

Psychological distress, quality of life, symptoms and unmet needs of colorectal cancer survivors near the end of treatment

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Received: 10 September 2014 / Accepted: 17 December 2014 / Published online: 9 January 2015
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Abstract

Purpose This study investigated psychological morbidity, quality of life (QoL), colorectal cancer (CRC)-specific symptoms and supportive care needs in a CRC population at the end of treatment (EOT).

Methods CRC survivors ($n=152$) completed a post-treatment baseline questionnaire as part of a multisite supportive care randomised controlled trial (SurvivorCare). CRC survivors had completed treatment with curative intent within 0 to 6 months. Measures are as follows: Brief Symptom Inventory 18 (BSI-18) (psychological morbidity), EORTC QLQ-C30 and QLQ-CR29 (QoL and CRC-specific symptoms and problems) and Cancer Survivors' Unmet Needs (CaSUN) measure with a simplified response format (unmet needs). Linear regression models were used to compare participants' QoL with

a general population sample. Correlation analysis examined associations between psychological morbidity, QoL and CRC-specific symptoms and problems.

Results Average participant age was 64 years, and 51 % were male. The majority (68 %) had stage 3 disease. In comparison to population norms, CRC survivors had lower depression and anxiety scores (47.4 and 45.6, respectively) but higher somatisation, and lower role, cognitive and social functioning ($p<0.001$). CRC survivors had higher fatigue, nausea/vomiting, appetite loss, diarrhoea and financial problems (all $p<0.001$), as well as pain ($p=0.002$) and constipation ($p=0.019$). CRC-specific psychological scores were positively correlated with all three BSI domain scores, and pain and fatigue symptom scores on the QLQ-C30 while negatively correlated with all five functional scales of the QLQ-C30.

Electronic supplementary material The online version of this article (doi:10.1007/s11764-014-0422-y) contains supplementary material, which is available to authorized users.

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Conclusions CRC survivors reported good mental health at EOT. Role and social functioning were impaired compared to population norms, possibly related to physical symptoms. **Implications for Cancer Survivors** Findings may help guide consultations with patients and inform the design of more tailored supportive care interventions.

Trial registration: ACTRN12610000207011

Keywords Colorectal cancer · Cancer survivor · Unmet needs · Quality of life · Psychological distress · End of treatment

Introduction

Colorectal cancer (CRC) is the most common cancer that affects both men and women with nearly 1.4 million new cases diagnosed worldwide in 2012 [1]. Outcomes are superior for people diagnosed with earlier stage disease. In 2007, in New South Wales, Australia, the 5-year survival rate for people diagnosed with localised CRC was 87 %, while regional and distant CRC diagnosis had a 5-year survival of 68 and 15 %, respectively [2]. Survival rates have improved substantially since the 1970s [3, 4]. In 2007, there were an estimated 100,000 Australian survivors of bowel cancer, one of the largest groups of cancer survivors [5]. The introduction and dissemination of national screening programmes for CRC, aiming to detect disease at an early stage, will further increase the number of survivors [6–8]. The impact of the disease and its treatments on long-term wellbeing is an important concern [9].

Cancer survivors may face numerous physical and psychological problems as a result of the disease and treatments. For example, in a study where CRC patients were followed up from 6 to 24 months post-surgery, participants reported many physical problems and information needs [10]. The main physical problems related to change in bowel habits with the three most frequently reported gastrointestinal problems being incomplete evacuation (75.2 %), excessive flatus (75.2 %) and urgency (73.3 %). The most frequently reported informational needs related to diet (50.5 %) and managing problems such as diarrhoea (31.7 %), bloating (28.7 %), pain (21.8 %) and incomplete emptying of the bowel (18.8 %). Many patients also feel ‘lost’ when they have finished their treatments for cancer [11]. Survivors frequently report fears about cancer recurrence, worries about leaving the health care system and uncertainties about the future [12]. In recognition of these survivorship issues, the American Society of Clinical Oncology and the US Institute of Medicine have issued recommendations encouraging further research into the experience and needs of cancer survivors [13]. While the general literature on cancer survivorship has burgeoned in the past few years, there are surprisingly few studies focusing on CRC. Furthermore, these few studies are limited in their generalisability due to small

sample size [14], low response rates [15, 16] or have a focus on long-term (>5 years) effects of CRC treatment [17]. Little is known about CRC patients’ quality of life (QoL), level of distress and needs following treatment completion and how these needs might inform the development of models of post-treatment care. The aims of this paper are to describe 1) psychological morbidity and quality of life in CRC patients at treatment completion, with reference to the general population, 2) CRC-specific symptoms and problems and supportive care needs and also 3) the association between psychological morbidity, quality of life and CRC-specific symptoms and problems.

Methods

Design and setting

This study reports post-treatment baseline data collected as part of a multisite randomised controlled trial evaluating a nurse-led survivorship care package for people with CRC treated with curative intent [18, 19]. Sites were selected based on their proximity to patients, availability of resources to conduct the study and the availability of at least one nurse to administer the intervention. Eighteen sites were involved in the trial from three states in Australia: Victoria, Tasmania and New South Wales. Public and private hospitals from regional and metropolitan areas were represented across the three states. All hospitals treat significant numbers of CRC patients. Approval was obtained from relevant Human Research Ethics Committees for all sites.

Patient population

Eligibility criteria for the trial required that each patient had a confirmed diagnosis of colon or rectal cancer with stage I, II or III disease; was treated for curative intent with surgery ± radiation ± chemotherapy; was no more than 6 months post-treatment completion; was over 18 years; and was able to understand English. Patients were ineligible if they had documented cognitive or psychological impairment, were too unwell as advised by the patient’s treating team, had a prior history of another malignancy (other than non-melanomatous skin cancer) or were enrolled in a conflicting supportive care trial that might impact the endpoints measured in the study. Only participants who had completed their treatment or were on the last day of treatment when they completed their baseline assessment were included in these analyses.

Recruitment and assessment procedure

Eligible patients were identified from outpatient clinic lists and treatment lists at each site between March 2011 and

January 2014 by trained data managers with the aim of approaching a consecutive sample of eligible patients. Potential participants were approached 0 to 6 months prior to the end of treatment (preferably) or up to 6 months after completing treatment. Written informed consent was obtained. Permission to collect basic demographic and clinical information from medical records was sought from patients who chose not to participate in the trial. Reasons for refusal were also requested and recorded. Consenting participants were asked to complete a baseline questionnaire on the day of randomisation, which could range between 2 weeks before end of treatment and 6 months post-treatment. Most questionnaires were filled out at the hospital while patients were waiting for randomisation arm allocation. Patients who completed questionnaires at home were followed up by the site data manager and reminded to return their questionnaire.

Measures

Age, gender, marital status, area of residence, country of birth, occupation and education level were self-reported via questionnaire. Patients' date of CRC diagnosis, site and stage of disease were collected from medical records.

Psychological morbidity was assessed using the Brief Symptom Inventory 18 (BSI-18) [20, 21]. The BSI-18 is an 18-item self-report symptom inventory in which each item is rated on a five-point scale. It was designed to assess somatisation, depression and anxiety in cancer populations and has demonstrated reliability, validity, acceptability and responsiveness. BSI-18 raw scores were converted to standardised scores using the community norms as recommended in the scoring and procedures manual. Higher scores indicate greater psychological morbidity.

Quality of life and CRC-specific symptoms and problems were assessed with the European Organisation for Research and Treatment of Cancer core questionnaire (QLQ-C30) [22] and CRC module (QLQ-CR29) [23]. Together, these questionnaires comprise 59 items assessing five domains of functioning (physical, role, emotional, cognitive and social), symptoms and problems associated with cancer and its treatment. The measures have good test-retest validity, reliability, acceptability and responsiveness and are both widely used. Higher QLQ-C30 functional scale scores indicate higher levels of functioning. Higher QLQ-C30 symptom scale/item scores and CR29 scale/item scores indicate greater intensity of symptomatology or problems.

Supportive care needs were assessed with the Cancer Survivors' Unmet Needs measure (CaSUN) [24]. It comprises 35 need items mapping to five domains of need (existential survivorship, comprehensive care, information, quality of life and relationships), six positive change items and an open-ended question. Preliminary evidence for acceptability, internal consistency and validity has been reported. A simplified

response format consistent with the strength of need scoring described in the CaSUN scoring manual was used in this study [25]. Higher item scores indicate higher levels of need.

Other data sources

QLQ-C30 general population data were provided by the lead investigator, University of Sydney, on behalf of the MAUCa Consortium. Data were gathered as part of a cancer-specific, multi-attribute, utility instrument development project. Study questionnaires, which included the QLQ-C30, were administered to a large Australian general population sample (or panel) via a web-based opinion-seeking company, PureProfile (<http://www.pureprofile.com/au>). As sample characteristics from the general population were unavailable, it was not possible to match them with the SurvivorCare sample on factors predictive of poorer outcomes (age, sex and marital status) [26], so an adjustment was made for these factors at the analysis stage [27]. Of 449 panel participants, 421 had complete data for regression modelling.

Statistical methods

Descriptive statistics were used to summarise patient characteristics and scale/item scores generated by study measures. The date of questionnaire completion and the date of the last day of treatment were used to calculate days since end of treatment; then, Spearman's rank correlation coefficient was used to investigate the association between days since end of treatment and scale/item scores.

Adjusted linear regression models were used to compare QLQ-C30 scale/item scores between the SurvivorCare and the general population samples. Adjusted models included the following variables: age, sex (male/female) and marital/relationship status (not married or not in a de facto relationship/married or in a de facto relationship). Evidence-based guidelines were used to interpret the sizes of between-group differences [28].

Responses to the CaSUN were recoded to discrete variables comprising two ordered categories (no/low need and moderate/high need); then, relative frequencies were computed for each variable.

Responses to CR29 items were used to compute mean intensity scores for urinary, bowel and psychological symptoms or problems. In this case, responses to items were summed then divided by the total number of items. The urinary summary included items 1, 2, 3 and 4; the bowel summary items 5, 7, 19, 20, 22, 23 and 25; and the Psychological summary items 13, 14, 15, 16, 17 and 24. Spearman's rank correlation coefficient was used to investigate the association between the CR29 summary scores and scales comprising the BSI-18 and QLQ-C30.

SPSS Version 21 (Chicago IL, USA) was used for exploratory data analysis, scoring and descriptive and regression analysis. R (reference index version 3.1.0 “Spring Dance”) [29] was used for correlational analysis; the “RVAideMemoire” package [30] was used to compute confidence intervals for Spearman’s rank correlation coefficients by bootstrapping. Coefficients were interpreted as follows: 0.1 small-sized association, 0.3 medium-sized association and 0.5 large-sized association [31]. Alpha was set at 0.05 (two-tailed) for all analyses with no adjustment for multiplicities [32].

Results

Participant characteristics

Of 220 patients recruited to the SurvivorCare trial, 152 completed baseline measures on or after the last day of treatment. Demographic and clinical characteristics for this group are reported in Table 1. Participants were 64 years of age on average and just over half (51 %) were male. Most were married or in a de facto relationship (70 %) and were born in Australia (82 %). A majority had been diagnosed with colon cancer (54 %). Most had stage III disease (68 %).

Patient reported outcome measures

Psychological distress

The mean BSI-18 Global Severity Score (49.2; Table 2) for CRC survivors was approximately at the community norm (mean 50, standard deviation 10). Mean Depression and Anxiety dimension *T* scores (47.4 and 45.6, respectively) were lower than community norms, whereas the mean somatisation dimension *T* score (54.1) was higher. Somatisation scores were higher for CRC survivors recruited closer to the end of treatment than those recruited further out from treatment ($\rho = -0.11$; Table 2).

Quality of life

Compared with the general population sample, CRC survivors reported lower role, cognitive and social functioning (all $p < 0.001$; Table 3). According to evidence-based guidelines [28], mean differences adjusted for age, sex and marital status were small-sized for role and cognitive functioning and medium-sized for social functioning. For CRC survivors, self-reported role and social functioning were lower in CRC survivors recruited closer to the end of treatment ($\rho = 0.19$ and 0.18 , respectively; Table 2). Statistically significant

Table 1 Patient characteristics

Characteristic	<i>N</i> (152)	Percentage
Age (years)		
Mean (SD)	63.9 (11.0)	
Median (IQR)	64 (55, 73)	
Gender		
Male	77	50.7
Remoteness area		
Major city	75	49.3
Regional	76	50.0
Remote/very remote	1	0.7
Marital status ^a		
Married/de facto	107	70.4
Not married/de facto	45	29.6
Country of birth		
Australia	124	81.6
Other	28	18.4
First language		
English	145	95.4
Other	7	4.6
Employment situation ^b		
Working	43	28.3
Retired	69	45.4
Other	40	26.4
Site of disease ^c		
Colon	82	53.9
Rectum	57	37.5
Overlapping	15	9.9
Disease stage		
I	12	7.9
II	36	23.7
III	104	68.4
Treatment		
Surgery	13	8.6
Surgery + chemotherapy	92	60.5
Surgery + chemo + radiotherapy	47	30.9

^a Includes never married, separated/divorced and widowed

^b Other includes sick leave, not employed, home duties and studying

^c Multiple responses, so does not add to 152

differences between the general population and CRC survivors were also observed for fatigue, nausea/vomiting, appetite loss, diarrhoea and financial problems (all $p < 0.001$; Table 3), as well as pain ($p = 0.002$) and constipation ($p = 0.019$). Most adjusted differences were small-sized. Self-reported pain was lower on average among CRC survivors. Fatigue, nausea/vomiting, appetite loss and diarrhoea were higher in CRC survivors recruited closer to the end of treatment ($\rho = -0.19$, -0.28 , -0.16 and -0.12 , respectively; Table 2).

Table 2 Descriptives for BSI and QLQ-C30 scales and items and their associations with days since the end of treatment

Measures	Number	Mean	SD	rho ^a	95 % CI for rho
BSI standardised community norms					
Somatisation	151	54.1	8.9	-0.11	(-0.26, 0.04)
Depression	151	47.4	8.1	-0.01	(-0.19, 0.16)
Anxiety	151	45.6	7.9	0.06	(-0.10, 0.21)
Global severity index	151	49.2	9.0	-0.05	(-0.21, 0.11)
EORTC QLQ-C30					
Global	151	68.9	19.5	0.20	(0.04, 0.35)
Physical	151	82.6	16.2	0.10	(-0.06, 0.26)
Role	151	73.0	26.7	0.19	(0.04, 0.35)
Emotional	151	82.3	17.9	-0.02	(-0.19, 0.13)
Cognitive	151	78.4	21.7	-0.08	(-0.25, 0.08)
Social	151	74.5	23.6	0.18	(0.02, 0.33)
Fatigue	151	35.8	22.6	-0.19	(-0.33, -0.03)
Nausea/vomiting	151	8.2	14.3	-0.28	(-0.42, -0.13)
Pain	151	18.0	24.8	-0.04	(-0.18, 0.10)
Dyspnoea	151	14.6	22.6	-0.01	(-0.17, 0.14)
Insomnia	150	28.2	26.1	-0.04	(-0.21, 0.11)
Appetite loss	151	16.1	23.7	-0.16	(-0.32, -0.01)
Constipation	150	15.6	25.5	0.00	(-0.16, 0.16)
Diarrhoea	150	20.2	24.7	-0.12	(-0.28, 0.06)
Financial problems	151	18.1	26.9	0.00	(-0.16, 0.16)

^a Spearman's rank correlation coefficient for days since the end of treatment with BSI-18 and QLQ-C30 scale/item scores. Associations are statistically significant if the 95 % CI for the estimate does not include 0

Table 3 Comparison between SurvivorCare and general population samples on QLQ-C30

Scale/item	Unadjusted mean		Adjusted difference ^a	95 % CI for adjusted difference	p value	Evidence-based effect size ^b
	Survivor care	General population				
Physical	82.6	84.8	-0.9	(-4.7, 2.9)	0.66	Trivial
Role	73.0	84.6	-12.9	(-18.1, -7.7)	<0.001	Small
Emotional	82.3	72.5	4.4	(0.0, 8.8)	0.051	
Cognitive	78.4	83.2	-7.9	(-12.2, -3.6)	<0.001	Small
Social	74.5	84.0	-11.2	(-16.3, -6.2)	<0.001	Medium
Fatigue	35.8	29.5	9.0	(4.5, 13.5)	<0.001	Small
Nausea/vomiting	8.2	6.2	5.1	(2.4, 7.7)	<0.001	Small
Pain	18.0	26.6	-8.6	(-14.0, -3.3)	0.002	Small
Dyspnoea	14.6	14.3	1.0	(-3.7, 5.7)	0.68	Trivial
Insomnia	28.2	28.7	4.3	(-1.4, 10.0)	0.14	Small
Appetite loss	16.1	10.9	8.7	(4.4, 13.0)	<0.001	Small
Constipation	15.6	11.1	5.3	(0.9, 9.8)	0.019	Small
Diarrhoea	20.2	8.3	15.6	(11.7, 19.6)	<0.001	At least medium
Financial problems	18.1	12.1	9.9	(4.8, 15.0)	<0.001	Small
Global health status	68.9	63.2	4.2	(-0.3, 8.6)	0.065	Small

^a Difference from general population (N=421) on QLQ-C30 scales and items adjusted for age, sex and marital status

^b Based on guidelines for trivial, small, medium and large effects provided in Table 4 of Cocks et al. [28] (no estimate provided for Emotional functioning and estimates for large effects not provided for diarrhoea and financial problems)

Colorectal cancer-specific symptoms and problems

At the end of treatment, many CRC survivors were still experiencing a number of symptoms and problems associated with CRC and its treatment (Online Resource 1). The following symptoms were experienced quite a bit or very much by 20 % or more of the entire sample: urinate frequently, day (31 %); worried about future health (27 %); and problems with taste (22 %). The following symptoms were experienced quite a bit or very much by 20 % or more of the no stoma sample (n=95): frequent bowel movements, day (25 %), and flatulence (24 %). Frequent bag changes during the day were experienced quite a bit or very much by 20 % of the sample with a stoma. Impotence was experienced quite a bit or very much by 34 % of male CRC survivors.

Supportive care needs

When ranked by prevalence, all of the top five supportive care needs related to comprehensive care needs (Online Resource 2). Specifically, approximately 50 % or more of CRC survivors rated the following as moderate or high needs: I need to know that all my doctors talk to each other to coordinate my care (68 %), I need to feel like I am managing my health together with the medical team (57 %), I need the very best medical care (56 %), I need any complaints regarding my care to be properly addressed (55 %) and I need local health services that are available when I require them (46 %). Also

Table 4 Associations for CR29 summary scores with BSI and QLQ-C30 scale scores

Measure	Urinary summary		Bowel summary		Psychological summary	
	Estimate	95 % CI for estimate	Estimate	95 % CI for estimate	Estimate	95 % CI for estimate
BSI						
Somatisation	0.20	(0.04, 0.34)	0.21	(0.05, 0.36)	<i>0.32</i>	(0.17, 0.45)
Depression	0.26	(0.10, 0.41)	0.24	(0.08, 0.39)	<i>0.51</i>	(0.38, 0.64)
Anxiety	0.21	(0.03, 0.37)	0.25	(0.07, 0.40)	<i>0.43</i>	(0.28, 0.56)
QLQ-C30						
Physical functioning	<i>-0.32</i>	(-0.48, -0.16)	<i>-0.34</i>	(-0.48, -0.20)	<i>-0.46</i>	(-0.58, -0.31)
Role functioning	-0.15	(-0.31, 0.01)	<i>-0.31</i>	(-0.45, -0.16)	<i>-0.39</i>	(-0.52, -0.25)
Emotional functioning	-0.15	(-0.30, 0.01)	-0.24	(-0.40, -0.07)	<i>-0.52</i>	(-0.63, -0.38)
Cognitive functioning	-0.11	(-0.28, 0.03)	<i>-0.30</i>	(-0.45, -0.13)	<i>-0.38</i>	(-0.52, -0.24)
Social functioning	-0.06	(-0.21, 0.09)	-0.28	(-0.42, -0.12)	<i>-0.51</i>	(-0.64, -0.39)
Fatigue	0.19	(0.03, 0.34)	<i>0.33</i>	(0.16, 0.49)	<i>0.49</i>	(0.36, 0.60)
Nausea/vomiting	-0.01	(-0.17, 0.15)	0.15	(-0.03, 0.31)	0.18	(0.04, 0.32)
Pain	0.14	(-0.02, 0.29)	<i>0.37</i>	(0.22, 0.51)	<i>0.39</i>	(0.25, 0.52)

All medium-sized associations are in italics for emphasis. Associations are statistically significant if the 95 % CI for the estimate does not include 0

prevalent was the need for understandable information (38 %), up-to-date information (29 %), help managing side effects/complications of treatment (29 %), help managing concerns about the cancer coming back (33 %), accessible hospital parking (34 %) and access to complementary and/or alternative therapies (30 %).

Correlations between BSI, QLQ-C30 and CR29 summary scores

The CR29 psychological summary exhibited medium- to large-sized associations with all three BSI-18 dimension *T* scores ($\rho=0.32$ to 0.51), all five QLQ-C30 functional scores ($\rho=-0.38$ to -0.52) and the QLQ-C30 fatigue ($\rho=0.49$) and pain ($\rho=0.39$) scores. In contrast, the CR29 bowel summary exhibited medium-sized associations with the QLQ-C30 physical, role and cognitive functioning scales ($\rho=-0.30$ to -0.34) and fatigue and pain scales ($\rho=0.33$ to 0.37). The CR29 urinary summary exhibited a medium-sized association with the QLQ-C30 physical functioning scale ($\rho=-0.32$). All other associations with the CR29 summary scores were trivial to small sized ($\rho=-0.29$ to 0.29).

Discussion

This study described psychological morbidity and quality of life in CRC patients at the end of treatment with reference to the general population and examined CRC-specific symptoms and problems and supportive care needs. We also assessed the

association between psychological morbidity, quality of life and CRC-specific symptoms and problems at the end of treatment.

Our study population reported lower levels of anxiety and depression compared to community norms. These results are consistent with other studies where low levels of distress were found in patients 6 and 12 months post-diagnosis in a study assessing prevalence, course and predictors of distress in CRC patients [16]. Also, a Swedish study reported overall levels of anxiety and depression to be low in people who were believed to be cured [33]. Somatisation was higher in our population compared to community norms but was higher in those patients recruited nearer to the end of treatment than those recruited up to 6 months after treatment completion. This may reflect persisting symptoms at the end of treatment that improve with time. Following treatment completion, more attention can be put to self-care such as managing diet. Future studies might usefully examine the changing nature of treatment and cancer bodily impacts and the approaches patients take to alleviate them.

Indeed, when compared to the general population, CRC patients who had recently completed treatment were still impacted in their role, cognitive and social functioning. They also experienced symptoms such as fatigue, nausea/vomiting, appetite loss, diarrhoea and constipation as well as reporting financial problems. However, as observed in other studies of CRC patients, symptoms of fatigue, nausea/vomiting, appetite loss and diarrhoea tended to decline as days since the end of treatment increased, while role and social functioning tended to improve [34, 35]. These findings are similar to a German study assessing QoL of CRC patients 1 year post-diagnosis

[9]. Interestingly, CRC participants in this study seemed to have better emotional functioning than the general population, perhaps explained by low levels of anxiety and depression.

Financial problems were a greater issue in the study population compared to the general population. This problem is reported in other cancer populations where post-treatment symptoms may prevent patients from returning to work, adding financial pressure. Long-term breast cancer survivors still experience financial difficulties after an average of 12.5 years post-treatment when compared to age-matched non-cancer controls [36], and poorer social functioning was associated with serious financial burden in head and neck cancer patients [37]. A qualitative study exploring the financial impact of a cancer diagnosis and treatment revealed “the multidimensional nature of the financial burden that cancer poses on patients and their family” [38]. It is important that patients with these issues are identified as early as possible and given advice and access to appropriate benefits.

Urinary frequency, flatulence and frequent bowel movement were the most frequently experienced CRC-specific symptoms and may have impacted role and social functioning among our study participants as urgency; incontinence and embarrassment may prevent social participation. The CR29 correlation matrix also highlights this association with urinary and bowel scores showing a negative relationship with role and social functioning, indicating that the stronger bowel and/or urinary symptoms were, the poorer participants performed socially and/or in their daily tasks. Over a third of the men in this study reported impotence as a main concern, which supports the findings that the prevalence of sexual dysfunction among CRC survivors is high [39]. This highlights the need for pre-treatment counselling and efforts to prevent and treat sexual problems. Problems with taste were also frequently endorsed. Although taste disturbance is more commonly reported by people currently on treatment, it may persist for some time after treatment completion [34, 40, 41].

Of the study population, 27 % reported worries about their future health. This may relate to the removal of regular contact with the medical team [42], it may suggest that patients need to better understand their risk and be guided to plan for the future [43], or it may be a reflection of some participants’ fear of cancer recurrence, as this is also a prevalent post-treatment concern in cancer survivors [44, 45]. This is supported by the reported needs of the participants, with a third of the study population needing help to manage concerns about their cancer coming back.

The psychological summary scores of the CR29 were positively associated with all three domains of the BSI, and with fatigue and pain symptoms on the QLQ-C30 meaning that patients with distress, fatigue and pain reported higher psychological morbidity. A negative association was observed between the psychological summary scores and all functional domains of the QLQ-C30: higher psychological morbidity

was associated with impaired physical, role, emotional, cognitive and social functioning.

Patients reported the need for comprehensive care. They wanted to receive understandable and up-to-date information and needed help to access complementary and/or alternative therapies, manage side effects/complications of treatment and help to access hospital parking. These results provide useful information to help guide discussions during patient consultations.

One strength of this study is that participants were recruited across three states from a wide range of hospitals. They were typical of the age range of CRC patients [15, 46]. These factors improve the ability to generalise from these results. However, 80 % of participants were Australian born and 96 % have English as their first language, which are not typical of the wider multicultural population of Australia. A requirement that participants have a good level of English understanding (as some measures were only available in English) is likely to have prevented the enrolment of people from culturally and linguistically diverse populations. The application of well-established QoL and distress measures enabled comparison with other studies.

The major limitations of this study are twofold. Firstly, there are limitations related to the general population sample used for comparison. The details of the sample are not known to the researchers preventing the assessment of the differences in demographic characteristics between the two groups. To compensate, adjustments for age, sex and marital status were made in these analyses; however, we were not able to adjust for other potential differences such as socio-economic status given the financial incentives used to recruit the comparison general population sample. Secondly, these analyses were based on a single time-point, and future research examining the pattern of symptoms, QoL and unmet needs over time is warranted.

In summary, this group of CRC survivors had good quality of life, good psychological status and moderate symptom scores. There is an indication that the adverse effects of CRC and its treatment abate over time. Importantly, a small subset of CRC survivors have higher needs, higher distress levels and lower quality of life in the first 6 months post-treatment. Further longitudinal studies are necessary to examine if these factors predict poorer adjustment over time.

Findings from this study have important implications for clinical care and for further research. In clinical practice, patients and clinicians can be advised that some symptoms may be expected but that psychological problems appear uncommon, compared with the general population. Clinicians should be alert to these symptoms and problems and make specific enquiries. From a research perspective, these are areas that might be the target for interventions. Our results also query whether distress or global quality of life are appropriate endpoints for studies that target this group of patients.

Acknowledgments The authors would like to thank all patients for volunteering their time to make this study possible. QLQ-C30 normative data were provided by Professor Madeleine King, The University of Sydney, on behalf of the MAUCa Consortium. Dr. Daniel Costa provided data management for the QLQ-C30 normative data. We also thank Lisa Demosthenous, Matthew Holmes, Anna Ugalde and Felicity Pendergast for their involvement with SurvivorCare.

Conflict of interest This project was funded by the Victorian Cancer Agency: Grant number: EO109_74 and Cancer Australia/Beyond Blue: Grant number: 628581. The funding bodies had no role in the design of the study nor in the collection, analysis and interpretation of data, or writing of the manuscript. Jane Young is supported by a Cancer Institute NSW Academic Leader in Cancer Epidemiology Award.

Lahiru Russell, Karla Gough, Allison Drosdowsky, Penelope Schofield, Sanchia Aranda, Phyllis N Butow, Jennifer A Westwood, Mei Krishnasamy, Jo Phipps-Nelson and Michael Jefford declare that they have no conflict of interest.

Informed consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

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