


# BMJ Open Prevalence and predictors of poor sexual well-being over 5 years following treatment for colorectal cancer: results from the ColoRECTal Wellbeing (CREW) prospective longitudinal study

Jane Frankland,<sup>1</sup> Sally Wheelwright,<sup>1</sup> Natalia V Permyakova,<sup>1</sup> David Wright,<sup>1</sup> Nicole Collaço,<sup>1</sup> Lynn Calman,<sup>1</sup> Jane Winter,<sup>2</sup> Deborah Fenlon,<sup>3</sup> Alison Richardson,<sup>2,4</sup> Peter W Smith,<sup>5</sup> Claire Foster <sup>1</sup>

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For numbered affiliations see end of article.

**Correspondence to**  
Professor Claire Foster;  
C.L.Foster@soton.ac.uk

## ABSTRACT

**Objectives** To describe prevalence and predictors of poor sexual well-being for men and women over 5 years following treatment for colorectal cancer.

**Design** Prospective longitudinal study, from presurgery to 5 years postsurgery, with eight assessment points. Logistic regression models predicted sexual well-being from presurgery to 24 months and 24 months to 60 months; time-adjusted then fully adjusted models were constructed at each stage.

**Setting** Twenty-nine hospitals in the UK.

**Participants** Patients with Dukes' stage A–C, treated with curative intent, aged ≥18 years and able to complete questionnaires were eligible.

**Outcome measures** The dependent variable was the Quality of Life in Adult Cancer Survivors sexual function score. Independent variables included sociodemographic, clinical and psychosocial characteristics.

**Results** Seven hundred and ninety participants provided a sexual well-being score for at least one time point. Thirty-seven per cent of men and 14% of women reported poor sexual well-being at 5 years. Baseline predictors for men at 24 months included having a stoma (OR 1.5, 95% CI 1.02 to 2.20) and high levels of depression (OR 2.69/2.01, 95% CI 1.68 to 4.32/1.12 to 3.61); men with high self-efficacy (OR confident 0.33/0.48, 95% CI 0.18 to 0.61/0.24 to 1.00; very confident 0.25/0.42, 95% CI 0.13 to 0.49/0.19 to 0.94) and social support (OR 0.52/0.56, 95% CI 0.33 to 0.81/0.35 to 0.91) were less likely to report poor sexual well-being. Predictors at 60 months included having a stoma (OR 2.30/2.67, 95% CI 1.22 to 4.34/1.11 to 6.40) and high levels of depression (OR 5.61/2.58, 95% CI 2.58 to 12.21/0.81 to 8.25); men with high self-efficacy (very confident 0.14, 95% CI 0.047 to 0.44), full social support (OR 0.26; 95% CI 0.13 to 0.53) and higher quality of life (OR 0.97, 95% CI 0.95 to 0.98) were less likely to report poor sexual well-being. It was not possible to construct models for women due to low numbers reporting poor sexual well-being.

**Conclusions** Several psychosocial variables were identified as predictors of poor sexual well-being among men. Interventions targeting low self-efficacy may be

## Strengths and limitations of this study

- This is the largest prospective longitudinal study to report the sexual well-being of people treated for colorectal cancer.
- The cohort was followed from a presurgery assessment up to 5 years postsurgery, with a total of eight assessment points.
- The cohort is a representative sample which achieved very high response rates (88%–71% over 5 years).
- Women were more likely to return a non-response to sexual well-being questions than men (12% vs 4% overall).
- Small numbers of women with poor sexual well-being meant that logistic regression models could not be constructed.

helpful. More research is needed to understand women's sexual well-being.

## INTRODUCTION

Cancer and its treatment can adversely affect a person's sex life. Across cancers, different treatments can cause physical side effects which may lead to sexual problems such as loss of interest in sex (libido), and functional problems such as erectile and ejaculatory problems for men, and dyspareunia (painful intercourse) and vaginal dryness or atrophy for women.<sup>1–8</sup> In addition, changes to body image and other symptoms, such as pain, anxiety and fatigue may contribute. Sexual problems can be short term but can also be a late effect of treatment and can continue long term. Many people living with and beyond cancer do not feel prepared for these consequences nor receive adequate support.<sup>9</sup>

Research into the effects of cancer treatment on sexual health has often taken a medicalised approach, with emphasis solely on function.<sup>10 11</sup> Such a focus fails to account for the patient's perspective,<sup>12</sup> neglecting the subjective meaning of functional changes.<sup>13 14</sup> In contrast, sexual well-being refers to an individual's assessment or evaluation of their sexual life,<sup>11 15</sup> and thus is a concept which is broader than function. Sexual well-being is part of overall sexual health<sup>16</sup> and an important contributor to quality of life.<sup>17</sup> While poorly operationalised in the literature,<sup>15</sup> and used interchangeably with the terms 'sexual quality of life/quality of sexual life', it is acknowledged as a multifaceted construct, and has been variously operationalised to include a range of dimensions within the individual-cognitive-affect (eg, function, satisfaction), interpersonal (eg, relationship well-being, intimacy) and sociocultural (eg, norms, stereotypes, socialisation) domains, with function and satisfaction being the most common measures used.<sup>15</sup> Reported levels of sexual well-being do not always correspond to reports of function, with reports of well-being despite reduced function.<sup>18</sup> Greater insight will be gained by the study of well-being as well as function. To date, studies of sexual well-being among people living with and beyond cancer have commonly focused on reproductive cancers, and an understanding of other cancers is needed.<sup>14</sup> In addition, there is commonly a focus on clinical rather than psychosocial associates and predictors of sexual well-being. However, Foster and Fenlon's framework of recovery of health and well-being following cancer suggests the importance of personal factors (such as personality, affective dispositions and general self-efficacy) and environmental factors (such as social support) in influencing coping and recovery, indicating the importance of including such factors as predictors of sexual well-being over time.<sup>19</sup>

Colorectal cancer is the third most common cancer worldwide, with 1.8 million new cases in 2018 representing 10.2% of all new cancers.<sup>20</sup> Sexual dysfunction following treatment for colorectal cancer is common and well documented, with levels typically higher than the normative population.<sup>21 22</sup> Research has identified demographic and treatment factors associated with sexual dysfunction among people who have been treated for colorectal cancer, for instance, age (older people having more sexual problems<sup>4 8 22-25</sup>) and type of treatment (eg, people receiving radiotherapy can experience significant impairment in function<sup>4</sup>). In addition, having a stoma may affect intimacy, body image and sexual frequency.<sup>1 8 23 26-28</sup> Psychosocial factors associated with sexual dysfunction have received less attention,<sup>24 29</sup> but include depressive symptoms, emotional well-being and partner relationship quality.<sup>4 22</sup>

As with other cancer types, the sexual well-being of people living with and beyond colorectal cancer is less well documented than sexual function. No studies which purported to assess predictors of sexual well-being were found, though a small number of studies used indicators of sexual well-being within broader quality of life studies,

and two recent studies focused on quality of sexual life. A review of papers addressing quality of sexual life up to 2010 indicates that type of cancer and type of treatment are related to satisfaction/sexual enjoyment, with equivocal findings for stoma.<sup>29</sup> Among men, satisfaction decreased after treatment and low satisfaction endured long term. The review found no studies considering satisfaction for women.<sup>29</sup> The more recent studies indicate different patterns of sexual quality of life for men and women, with quality of sexual life reducing with time.<sup>25</sup> Reported predictors of low quality of sexual life were depressive symptoms, having rectal cancer,<sup>25</sup> and associations have been reported between sexual distress and relationship quality, depression and health related quality of life, and between perceived impact of treatment and depression and quality of life.<sup>30</sup> The majority of these studies were limited by being cross-sectional and having small sample sizes.<sup>29</sup> Few studies have explored associations between self-efficacy and sexual well-being, and none with colorectal cancer patients specifically. Within other cancer types, associations have been shown between self-efficacy and sexual well-being outcomes for women with breast cancer (sexual self-efficacy)<sup>31</sup> but not men with prostate cancer (self-efficacy for symptom control).<sup>32</sup> Correlations have been shown between sexual distress and psychosocial variables including sexual self-efficacy and self-efficacy to communicate about sex and intimacy (SECSI) for women with various cancer types.<sup>33</sup>

Within this context, there is a need for larger, longer-term longitudinal studies to understand changes in sexual well-being and predictors over time.<sup>3 5</sup> Taking account of the gendered nature of sexual well-being and its predictors,<sup>34 35</sup> it is important to do this for men and women separately. This need is addressed here through analysis of data from the UK ColoRECTal Wellbeing study (CREW), a large-scale prospective cohort study of a representative sample of people diagnosed with colorectal cancer and treated with curative intent, investigating factors associated with recovery of health and well-being.<sup>36</sup>

The aim of the paper is to investigate men and women's sexual well-being from a pre-surgery baseline to 24 months postsurgery, and from 24 to 60 months postsurgery. Here, sexual well-being is defined as an individual's subjective assessment of their sexual function and is operationalised using a subdomain of sexual satisfaction and bother within a quality of life measure. The 24-month post-treatment time point is significant because, although surveillance commonly continues beyond this point,<sup>37 38</sup> treatment has usually ended and there may be fewer face-to-face opportunities to discuss problems with a health-care professional.<sup>39</sup> In the UK, for example, policy embeds a stratified approach to follow up care for people with colorectal cancer, meaning that the majority will experience a supported self-management approach to care in the latter years of follow-up.<sup>40</sup> The following questions are addressed in the paper: (1) What is the prevalence of poor sexual well-being among men and women with colorectal cancer from pre-surgery and up to 60 months

postsurgery; (2) which presurgery sociodemographic and psychosocial variables are associated with poor sexual well-being for men and women (separately) over 24 months and (3) which treatment, sociodemographic and psychosocial variables at 24 months are associated with poor sexual well-being for men and women (separately) onwards to 60 months?

## METHOD

### Design

CREW is a multicentre prospective, longitudinal cohort study of a representative sample of people newly diagnosed with colorectal cancer undergoing curative intent surgery. Full details of the aims and methods of the study are provided elsewhere.<sup>36</sup>

### Patient and public involvement

People affected by cancer were involved from the early stages of the project, through a launch event to talk about study design. Research questions were informed by a previous study asking people living with and beyond cancer about their concerns.<sup>41</sup> People living with and beyond cancer were also involved in the Study Advisory Committee, through which they had input into study processes and plans for dissemination. They helped support recruitment through involvement in site meetings with recruiting hospitals and in a project film to promote the study.

### Participants

Eligible participants had a diagnosis of non-metastatic colorectal cancer (Dukes' A–C); were being treated with curative intent surgery;  $\geq 18$  years old and had the ability to read and understand English. People who had had another cancer diagnosis prior to their colorectal cancer were excluded.

### Procedure

Participants were recruited from 29 UK hospitals between November 2010 and March 2012. Baseline questionnaires were completed before primary surgery (baseline), with subsequent follow-up questionnaires mailed at 3, 9, 15 and 24 months and then annually up to 60 months. The questionnaires comprised both validated measures and additional questions to assess domains identified in Foster and Fenlon's<sup>19</sup> framework of recovery of health and well-being in cancer survivorship.<sup>19</sup> Clinical and treatment data (stage, grade of disease, type of treatment) were gathered from participants' National Health Service (NHS) medical records at 6 months and verified at 24 months postsurgery.

All participants provided written informed consent.

### Measures

Full details of the measures used in the study have been reported elsewhere.<sup>36</sup> A summary of the measures used is included in online supplemental table 1. Only sociodemographic, clinical and psychosocial variables hypothesised

to be relevant to sexual well-being were included in the analyses, and these are described here.

### Sexual well-being

The main outcome was sexual well-being, operationalised using the 'sexual function' domain of a quality of life measure—the Quality of Life in Adult Cancer Survivors (QLACS) scale.<sup>42</sup> The QLACS contains 47 items and 12 domains. Questions pertain to the previous 4 weeks and are scored as 1–7 (never, seldom, sometimes, as often as not, frequently, very often, always). The QLACS sexual function domain includes two questions: 'You were bothered by being unable to function sexually' and 'You were dissatisfied with your sex life'. The two scores are summed to give the domain score, ranging from 2 to 14, with higher scores indicating poorer sexual well-being. The score was highly skewed towards better sexual well-being in both men and women with median scores of 4 and 2, respectively (see online supplemental figure 1). Because of this, and for purposes of clinical interpretation, we chose to dichotomise the variable rather than examine scores continuously. In the absence of published cut-offs for the measure, we defined poor sexual well-being as scores greater than seven, to incorporate bother and dissatisfaction which was 'as often as not' or more frequent.

The sexual interest scale of the QLACS, which comprises the questions: 'You lacked interest in sex,' and 'You avoided sexual activity' was included in the description of baseline characteristics. With the same reasoning as above, a score of greater than seven was used to indicate a lack of interest in sex.

### Sociodemographic, clinical and treatment data

Sociodemographic variables which are indicated in the literature as associated with sexual function/well-being were included. Self-reported sociodemographic data collected included employment status and domestic status. Index of Multiple Deprivation quintiles were derived from postcodes.<sup>43</sup> Tumour site, type of surgery, age and additional treatment (radiotherapy and/or chemotherapy) were collected from NHS medical records.

### Self-efficacy

No previous studies were found which assessed an association between self-efficacy and sexual well-being, however, previous analysis of the CREW data set has indicated that self-efficacy is a predictor of quality of life, health status and well-being. It was, therefore, hypothesised that there would be a relationship between low self-efficacy and poor sexual well-being. The Self-efficacy for Managing Chronic Disease (SEMCD) 6-item instrument<sup>44</sup> was used to assess self-efficacy from baseline to 9 months. From 15 months, the Cancer Survivor Self-efficacy Scale<sup>41</sup> was used. This scale adds five items to the SEMCD and

asks about 'your cancer' rather than 'your disease'. For both instruments, all items are scored from 1 (not at all confident) to 10 (totally confident) and a mean score is calculated. The following cut-offs, derived from previous CREW analysis of trajectories of self-efficacy,<sup>45</sup> were applied to both scales: 1–4 'low confidence', 5–6 'moderate confidence', 7–8 'confident' and 9–10 'very confident'.

### Depression and anxiety

Following other studies,<sup>22 25</sup> we hypothesised that high rates of depression and anxiety would be associated with poor sexual well-being. The 20 item Centre for Epidemiological Studies Depression scale<sup>46</sup> was used to assess depression. Respondents are asked to indicate how often they experience symptoms, indicating the frequency on a 4-point Likert scale. Higher scores indicate more symptoms of depression and scores of  $\geq 20$  suggest clinical levels of depression.<sup>47</sup> The State Trait Anxiety Inventory<sup>48</sup> was used to measure current anxiety symptoms. Respondents are invited to use a 4-point Likert scale to indicate how often they have experienced 20 items. Greater anxiety is associated with higher scores and scores  $\geq 40$  suggest clinically significant levels of anxiety.<sup>49</sup>

### Social support

Low social support is associated with increased risk of sexual dysfunction<sup>24</sup>; we, therefore, hypothesised that low social support would be associated with poor sexual well-being. Social support was measured using the Medical Outcomes Study Social Support Survey (MOS-SSS).<sup>50</sup> The instrument consists of 19 items concerning the availability of different types of support, with responses recorded on a 5-point Likert scale ('none of the time' to 'all of the time'). As this measure is highly skewed, we divided scores on the MOS-SSS into ceiling (feeling fully supported) and below.

### Health-related quality of life

Literature indicates associations between sexual dysfunction/quality of sexual life and global quality of life,<sup>24</sup> having a stoma,<sup>1 22 24 25</sup> fatigue<sup>24</sup> and body image.<sup>25</sup> We hypothesised pain, fatigue, having a stoma and poor body image to be associated with poor sexual well-being, and high quality of life with good sexual well-being. Quality of life was assessed from 3 months onwards using the European Organisation for Research and Treatment of Cancer Quality of Life questionnaire Core Questionnaire the (the QLQ-C30)<sup>51</sup> and colorectal cancer module (the QLQ-CR29).<sup>52</sup> The scales included in this paper were the global health status/quality of life, pain and fatigue scales of the QLQ-C30 and the impotence, dyspareunia and body image scales of the QLQ-CR29. Self-reported stoma status was taken from the QLQ-CR29. For both the QLQ-C30 and the QLQ-CR29, respondents were asked to what extent each item applied to them, with response options of not at all (1), a little (2), quite a bit (3) or very much (4) for all items except the global health and quality of

life items of the QLQ-C30, which uses a seven-point scale. A linear transformation was used for all scales to produce a score between 0 and 100. Thresholds of clinical importance have been published for the pain ( $>25$ ) and fatigue ( $>39$ ) scales.<sup>53</sup> For the QLQ-CR29, clinical importance was indicated if any individual item within a scale received a score of 3 or 4.

### Statistical methods

All analyses were undertaken separately for men and women. Summary statistics for participant characteristics at baseline (pre-surgery) and the prevalence of poor sexual well-being over the 60 months of the study were calculated.

Two sets of logistic regression models were produced with sexual well-being as a time-varying outcome. The population-average approach was used to combine data for each individual across the required time points for each regression model. Standard Errors were adjusted to account for repeated observations of the same individuals. The first set of models focused on the associations between participant characteristics at baseline and sexual well-being up to 24 months after surgery. The second set of models examined the associations between participant characteristics at 24 months postsurgery (along with time-constant covariates related to tumour type, treatment and deprivation index quintiles) and sexual well-being over the next 3 years.

Each set of models consisted of two steps: in step 1, models adjusted for time only (one per covariate) were constructed; in step 2, a fully adjusted model was constructed using the same covariates. A category for missing data was included for a variable if there was  $>5\%$  missing data in that variable. Analyses were performed using Stata V.14 software. Statistical significance was set at 5% throughout.

## RESULTS

### Participants

The flow of participants through the study has been reported elsewhere.<sup>54</sup> A total of 872 people provided full consent, with response rates between 88% at baseline and 71% at 60 months. Of the consented participants, 790 had a sexual well-being outcome on at least one time point throughout the study and are included in [table 1](#) (baseline characteristics), and [figure 1](#) (prevalence of poor sexual well-being).

### Prevalence of poor sexual well-being among men and women from presurgery baseline and over 5 years post-treatment

Presurgery baseline reports of poor sexual well-being were significantly associated with having lower self-efficacy, anxiety and depression among men, whereas women were significantly more likely to report poor sexual well-being at baseline if they had radiotherapy (see online supplemental Table 2). [Figure 1](#) shows that men were significantly more likely to report

**Table 1** Baseline characteristics for men (N=479) and women (N=311) who provided a sexual well-being score for at least one of the eight assessment points

Baseline variables	Men		Women	
	N	%	N	%
<b>Total (N=790)</b>	<b>479</b>	<b>100</b>	<b>311</b>	<b>100</b>
<b>Age groups</b>				
≤59	75	15.6	66	21.2
60–69	201	42.0	105	33.8
70+	202	42.2	139	44.7
Unknown	1	0.2	1	0.3
<b>Employment status</b>				
Employed	129	26.9	72	23.2
Unemployed/retired	308	64.3	220	70.7
Unknown	42	8.8	19	6.1
<b>Domestic status</b>				
Married/coresiding	350	73.1	177	56.9
Single/widowed/divorced	87	18.2	118	37.9
Unknown	42	8.8	16	5.1
<b>Deprivation Index Quintiles</b>				
First—least deprived	94	19.6	60	19.3
Second	112	23.4	49	15.8
Third	88	18.4	63	20.3
Fourth	86	18.0	62	19.9
Fifth—most deprived	88	18.4	72	23.2
Unknown	11	2.3	5	1.6
<b>Tumour</b>				
Colon	294	61.4	211	67.8
Rectum	182	38.0	100	32.2
Unknown	3	0.6	0	0.0
<b>Dukes' stage</b>				
A	79	16.5	35	11.3
B	250	52.2	174	55.9
C1	86	18.0	68	21.9
C2	55	11.5	30	9.6
Unknown*	9	1.9	4	1.3
<b>Surgery type</b>				
Laparoscopic	267	55.7	167	53.7
Open surgery	186	38.8	125	40.2
Unknown	26	5.4	19	6.1
<b>Radiotherapy</b>				
No	381	79.5	258	83.0
Yes	95	19.8	53	17.0
Unknown	3	0.6	0	0.0
<b>Chemotherapy</b>				
No	296	61.8	176	56.6
Yes	178	37.2	132	42.4
Unknown	5	1.0	3	1.0

Continued

Table 1 Continued

Baseline variables	Men		Women	
	N	%	N	%
<b>Total (N=790)</b>	<b>479</b>	<b>100</b>	<b>311</b>	<b>100</b>
Stoma status† (European Organisation for Research and Treatment of Cancer (EORTC) QLQ-CR29)				
No	246	51.3	193	62.1
Yes	154	32.2	65	20.9
Unknown	1	0.2	0	–
Did not complete 3-month assessment	78	16.3	53	17.0
Impotence (men only)† (EORTC QLQ-CR29)				
No	192	40.1	n/a-	n/a-
Yes, clinically significant	169	35.3	n/a-	n/a-
Unknown	78	16.3	n/a-	n/a-
Did not complete 3-month assessment	40	8.3%	n/a	n/a
Dyspareunia (women only)† (EORTC QLQ-CR29)				
	n/a-	n/a-	146	50.0
Yes, clinically significant	n/a-	n/a-	11	3.5
Unknown	n/a-	n/a-	34	17.0
Did not complete 3-month assessment	n/a	n/a	101	32.5
Quality of Life in Adult Cancer Survivors sexual interest scale				
Interested in sex (score 1–7)	305	63.7	155	49.8
Lack of interest in sex (score 8–14)	120	25.1	110	35.4
Unknown	54	11.3	46	14.8

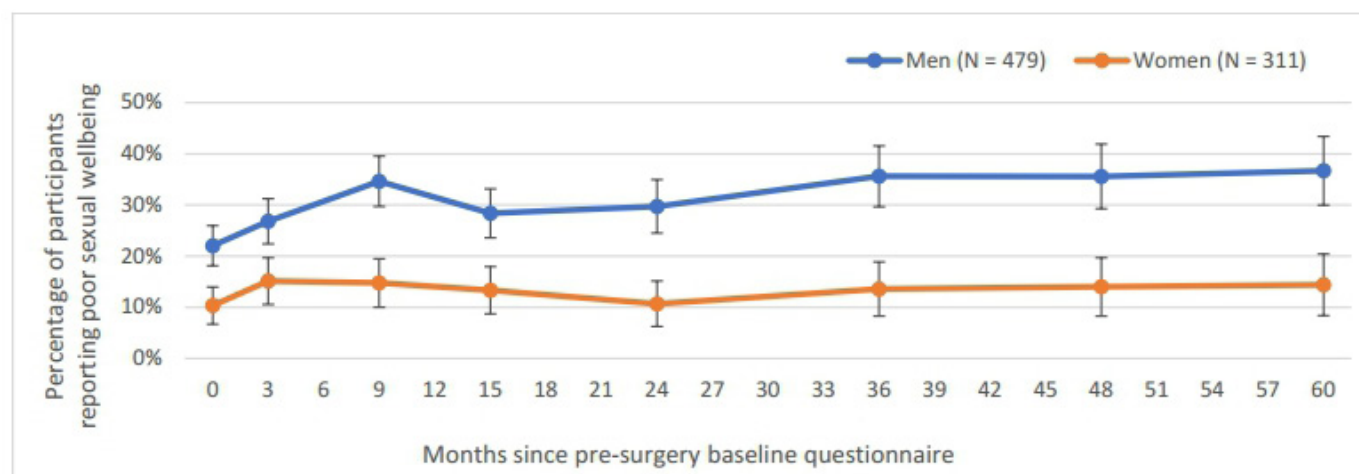
\*Dukes' stage could not be determined for 11 full consent patients with small tumours following neoadjuvant therapy.

†Reported at 3 months; non-completion of 3-month assessment point is reported.

n/a, not applicable.

poor sexual well-being than women both presurgery and throughout the 5 years postsurgery (the 95% CIs do not overlap between men and women at any time point). The prevalence of poor sexual well-being in

women did not change significantly across time points after baseline. In contrast, the prevalence of poor sexual well-being among men significantly increased with respect to baseline (at 9 months and after 24



**Figure 1** Prevalence of poor sexual well-being among men and women over the 5 years from presurgery baseline, showing 95% CIs.

**Table 2** Logistic regression modelling (ORs and 95% CIs) of poor sexual well-being among men between 3 and 24 months by the covariates reported at baseline (N=433)

	Step 1* OR (95% CI)	Step 2† OR (95% CI)
<b>Age group</b>		
≤59	REF	REF
60–69	0.83 (0.49 to 1.41)	1.11 (0.60 to 2.04)
70+	0.77 (0.45 to 1.32)	0.96 (0.50 to 1.82)
<b>Deprivation Index Quintiles</b>		
First—least	REF	REF
Second	1.38 (0.79 to 2.40)	1.46 (0.80 to 2.67)
Third	1.31 (0.73 to 2.38)	1.23 (0.67 to 2.27)
Fourth	1.26 (0.69 to 2.31)	0.95 (0.50 to 1.81)
Fifth—most	1.18 (0.65 to 2.14)	1.03 (0.56 to 1.91)
<b>Domestic status</b>		
Married/coresiding	REF	REF
Single/widowed/divorced	0.97 (0.61 to 1.55)	0.79 (0.47 to 1.33)
<b>Tumour</b>		
Colon	REF	REF
Rectum	1.42 (0.98 to 2.06)	1.05 (0.60 to 1.84)
<b>Radiotherapy</b>		
No	REF	REF
Yes	1.61‡ (1.05 to 2.46)	1.47 (0.82 to 2.63)
<b>Chemotherapy</b>		
No	REF	REF
Yes	1.07 (0.74 to 1.55)	0.83 (0.55 to 1.24)
<b>Stoma (at 3 months)</b>		
No	REF	REF
Yes	1.50‡ (1.02 to 2.20)	1.24 (0.74 to 2.06)
Did not participate at 3 months	1.85 (0.93; 3.67)	1.51 (0.70 to 3.29)
<b>Surgery type</b>		
Laparoscopic	REF	REF
Open surgery	0.98 (0.67 to 1.44)	0.84 (0.55 to 1.27)
Unknown	1.94 (0.91 to 4.12)	1.33 (0.53 to 3.31)
<b>Self-efficacy (Self-efficacy for managing chronic disease instrument)</b>		
Low confidence	REF	REF
Moderate confidence	0.53 (0.27 to 1.04)	0.64 (0.31 to 1.35)
Confident	0.33§ (0.18; 0.61)	0.48‡ (0.24 to 1.00)
Very confident	0.25§ (0.13; 0.49)	0.42‡ (0.19 to 0.94)
<b>Anxiety STAI (STAI score &gt;40)</b>		
No	REF	REF
Yes	1.77¶ (1.20 to 2.60)	1.08 (0.64 to 1.81)
<b>Depression Centre for Epidemiological Studies Depression scale score &gt;20)</b>		
No	REF	REF
Yes	2.69§ (1.68 to 4.32)	2.01‡ (1.12 to 3.61)

Continued

Table 2 Continued

	Step 1* OR (95% CI)	Step 2† OR (95% CI)
Social support Medical Outcomes Study Social Support Survey)		
<100 score	REF	REF
Score=100 (full support)	0.52¶ (0.33 to 0.81)	0.56‡ (0.35 to 0.91)

\*Adjusting for time and considering each covariate separately.

†Fully adjusted model, including time and all covariates.

‡p<.05.

§p<.001.

¶p<.01.

STAI, State Trait Anxiety Inventory.

months). Given the low prevalence of poor sexual well-being in women, logistic regression models were only produced for men.

### Presurgery predictors of poor sexual well-being among men at 24 months postsurgery

Data were analysed for 433 men who provided at least one report of sexual well-being over 3–24 months. Of these, 37 did not participate at baseline, and therefore, were excluded from the analyses. The total analytical sample consisted of 1304 observations from 396 men. Results are presented in table 2. (Prevalence of poor sexual well-being by each of the covariates is shown in online supplemental table 3).

In the first step, modelling the prevalence of poor sexual well-being from baseline up to 24 months (adjusting for time and considering each covariate separately), having radiotherapy or a stoma increased the odds of poor sexual well-being up to 24 months postsurgery by 50%–60% (OR=1.61 and OR=1.50, respectively, p<0.05). In addition, all four of the psychosocial measures at baseline were significantly associated with poor sexual well-being (p<0.01). The analyses show that the odds of reporting poor sexual well-being over the first 24 months postsurgery were: 67%–75% lower among confident/very confident men (OR=0.33 and OR=0.25, respectively); 48% lower for men who received full social support (OR=0.52); 77% higher for men with high anxiety (OR=1.77); and almost three times higher for men with clinically significant levels of depression (OR=2.69) at baseline. In the second step of modelling (including time and all covariates), neither of the clinical variables remained significantly associated with sexual well-being. However, all the psychosocial variables except anxiety remained significant. The odds of reporting poor sexual well-being were: 52%–58% lower for confident/very confident men (OR=0.48 and 0.42); twice as high for men with clinical levels of depression (OR+2.01); and 44% lower for men with full social support at baseline (OR=0.56).

### Twenty-four-month postsurgery predictors of poor sexual well-being up to 60 months postsurgery

There were 281 men with at least one reported outcome of sexual well-being over 36–60 months, of whom 21 did not participate at 24 months and therefore were excluded from the analyses. The total analytical sample consisted of 640 observations from 260 men. Model results are presented in table 3. (Prevalence of poor sexual well-being by each of the predictors is shown in online supplemental table 4).

In the first step of modelling (adjusting for time and considering each predictor separately), having a stoma at 24 months predicted poor sexual well-being at later time points (OR=2.30). In addition, all the psychosocial and quality of life factors at 24 months were significantly associated with sexual well-being up to 60 months. The odds of having poor sexual well-being over the last 3 years of follow-up were: 3–5 times higher among men with high anxiety (OR=3.41) and clinical levels of depression (OR=5.61); and were significantly lower among men who were very confident (OR=0.14) and men who had full social support (OR=0.26). Men with a higher quality of life/Global Health score at 24 months were less likely to report poor sexual well-being in later years (OR=0.97). The odds of poor sexual well-being at 3–5 years postsurgery significantly increased if men reported clinically significant problems with body image (OR=3.90), fatigue (OR=3.04) or pain (OR=1.73) at 24 months.

In the second step of the modelling (including time and all predictors in one model), having a stoma at 24 months remained a strong predictor of poor sexual well-being at later time points (OR=2.67). However, none of the psychosocial or quality of life factors remained significant, suggesting that their relationship with poor sexual well-being was explained by the presence of a stoma at 24 months.

### DISCUSSION

Sexual morbidity is a known consequence of treatment for colorectal cancer,<sup>55</sup> although it has been identified



**Table 3** Logistic regression modelling (ORs and 95% CIs) of poor sexual well-being among men after 24 months by the covariates reported at 24 months (N=260)

	Step 1* ORs (95% CI)	Step 2† ORs (95% CI)
<b>Age group</b>		
≤59	REF	REF
60–69	1.52 (0.64 to 3.61)	3.11 (0.97 to 9.95)
70+	1.29 (0.54 to 3.08)	2.01 (0.59 to 6.86)
<b>Deprivation index quintiles</b>		
First—least	REF	REF
Second	1.25 (0.61 to 2.58)	1.30 (0.54 to 3.16)
Third	1.43 (0.67 to 3.02)	1.09 (0.44 to 2.68)
Fourth	1.71 (0.81 to 3.63)	1.08 (0.43 to 2.71)
Fifth—most	1.87 (0.89 to 3.92)	1.57 (0.60 to 4.11)
<b>Domestic status</b>		
Married/coresiding	REF	REF
Single/widowed/divorced	1.18 (0.66 to 2.11)	0.57 (0.28 to 1.15)
<b>Tumour</b>		
Colon	REF	REF
Rectum	1.32 (0.82 to 2.14)	1.30 (0.57 to 2.96)
<b>Radiotherapy</b>		
No	REF	REF
Yes	1.40 (0.79 to 2.51)	0.47 (0.18 to 1.22)
<b>Chemotherapy</b>		
No	REF	REF
Yes	0.84 (0.52 to 1.37)	0.56 (0.30 to 1.07)
<b>Stoma</b>		
No	REF	REF
Yes	2.30‡ (1.22 to 4.34)	2.67‡(1.11 to 6.40)
<b>Surgery type</b>		
Laparoscopic	REF	REF
Open surgery	0.80 (0.48 to 1.33)	0.54 (0.28 to 1.04)
Unknown	3.40‡ (1.18 to 9.74)	1.74 (0.52 to 5.74)
<b>Self-efficacy Cancer Survivor Self-efficacy Scale)</b>		
Low confidence	REF	REF
Moderate confidence	1.01 (0.307 to 3.335)	1.30 (0.29 to 5.84)
Confident	0.70 (0.232 to 2.096)	1.58 (0.31 to 8.05)
Very confident	0.14§ (0.047 to 0.44)	0.33 (0.05 to 1.97)
<b>Anxiety State Trait Anxiety Inventory score &gt;40)</b>		
No	REF	REF
Yes	3.41¶ (1.62 to 7.18)	1.13 (0.31 to 4.11)
<b>Depression Centre for Epidemiological Studies Depression scale score &gt;20)</b>		
No	REF	REF
Yes	5.61§ (2.58 to 12.21)	2.58 (0.81 to 8.25)
<b>Social support (Medical Outcomes Study Social Support Survey)</b>		
<100 score	REF	REF
Score=100 (full support)	0.26§ (0.13 to 0.53)	0.59 (0.26 to 1.32)

Continued



Table 3 Continued

	Step 1* ORs (95% CI)	Step 2† ORs (95% CI)
QLQ-CR29 Body Image (European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C29)		
No	REF	REF
Yes, clinically significant	3.90§ (1.92 to 7.93)	1.71 (0.66 to 4.43)
Fatigue (EORTC QLQ-C30)		
No	REF	REF
Yes, clinically significant	3.04§ (1.74 to 5.32)	1.67 (0.77 to 3.64)
Pain (EORTC QLQ-C30)		
No	REF	REF
Yes, clinically significant	1.73‡ (1.04 to 2.88)	0.61 (0.29 to 1.26)
Quality of life/Global Health (EORTC QLQ-C30)		
Mean (SD)	0.97§ (0.95 to 0.98)	0.99 (0.97 to 1.02)

\*Adjusting for time and considering each covariate separately.

†Fully adjusted model, including time and all covariates.

‡p<.05.

§p<.001.

¶p<.01.

that support for sexual problems is seldom offered or sought.<sup>56</sup> Health professionals may lack knowledge, skills and confidence to address these issues<sup>57</sup>; patients may lack confidence, have low expectations of help or feel unentitled to help.<sup>58</sup> Knowing which people treated for colorectal cancer are likely to experience problems with sexual well-being, and over what time frame, is important for the delivery of personalised care and for the development of interventions to address such problems. CREW is the largest longitudinal study to date to explore a broad range of aspects of recovery from colorectal cancer, including sexual well-being. It has followed a representative UK sample from presurgery to 5 years postsurgery between 2010 and 2012. It is also one of a few studies to consider psychosocial predictors of sexual well-being.

More than one-third of the men in the study reported poor sexual well-being 5 years after their treatment for colorectal cancer. We identified a range of psychosocial variables—depression, anxiety, social support and self-efficacy—that were predictive of poor sexual well-being among men over the 5-year period. This is in support of Foster and Fenlon's framework of recovery of health and well-being,<sup>19</sup> which suggests the importance of wider personal and environmental factors in influencing well-being and coping. Use of such markers to identify people at risk would allow early intervention. Of particular note is that men who had higher levels of self-efficacy were less likely to report poor sexual well-being. This finding suggests that targeting improvements in self-efficacy may be a helpful focus for intervention to enhance sexual well-being. This is supported by reviews of interventions for sexual difficulties following cancer,<sup>59 60</sup> which highlight the importance of a self-efficacy element. However, further investigation of this association and of appropriate

interventions to boost self-efficacy is warranted. As self-efficacy is domain specific, with cancer survivors potentially having different levels of self-efficacy according to task<sup>61</sup>, the use of measures specific to sexual well-being, such as the Sexual Self-Efficacy Scale for Female Functioning<sup>62</sup> or the SECSI scale<sup>33</sup> should be considered.

Men with a stoma were also at increased risk of poor sexual well-being. Stoma-related sexual problems and negative associations of stoma with overall quality of life have been shown cross-sectionally.<sup>63 64</sup> Our findings indicate that it is important to discuss sexual well-being with men who require a stoma soon after their surgery and to continue those conversations over the longer term.

There was also a significant increase in poor sexual well-being among men over time. It has previously been suggested that there may be a focus on survival in the early phase of the cancer trajectory, with other issues becoming more important over time.<sup>58 65</sup> This illustrates the importance of continued screening and attention to sexual well-being among men over the whole course of surveillance.

Fewer women reported poor sexual well-being, with a stable pattern of around 10%–15% over time. Questions about sexual well-being were asked of all participants regardless of their sexual activity level, partnership status or level of interest in sex at baseline. The fact that fewer women than men reported being married/co-residing and fewer reported an interest in sex might explain why fewer women reported poor sexual well-being. Conversely, women may undertake a renegotiation of sexual activity, through non-coital sexual practices and a focus on intimacy.<sup>66</sup> Nonetheless, poor sexual well-being is clearly an issue for some women post cancer treatment and further research to provide greater understanding of this group remains important.

## Limitations

While there are numerous strengths to the study, such as the prospective, longitudinal design with presurgery assessment point and long-term follow-up, and the large and representative sample, there are some limitations which need to be considered. First, while study response rates were high, there were lower response rates to sexual well-being questions. For instance, at presurgery baseline 3% of men and 13% of women did not provide a sexual well-being score. Women were more likely overall to return a non-response to these questions. Second, it was not possible to run predictive models for women, due to the small number reporting poor sexual well-being. Less is known about women's sexual problems after colorectal cancer, partly because of commonly lower response rates to questions about sexuality from women.<sup>24</sup> We did not ask about sexual activity and cannot assess whether non-response was due to perceived irrelevance of the questions among those who were sexually inactive. Finally, while sexual well-being is a multifaceted construct,<sup>66</sup> it was operationalised using a two item scale of bother and satisfaction. Research in this field would benefit from standardised definitions and measures.

## Clinical implications

Screening, support and appropriate referral for the sexual consequences of cancer and its treatment is an essential part of personalised care. Clinicians should consider sexual well-being as well as sexual function, in order to take account of meanings that patients attribute to sexual changes following cancer treatment<sup>13</sup> and to best understand where intervention might be welcomed. Psychosocial indicators could be useful for identifying people at risk of poor sexual well-being, allowing early intervention to enhance sexual adaptation. A focus on improving self-efficacy levels could help to improve sexual well-being. The long-term nature of sexual well-being issues reinforces the need for ongoing survivorship support.

## CONCLUSION

While previous research has provided understanding of the prevalence and predictors of sexual dysfunction postcolorectal cancer treatment, much less is understood about sexual well-being. This is one of a few studies to consider a broad range of treatment and psychosocial factors associated with sexual well-being for people treated for colorectal cancer. Assessment of psychosocial factors could help identify those at risk of poor sexual well-being, allowing for early and continued intervention. In light of findings that patients rarely seek help for sexual problems, such predictors are of vital importance to a proactive approach from health professionals.

## Author affiliations

<sup>1</sup>Macmillan Survivorship Research Group, School of Health Sciences, University of Southampton, Southampton, UK

<sup>2</sup>University Hospital Southampton NHS Foundation Trust, Southampton, UK

<sup>3</sup>College of Human and Health Sciences, Swansea University, Swansea, UK

<sup>4</sup>School of Health Sciences, University of Southampton, Southampton, UK

<sup>5</sup>Social Statistics and Demography, University of Southampton, Southampton, UK

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## ORCID iD

Claire Foster <http://orcid.org/0000-0002-4703-8378>

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