matched pairs	71	0.268	1.155	0.0	1.0	< .0001	***
Urge incontinence	Wilcoxon matched pairs	71	0.155	0.944	0.0	0.0	< .0001	***
Incontinence frequency	Wilcoxon matched pairs	71	0.239	1.028	0.0	0.0	< .0001	***
Incontinence while active	Wilcoxon matched pairs	71	0.070	0.662	0.0	0.0	< .0001	***
Incontinence without urgency	Wilcoxon matched pairs	71	0.028	0.563	0.0	0.0	.0004	***
Nocturnal incontinence	Wilcoxon matched pairs	71	0.056	0.451	0.0	0.0	.0060	**
Sex life spoiled	Wilcoxon matched pairs	70	0.114	0.371	0.0	0.0	.0215	*
Incontinence during intercourse	Wilcoxon matched pairs	70	0.057	0.243	0.0	0.0	.0523	ns
Changing clothes due to symptoms	Wilcoxon matched pairs	71	0.042	0.465	0.0	0.0	.0012	**
Reducing fluid intake	Wilcoxon matched pairs	71	0.042	0.761	0.0	0.0	.0002	***
Effect on daily tasks	Wilcoxon matched pairs	71	0.099	0.521	0.0	0.0	.0026	**

Variables analyzed	Test	n	Mean		Median		p value	Significance
			Pre	Post	Pre	Post		
Avoidance of situations due to symptoms	Wilcoxon matched pairs	71	0.056	0.761	0.0	0.0	.0001	***
Degree of interference with life	Wilcoxon matched pairs	71	0.042	0.873	0.0	0.0	< .0001	***
Total Bristol Score (out of 71)	Wilcoxon matched pairs	69	3.478	14.450	0.0	9.0	< .0001	***
Combined Quality of Life Scores								
Effect of back pain on sex life	Fisher's exact	60	0.100	0.450	0.0	0.0	< .0001	***
Patient Perception of Bladder Condition	Wilcoxon matched pairs	68	0.221	1.279	0.0	1.0	< .0001	***
EQ-5D-5L Index	Wilcoxon matched pairs	71	0.785	0.503	1.0	0.6	< .0001	***
Modified IIEF Questionnaire (Male only)								
Frequency of erections	Wilcoxon matched pairs	41	0.683	1.927	0.0	1.0	.0004	***
Ability to penetrate	Wilcoxon matched pairs	40	0.500	1.625	0.0	0.0	.0015	**
Maintenance of erection	Wilcoxon matched pairs	40	0.425	1.675	0.0	0.0	.0004	***
Frequency of intercourse attempts	Wilcoxon matched pairs	40	1.075	2.575	0.0	3.0	.0004	***
Frequency of orgasm	Wilcoxon matched pairs	41	0.537	1.634	0.0	0.0	.0010	**
Satisfaction with sex life	Wilcoxon matched pairs	41	1.488	2.732	1.0	2.0	.0004	***
Genital sensory changes	Wilcoxon matched pairs	41	0.244	0.902	0.0	0.0	.0119	*
Pain during intercourse	Wilcoxon matched pairs	41	0.195	0.325	0.0	0.0	.5000	ns
Fear of incontinence	Wilcoxon matched pairs	40	0.100	0.128	0.0	0.0	1.0000	ns
Total Modified IIEF Score (out of 41)	Wilcoxon matched pairs	40	5.150	13.330	2.0	9.0	< .0001	***
Modified PISQ-12 Questionnaire (Female only)								
Incontinence during sexual activity	Wilcoxon matched pairs	24	0.125	0.417	0.0	0.0	.3573	ns
Fear of incontinence	Wilcoxon matched pairs	25	0.000	0.480	0.0	0.0	.0579	ns
Pain during intercourse	Wilcoxon matched pairs	23	0.217	0.870	0.0	0.0	.0350	*
Genital sensory changes	Wilcoxon matched pairs	23	0.087	1.478	0.0	0.0	.0048	**
Frequency of orgasm	Wilcoxon matched pairs	22	1.136	2.045	0.0	2.0	.0083	**
Total Modified PISQ-12 Score (out of 20)	Wilcoxon matched pairs	22	1.591	5.409	1.0	4.0	.0018	**

ns = not statistically significant ($p > .05$).

* = statistically significant ($p < .05$).

** = statistically significant ($p < .01$).

*** = statistically significant ($p < .001$).

Table 2. Proportions of patients reporting problems pre and post cauda equina syndrome (CES)

Symptom	n	Pre	%	Post	%	
Anal/coccyx/rectal pain	71	4	5.6%	17	23.9%	■ Pre ■ Post
Tenesmus	71	11	15.5%	31	43.7%	
Abdominal pain	71	8	11.3%	22	31.0%	
Over 5 minutes to open bowels	71	10	14.1%	29	40.8%	
Laxatives/digital evacuation	71	2	2.8%	21	29.6%	
Lavatory return visits	71	4	5.6%	19	26.8%	
Loss of anal sensation	71	3	4.2%	17	23.9%	
Fecal incontinence	71	2	2.8%	9	12.7%	
Nocturnal urination	71	22	31.0%	46	64.8%	
Urgency – rushing	70	10	14.3%	34	48.6%	
Bladder pain	71	3	4.2%	14	19.7%	
Urinating more than 4 hourly	71	19	26.8%	36	50.7%	
Delay in initiation	71	9	12.7%	29	40.8%	
Straining	71	9	12.7%	24	33.8%	
Intermittent stream	71	10	14.1%	36	50.7%	
Incontinence: before toilet	71	6	8.5%	29	40.8%	
incontinence: all	71	7	9.9%	27	38.0%	
Incontinence: stress	71	4	5.6%	22	31.0%	
Incontinence: without urgency	71	2	2.8%	16	22.5%	
Incontinence: sleep	71	2	2.8%	13	18.3%	
Sex life spoiled	70	3	4.3%	10	14.3%	
Incontinence: sex	70	2	2.9%	5	7.1%	
Incontinence: changing clothes	71	1	1.4%	17	23.9%	
Impact: decreased fluid intake	71	2	2.8%	19	26.8%	
Impact: ADLs	71	3	4.2%	16	22.5%	
Impact: going out	71	3	4.2%	20	28.2%	
Impact: life	71	2	2.8%	30	42.3%	
<i>Patient-reported bladder problem</i>	68	8	11.8%	35	51.5%	
Walking problems	70	42	60.0%	58	82.9%	
Washing/ dressing problems	70	34	48.6%	50	71.4%	
Activity problems	70	39	55.7%	52	74.3%	
Pain/discomfort	70	46	65.7%	60	85.7%	
Anxiety/depression	70	37	52.9%	47	67.1%	
Difficulty maintaining erection	40	4	10.0%	19	47.5%	
Unsatisfied	41	3	7.3%	15	36.6%	
Genital sensation changes	41	3	7.3%	11	26.8%	
Pain	41	2	4.9%	4	9.8%	
Fear of incontinence	40	1	2.5%	2	5.0%	
Incontinence: sex	24	2	8.3%	4	16.7%	
Fear of incontinence	25	0	0.0%	5	20.0%	
Pain	23	2	8.7%	8	34.8%	
Genital sensation changes	23	1	4.3%	11	47.8%	

Note: Higher proportions of patients reported that they experienced bladder, bowel, sexual, and functional problems post-CES compared to pre-CES.

quality of life and activities of daily living, and ease of use. There is no widely accepted screening tool at present, however a recent study of 60 patients by König et al found a positive correlation between a high score according to the Shi stages of CES described by Shi et al and bladder dysfunction and fecal incontinence.^{14,18} They went on to propose the Berlin CES score based on preoperative symptoms; this was shown to correlate with reduced anal tone and sensory loss but not fecal and urinary incontinence.¹⁴ A number of validated data sets for spinal cord injury (including cauda equina) have been developed and approved by the International Spinal Cord Society and American Spinal Injury Association, including bowel, lower urinary tract, and sexual function.¹⁹⁻²² Use of standardized data sets may aid screening and facilitate multicenter studies of post-CES dysfunction. In addition to clinical assessment-based tools, urodynamic and electromyographical tools have also been shown to predict bladder dysfunction outcomes, including electrically induced bulbocavernosus reflex, Qmax and Bladder Contractility Index.^{23,24}

The importance of a proactive approach is highlighted by Korse et al. who recently reviewed literature sources reporting improvement in micturition, defecation, and sexual dysfunction occurring for several years post-CES.⁶ This argues for a rehabilitation-focused approach toward patients with post-CES dysfunction rather than a passive approach of monitoring and symptom control. Moreover, long-term support is required for these patients; mean minimal follow-up time post-CES surgery of 17 months as found by the systematic review by Korse et al may not be adequate given the duration of symptoms post-CES.¹⁵ Patients in our study reported symptoms up to 6.5 years post-CES.

The symptoms reported by the majority of patients in our study were diverse and coexist, falling under medical, surgical, nursing, primary care, and psychosocial facets of uro-neurology, uro-gynecology, andrology, pain services, and colorectal. This emphasizes the unmet need for multidisciplinary one-stop care for these patients, reflected in European Association of Urology guidelines on neuro-urology, and highlights the need for adequate urological and psycho-sexual

management of neurological patients.²⁵ A successful example of this is the management of multiple sclerosis for which consensus exists in countries including UK, France, Belgium, and Turkey for the multidisciplinary follow-up and management strategies for patients.²⁶ In addition, patients with spinal cord injury are routinely followed up in specialist centers.²⁷ In the absence of dedicated centers for CES, CES patients may benefit from follow-up programs in spinal cord injury units.

Limitations of our study entail all the caveats of a retrospective survey, including recall bias. We attempted to minimize these limitations through validated and modified questionnaires, more objective response options, and intrarespondent comparison of pre- and post-CES responses. Potential differences between patients who answered the telephone and those who did not introduces a nonresponse bias, impacting the external validity of the study. Because all patients who responded participated, volunteer bias was eliminated.²⁸

Further work may include a prospective study of CES-related complications; the use of alternative, objective screening tools; an interventional study comparing outcomes for patients with screening, long-term follow-up, and support to those without; and a controlled analysis of the impact of age, gender, vertebral level, and timing to surgery on outcomes for prognostication purposes. These are, however, out of the scope of our study, which aimed to establish the extent and subjective impact on CES-related complications.

In summary, our study unequivocally demonstrates the high prevalence and coexistence of post-CES bowel, bladder, and sexual dysfunction and the resulting significant impairment of quality of life. There is a need for long-term multidisciplinary support for these patients. We advocate developing a screening process, addressing barriers to open proactive communication, and setting foundations for regional coordinated services that are accessible to patients post-CES.

Conflicts of Interest

The authors declare no conflicts of interest.

APPENDIX A**Questionnaires***Modified Wexner Constipation Questionnaire*

1 - How frequently have your bowels opened?

1. 1-2 times per 1-2 days
2. 2 times per week
3. once per week
4. less than once per week
5. more than once per month

2 - How often have you had anal/rectal/coccyx pain before, during, or after opening your bowels?

1. Never
2. Rarely
3. Sometimes
4. Usually
5. Always

3 - How often have you felt that your bowels are incompletely emptied, like you didn't finish?

1. Never
2. Rarely
3. Sometimes
4. Usually
5. Always

4 - How often have you had abdominal pain because of difficulty with your bowels?

1. Never
2. Rarely
3. Sometimes
4. Usually
5. Always

5 - How long would you typically spend in the lavatory trying to go?

1. Less than 5 minutes
2. 5-10 minutes
3. 10-20 minutes
4. 20-30 minutes
5. More than 30 minutes

6 - Do you need to do the following to help you move your bowels?

1. No assistance needed
2. Laxative
3. Digital assistance (placing a finger in the vagina, anus, or between to help empty bowels) or enema

7 - On average, how often would you revisit the lavatory because you hadn't completely emptied your bowels?

1. Never
2. 1-3 times a day
3. 3-6 times a day
4. 6-9 times a day
5. More than 9 times a day

8 - For how many years have you had difficulty evacuating your bowel?

1. Less than 1 year
2. 1-5 years
3. 5-10 years
4. 10-20 years
5. More than 20 years

9 - Do you have any loss of sensation in your anus?

1. Never
2. Rarely
3. Sometimes
4. Usually
5. Always

10 - Do you have any leaking of stool?

1. Never
2. Rarely
3. Sometimes
4. Usually
5. Always

Total /34

Bristol Female Lower Urinary Tract Symptoms Questionnaire

1 - During the night, how many times do you have to get up to urinate, on average?

- 0 = None
 1 = 1
 2 = 2
 3 = 3
 4 = 4 or more

2 - Do you have to rush to the toilet to urinate?

- 0 = Never
- 1 = Occasionally
- 2 = Sometimes
- 3 = Most of the time
- 4 = All of the time

3 - Do you have pain in your bladder?

- 0 = Never
- 1 = Occasionally
- 2 = Sometimes
- 3 = Most of the time
- 4 = All of the time

4 - How often do you pass urine during the day?

- 0 = Every 4 hours or more
- 1 = Every 3 hours
- 2 = Every 2 hours
- 3 = Hourly

5 - Is there a delay before you can start to urinate?

- 0 = Never
- 1 = Occasionally
- 2 = Sometimes
- 3 = Most of the time
- 4 = All of the time

6 - Do you have to strain to urinate?

- 0 = Never
- 1 = Occasionally
- 2 = Sometimes
- 3 = Most of the time
- 4 = All of the time

7 - Do you stop and start more than once while you urinate?

- 0 = Never
- 1 = Occasionally
- 2 = Sometimes
- 3 = Most of the time
- 4 = All of the time

8 - Does urine leak before you can get to the toilet?

- 0 = Never
- 1 = Occasionally
- 2 = Sometimes
- 3 = Most of the time
- 4 = All of the time

9 - How often do you leak urine?

- 0 = Never
- 1 = Once or less per week
- 2 = 2-3 times per week
- 3 = Once per day
- 4 = Several times per day

10 - Does urine leak when you are physically active, exert yourself, cough, or sneeze?

- 0 = Never
- 1 = Occasionally
- 2 = Sometimes
- 3 = Most of the time
- 4 = All of the time

11 - Do you ever leak for no obvious reason and without feeling that you want to go?

- 0 = Never
- 1 = Occasionally
- 2 = Sometimes
- 3 = Most of the time
- 4 = All of the time

12 - Do you leak urine when you are asleep?

- 0 = Never
- 1 = Occasionally
- 2 = Sometimes
- 3 = Most of the time
- 4 = All of the time

13 - To what extent do you feel that your sex life has been spoiled by your urinary symptoms?

- 0 = Not at all
- 1 = A little
- 2 = Somewhat
- 3 = A lot

14 - Do you leak urine when you have sexual intercourse?

- 0 = Not at all
- 1 = A little
- 2 = Somewhat
- 3 = A lot

15 - Do you need to change your outer clothing during the day because of urine leakage?

- 0 = Never
- 1 = Occasionally
- 2 = Sometimes
- 3 = Most of the time
- 4 = All of the time

16 - Do you cut down on the amount of fluid you drink so that your urinary symptoms improve, and you can do the things that you want to do?

- 0 = Never
- 1 = Occasionally
- 2 = Sometimes
- 3 = Most of the time
- 4 = All of the time

17 - To what extent have your urinary symptoms affected your ability to perform daily tasks (e.g., cleaning, DIY, lifting objects)?

- 0 = Not at all
- 1 = A little
- 2 = Somewhat
- 3 = A lot

18 - Do you avoid places and situations where you know a toilet is not nearby (e.g., shopping, traveling, theatre, church)?

- 0 = Never
- 1 = Occasionally
- 2 = Sometimes
- 3 = Most of the time
- 4 = All of the time

19 - Overall, how much do your urinary symptoms interfere with your life?

- 0 = Not at all no
- 1 = A little
- 2 = Somewhat
- 3 = A lot

Total /71

Patient Perception of Bladder Condition

1. My bladder condition does not cause me any problems at all.
2. My bladder condition causes me some very minor problems.

3. My bladder condition causes me some minor problems.

4. My bladder condition causes me (some) moderate problems.

5. My bladder condition causes me severe problems.

6. My bladder condition causes me many severe problems.

Modified Pelvic Organ Prolapse/Urinary Incontinence Sexual Questionnaire

1 - Are you incontinent of urine (leak urine) with your sexual activity?

1. Always
2. Usually
3. Sometimes
4. Seldom
5. Never

2 - Does fear of incontinence (either stool or urine) restrict your sexual activity?

1. Always
2. Usually
3. Sometimes
4. Seldom
5. Never

3 - Do you feel pain during sexual intercourse?

1. Always
2. Usually
3. Sometimes
4. Seldom
5. Never

4 - Do you have any numbness or changes in sensation in your genital area that affects your ability to enjoy sexual activity? Is this worse after your back problem?

1. Always
2. Usually
3. Sometimes
4. Seldom
5. Never

5 - Do you climax (have an orgasm) when having sexual intercourse before and after operation?

1. Always
2. Usually
3. Sometimes
4. Seldom
5. Never

Total /20

Modified International Index of Erectile Function Questionnaire (mIIEF)

1 - How often were you able to get an erection during sexual activity?

0. No sexual activity
1. Almost never or never
2. A few times (much less than half the time)
3. Sometimes (about half the time)
4. Most times (much more than half the time)
5. Almost always or always

2 - When you attempted intercourse, how often were you able to penetrate (enter) the other person?

0. Did not attempt intercourse
1. Almost never or never
2. A few times (much less than half the time)
3. Sometimes (about half the time)
4. Most times (much more than half the time)
5. Almost always or always

3 - During sexual intercourse, how difficult was it to maintain your erection to completion of intercourse?

0. Did not attempt intercourse
1. Extremely difficult
2. Very difficult
3. Difficult
4. Slightly difficult
5. Not difficult

4 - How many times have you attempted sexual intercourse?

0. No attempts
1. One to two attempts
2. Three to four attempts
3. Five to six attempts
4. Seven to ten attempts
5. Eleven or more attempts

5 - When you had sexual stimulation or intercourse, how often did you have the feeling of orgasm or climax?

0. No sexual stimulation or intercourse
1. Almost never or never
2. A few times (much less than half the time)
3. Sometimes (about half the time)
4. Most times (much more than half the time)
5. Almost always or always

6 - How satisfied have you been with your overall sex life?

1. Very dissatisfied
2. Moderately dissatisfied
3. About equally satisfied and dissatisfied
4. Moderately satisfied
5. Very satisfied

7 - Do you have any numbness or changes in sensation in your genital area that affects your ability to enjoy sexual activity? Is this worse after your back problem?

0. Never
1. Occasionally
2. Sometimes
3. Most of the time
4. All of the time

8 - Do you feel pain during sexual intercourse?

0. Never
1. Occasionally
2. Sometimes
3. Most of the time
4. All of the time

9 - Does fear of incontinence (urine or feces) limit your ability to enjoy sexual intercourse?

0. Never
1. Occasionally
2. Sometimes
3. Most of the time
4. All of the time

Total /41

Effect of Back Pain on Sex Life

Does back pain affect your sex life?

Yes No

EQ-5D-5L Index

Mobility

1. I have no problems in walking about
2. I have slight problems in walking about
3. I have moderate problems in walking about
4. I have severe problems in walking about
5. I am unable to walk about

Self-care

1. I have no problems washing or dressing myself
2. I have slight problems washing or dressing myself
3. I have moderate problems washing or dressing myself
4. I have severe problems washing or dressing myself
5. I am unable to wash or dress myself

Usual activities (e.g., work, study, housework, family or leisure activities)

1. I have no problems doing my usual activities

2. I have slight problems doing my usual activities
3. I have moderate problems doing my usual activities
4. I have severe problems doing my usual activities
5. I am unable to do my usual activities

Pain/Discomfort

1. I have no pain or discomfort
2. I have slight pain or discomfort
3. I have moderate pain or discomfort
4. I have severe pain or discomfort
5. I have extreme pain or discomfort

Anxiety/Depression

1. I am not anxious or depressed
2. I am slightly anxious or depressed
3. I am moderately anxious or depressed
4. I am severely anxious or depressed
5. I am extremely anxious or depressed

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