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ORIGINAL REPORT

Identifying Social Distress: A Cross-Sectional Survey of Social Outcomes 12 to 36 Months After Colorectal Cancer Diagnosis

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Terms in blue are defined in the glossary, found at the end of this article and online at www.jco.org.

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ABSTRACT

Purpose
To establish the prevalence and determinants of poor social outcomes after a diagnosis of colorectal cancer (CRC).

Patients and Methods
All 12- to 36-month survivors of CRC (International Classification of Diseases [10th revision] codes C18 to C20) diagnosed in 2010 or 2011 and treated in the English National Health Service were identified and sent a questionnaire from their treating cancer hospital. This included the Social Difficulties Inventory, a 16-item scale of social distress (SD) comprising everyday living, money matters, and self and others subscales, plus five single items. Sociodemographic and clinical data were also collected. Analyses using descriptive statistics, χ^2 tests, and logistic regression models were conducted.

Results
Response rate was 63.3% (21,802 of 34,467). Of the 21,802 participants, 17,830 (81.8%) completed all SD items; 2,688 (15.1%) of these 17,830 respondents were classified as experiencing SD (everyday living, 19.5%; money matters, 15.6%; self and others, 18.1%). Multivariable analysis demonstrated having ≥ three long-term conditions was the strongest predictor of SD (odds ratio [OR], 6.64; 95% CI, 5.67 to 7.77 compared with no long-term conditions), followed by unemployment (OR, 5.11; 95% CI, 4.21 to 6.20 compared with being employed), having recurrent or nontreatable disease (OR, 2.75; 95% CI, 2.49 to 3.04 compared with being in remission), and having a stoma (OR, 2.10; 95% CI, 1.86 to 2.36 compared with no stoma). Additional predictors of SD were young age (< 55 years), living in a more deprived area, nonwhite ethnicity, having advanced-stage disease, having undergone radiotherapy, and being a carer.

Conclusion
Although it is reassuring a majority do not experience social difficulties, a minority reported significant SD 12 to 36 months after diagnosis of CRC. The identified clinical and social risk factors are easy to establish and should be used to target support.

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INTRODUCTION

Improvements in survival and a slight rise in incidence have resulted in an increase in the number of people living with and beyond a diagnosis of colorectal cancer (CRC).[1,2] Most patients report good health-related quality of life (QOL) in the years after treatment, but some fare less well, especially those with comorbidity.[3-6] One study reported high overall QOL, with relatively good physical functioning, but poor social and emotional outcomes compared with the general population in 307 survivors of CRC at 12 and 36 months postdiagnosis.[3] This has implications for how health and social care providers may best identify those in need of support or rehabilitation after primary cancer treatment.

To date, large-scale surveys of patients with cancer have included QOL instruments measuring psychological distress and unmet needs. The importance of social impacts is recognized as the number of people reintegrating into everyday life with rehabilitation needs increases, but measurement of social impacts has been neglected.[7] A number of instruments covering a range of social impacts have been developed over the last decade.[8] The Social Difficulties Inventory (SDI-21) specifically assesses difficulties patients with cancer may experience with everyday issues involving home and work, finances

and relationships, and recreation.[9] It has been used to collect information on problems experienced by individuals living with and beyond cancer.[10-13]

This study reports the findings of the SDI-21 in a survey of all individuals alive 12 to 36 months after a CRC diagnosis in England. The primary aims were to establish the prevalence and determinants of poor social outcomes after CRC and identify factors that can be used to support targeted delivery of social support.

PATIENTS AND METHODS

Study Design

The study design has been described in detail elsewhere.[10] Briefly, approval was given to approach patients without informed consent by the National Information Governance Board (reference No. ECC 5-02[FT8]/12), and research ethical approval on the survey data captured was granted by the East of Scotland Research Ethics Committee (reference No. 08/S0501/66). The National Cancer Registration Service identified all individuals age > 16 years who had survived 1 to 3 years from a diagnosis of CRC (International Classification of Diseases [10th revision] codes C18 to C20) in 2010 or 2011 and were treated in the National Health Service in England. Identified individuals were sent a standard letter from their cancer center and a questionnaire (Data Supplement). Two reminders were sent to nonresponders. The questionnaire included a validated measure of social problems in cancer patients (ie, SDI-21).[9]

Data Handling

Age categories (< 55, 55 to 64, 65 to 74, 75 to 84, and ≥ 85 years), sex, and Dukes' stage at diagnosis were obtained from cancer registry data. Deprivation category was based on the Index of Multiple Deprivation,[14] derived from the postcode of residence. Self-reported ethnicity was grouped (white v nonwhite). Long-term conditions (LTCs) other than cancer were selected from a list used in English health surveys by the Department of Health (Data Supplement), categorized as follows: no other, one other, two other, or ≥ three other LTCs or not known (no response). Self-reported disease status was categorized as either remission or other (recurrent, nontreatable disease, or uncertain about disease status). The questionnaire asked about treatment (any surgery, radiotherapy, or chemotherapy), stoma status (present, reversed, or never formed), and current employment status (employed, unemployed [with subcategories of seeking work or unable to work for health reasons], retired, or other or not known), living arrangements (living with partner, spouse, family, or friends, living alone, or other or not known), and carer responsibilities (looking after family, friend, or neighbor because of long-term health problems or old age [yes v no]).

The SDI-21 is a 21-item questionnaire with the following response categories: no difficulty (rated 0), a little difficulty (rated 1), quite a bit of difficulty (rated 2), very much difficulty (rated 3), does not apply (rated 0; Data Supplement).[9] Sixteen of the items form a measure of social distress (SD), with a score range (following Rasch-adjusted scoring on four items) of 0 to 44 (SD-16 scale)[15] and comprising three subscales: everyday living, money matters, and self and others (Fig 1).[16] A validated cut point of ≥ 10 on the SD-16 scale indicates SD warranting follow-up up by health or social care staff[17]; this was used in our analyses as a binary cut point (not socially distressed v socially distressed). Subscale group cut points for the purpose of this work were estimated based on the number of items in each subscale, using observations from the original Rasch analysis, in which items from the money matters subscale were hardest to endorse and those from the everyday living subscale easiest to endorse,[15] and examining clinically meaningful subscale differences from earlier work.[16] This resulted in estimated cut points of 5 for the everyday living subscale, 2 for the money matters subscale, and 3 for the self and others subscale.

The SDI-21 also includes five single items. These indicate difficulties with the following: sexual matters, plans to have a family, where you live, plans to travel or take a holiday, and any other difficulty.
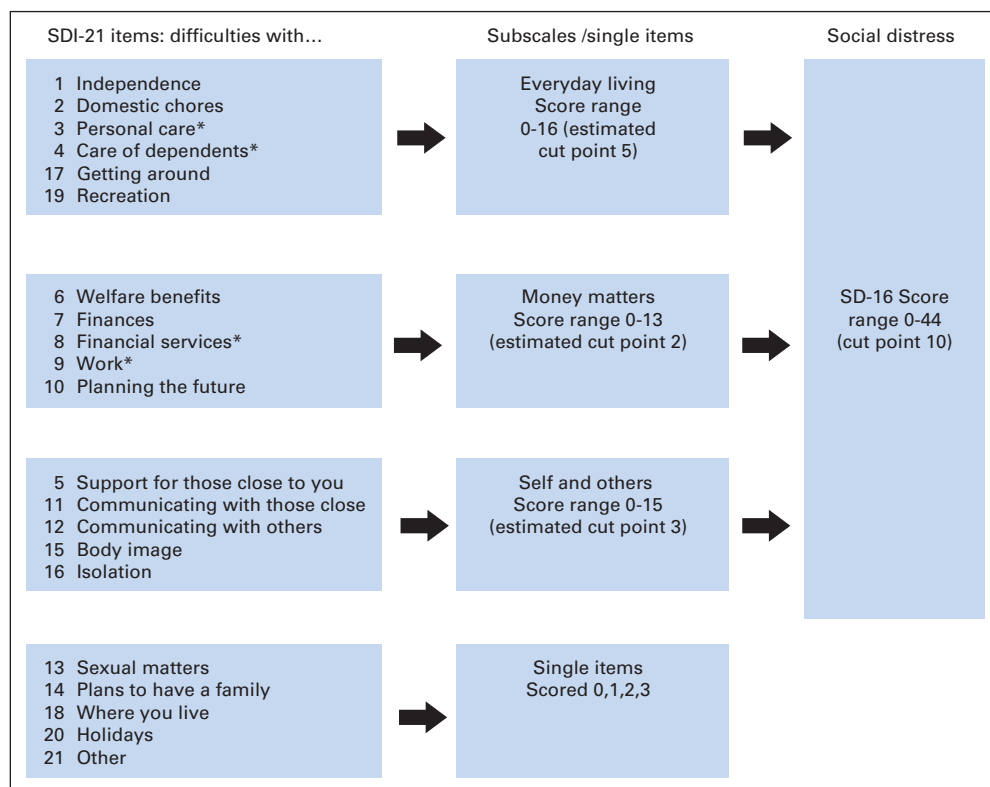

Fig 1. Social Difficulties Inventory (SDI) scoring guidance. SD, social distress. (*) Adjusted scoring derived from Rasch analysis (0,1,2,2).

Table 1. Characteristics of Survey Respondents				
	All Respondents (N = 21,802)		SD-16 Respondents (n = 17,830)	
Characteristic	No.	%	No.	%
Sex				
Male	12,683	58.2	10,715	60.1
Female	9,119	41.8	7,115	39.9
Age, years				
< 55	2,040	9.4	1,860	10.4
55-64	5,154	23.6	4,602	25.8
65-74	7,824	35.9	6,428	36.1
75-84	5,633	25.8	4,151	23.3
≥ 85	1,151	5.3	789	4.4
Index of Multiple Deprivation				
1 (least deprived)	5,484	25.2	4,682	26.3
2	5,360	24.6	4,435	24.9
3	4,742	21.8	3,858	21.6
4	3,658	16.8	2,894	16.2
5 (most deprived)	2,558	11.7	1,961	11.0
Race/ethnicity				
White	20,758	95.2	17,084	95.8
Nonwhite	454	2.1	355	2.0
Not known	590	2.7	391	2.2
Dukes' disease stage at diagnosis				
A	3,533	16.2	2,938	16.5
B	7,376	33.8	5,921	33.2
C	7,638	35.0	6,280	35.2
D	1,379	6.3	1,137	6.4
Not known	1,876	8.6	1,554	8.7
No. of LTCs				
None	4,651	21.3	4,090	22.9
1	6,476	29.7	5,414	30.4
2	4,523	20.7	3,645	20.4
≥ 3	4,981	22.8	3,858	21.6
No response	1,171	5.4	823	4.6
Tumor site				
Colon	13,577	62.3	11,031	61.9
Rectosigmoid	1,512	6.9	1,252	7.0
Rectum	6,713	30.8	5,547	31.1
Treatment				
Surgery				
No	1,702	7.8	1,212	6.8
Yes	20,100	92.2	16,618	93.2
Radiotherapy				
No	17,502	80.3	14,300	80.2
Yes	4,300	19.7	3,530	19.8
Chemotherapy				
No	11,599	53.2	9,160	51.4
Yes	10,203	46.8	8,670	48.6
Stoma status				
No stoma	11,821	54.2	9,949	55.8
Reversed	3,378	15.5	2,891	16.2
Present	4,487	20.6	3,571	20.0
No response	2,116	9.7	1,419	8.0
Disease status				
Remission	16,642	76.3	14,067	78.9
Other or not known	5,160	23.7	3,763	21.1
Current employment status				
Employed	3,493	16.0	3,205	18.0
Unemployed	936	4.3	792	4.4
(continued in next column)				

Table 1. Characteristics of Survey Respondents (continued)				
	All Respondents (N = 21,802)		SD-16 Respondents (n = 17,830)	
Characteristic	No.	%	No.	%
Retired	15,314	70.2	12,443	69.8
Other or not known	2,059	9.4	1,390	7.8
Current living arrangements				
Live with spouse or family	14,297	65.6	12,182	68.3
Live alone	4,709	21.6	3,646	20.5
Other or not known	2,796	12.8	2,002	11.2
Current carer status				
No	17,339	79.5	14,156	79.4
Yes	4,463	20.5	3,674	20.6
Total	21,802	100.0	17,830	100.0

Abbreviations: LTC, long-term condition; SD, social distress.

Statistical Analysis

Descriptive statistics compared those who completed the SD-16 measure and those who did not, as well as responses across the SD scale, subscales, and five single items. χ^2 tests compared categorical variables. Variables were entered into logistic regression models based on their a priori clinical and public health importance. Where variables were highly correlated (eg, tumor site and stoma status), only one was included in multivariable analyses (based on clinical interpretation). Statistical significance was set at 1%. Analyses were performed using STATA software (version 13.1; STATA, College Station, TX).

RESULTS

Response Rates

The response rate was 63.3% (21,802 of 34,467). The elderly, those from ethnic minorities, and those living in more deprived areas were less likely to participate (all $P < .001$). Of the 21,802 responders, 16,962 (77.8%) completed all SDI-21 items, and 17,830 (81.8%) completed the questions making up the SD-16 measure. Completion rates for the five single items were as follows: sexual matters, 17,504 (80.3%); plans to have a family, 17,550 (80.5%); where you live, 17,784 (81.6%); plans to travel or take a holiday, 17,750 (81.4%); and any other difficulty, 17,588 (80.7%). Women ($P < .001$), older patients ($P < .001$), those living in more deprived areas ($P < .001$), and those from ethnic minority groups ($P = .024$) were less likely to fully complete the SD-16.

Characteristics of the Population

Table 1 lists the characteristics of the SD-16 respondents. There were more men than women (60.1% v 39.9%), reflecting the proportion of men (57%) and women (43%) surveyed. A majority were age > 65 years, with 36.2% age < 65 years. Approximately one quarter lived in the least deprived areas, compared with 11% living in the most deprived areas. Only 2.0% of respondents came from nonwhite ethnic groups. LTCs were common, with only 22.9% of respondents stating they had no LTCs, and 46.6% reporting ≥ two.

When split by tumor site, 61.9% had colon tumors, 7.0% rectosigmoid tumors, and 31.1% rectal tumors. A majority had undergone surgery (93.2%), with 19.8% receiving radiotherapy and 48.6% receiving chemotherapy. One fifth (20.0%) had a stoma present, with

Table 2. Proportion of Respondents Scoring ≥ 10* on SD-16 Measure by Characteristic

Characteristic	SD No.	SD %	No SD No.	No SD %	P
Sex					.597
Male	1,603	15.0	9,112	85.0	
Female	1,085	15.2	6,030	84.8	
Age, years					< .001
< 55	540	29.0	1,320	71.0	
55-64	761	16.5	3,841	83.5	
65-74	690	10.7	5,738	89.3	
75-84	534	12.9	3,617	87.1	
≥ 85	163	20.7	626	79.3	
Index of Multiple Deprivation					< .001
1 (least deprived)	535	11.4	4,147	88.6	
2	570	12.9	3,865	87.1	
3	595	15.4	3,263	84.6	
4	530	18.3	2,364	81.7	
5 (most deprived)	458	23.4	1,503	76.6	
Race/ethnicity					< .001
White	2,498	14.6	14,586	85.4	
Nonwhite	104	29.3	251	70.7	
Not known	86	22.0	305	78.0	
Dukes' disease stage at diagnosis					< .001
A	304	10.3	2,634	89.7	
B	807	13.6	5,114	86.4	
C	1,025	16.3	5,255	83.7	
D	278	24.5	859	75.5	
Not known	274	17.6	1,280	82.4	
No. of LTCs					< .001
None	353	8.6	3,737	91.4	
1	623	11.5	4,791	88.5	
2	521	14.3	3,124	85.7	
≥ 3	1,050	27.2	2,808	72.8	
No response	141	17.1	682	82.9	
Tumor site					< .001
Colon	1,506	13.7	9,525	86.3	
Rectosigmoid	185	14.8	1,067	85.2	
Rectum	997	18.0	4,550	82.0	
Treatment					
Surgery					< .001
No	233	19.2	979	80.8	
Yes	2,455	14.8	14,163	85.2	
Radiotherapy					< .001
No	1,876	13.1	12,424	86.9	
Yes	812	23.0	2,718	77.0	
Chemotherapy					< .001
No	1,167	12.7	7,993	87.3	
Yes	1,521	17.5	7,149	82.5	
Stoma status					< .001
No stoma	1,167	11.7	8,782	88.3	
Reversed	384	13.3	2,507	86.7	
Present	937	26.2	2,634	73.8	
No response	200	14.1	1,219	85.9	
Disease status					< .001
Remission	1,587	11.3	12,480	88.7	
Other or not known	1,101	29.3	2,662	70.7	
Current employment status					< .001
Employed	426	13.3	2,779	86.7	
Unemployed	450	56.8	342	43.2	
Retired	1,546	12.4	10,897	87.6	
Other or not known	266	19.1	1,124	80.9	
(continued in next column)					

Table 2. Proportion of Respondents Scoring ≥ 10* on SD-16 Measure by Characteristic (continued)

Characteristic	SD No.	SD %	No SD No.	No SD %	P
Current living arrangements					.031
Live with spouse or family	1,778	14.6	10,404	85.4	
Live alone	590	16.2	3,056	83.8	
Other or not known	320	16.0	1,682	84.0	
Current carer status					< .001
No	2,053	14.5	12,103	85.5	
Yes	635	17.3	3,039	82.7	
Total	2,688	15.1	15,142	84.9	

Abbreviations: LTC, long-term condition; SD, social distress.
*Indicating SD.

16.2% reporting a stoma reversal. Some 78.9% of individuals reported they were in remission.

A majority were retired (69.8%); 18.0% were employed either full- or part-time; 4.4% were unemployed, of whom 616 (77.8%) of 792 were unable to work for health reasons, with the others actively seeking work; and 7.8% were in the other or not known group. Among those of working age (< 65 years), 42.4% were employed, 11.7% were unemployed (actively seeking work, 2.5%; unable to work, 9.2%), 35.1% were retired, and 10.8% were in the other or not known group. Some 68.3% reported living with a partner, spouse, or family; 20.5% reported living alone; and 11.2% had other living arrangements (eg, nursing home) or did not respond. One fifth (20.6%) stated they had carer responsibilities.

SD-16

Overall, 2,688 (15.1%) of 17,830 respondents were classed as socially distressed (score ≥ 10; Table 2); no differences in sex were observed. High levels of distress were found in the youngest (age < 55 years; 29.0%) and oldest respondents (≥ 85 years; 20.7%), those living in the most deprived areas (23.4%), nonwhite respondents (29.3%), those with advanced disease (Dukes' stage D; 24.5%), and those with ≥ three other LTCs (27.2%).

Levels of SD were higher in respondents with rectal cancer than in those with colon or rectosigmoid cancer (18.0%, 13.7%, and 14.8%, respectively) and in those reporting having a stoma (26.2% v 11.7% [no stoma] and 13.3% [reversed stoma]). Stomas are used mainly in treatment of rectal cancer (73.6% of patients with rectal cancer had stoma at some point v 16.7% of those with colon cancer). Of respondents with rectal cancer, 25.3% of those with a stoma were experiencing SD, compared with 12.3% of those who never had a stoma and 12.2% of those with a reversal. High levels of distress were reported by respondents after radiotherapy (23.0%) and by those with recurrent or nontreatable disease (29.3%).

Respondents unemployed at the time of the survey had high levels of SD (56.8%). However, the proportion of socially distressed respondents who were actively seeking work was lower (29.0%) than the proportion of those unable to work because of health reasons (64.8%). There was little difference in distress according to living arrangements. Respondents who reported being a carer had higher levels of SD (17.3%) than those who were not a carer (14.5%).

Multivariable analysis showed having ≥ three other LTCs was the strongest predictor of social distress (odds ratio [OR], 6.64; 95%

CI, 5.67 to 7.77 v no LTCs), followed by being unemployed (OR, 5.11; 95% CI, 4.21 to 6.20 v employed), having recurrent or nontreatable disease (OR, 2.75; 95% CI, 2.49 to 3.04 v remission), and having a stoma (OR, 2.10; 95% CI, 1.86 to 2.36 v never had stoma). Younger age, living in a more deprived area, being nonwhite, having more advanced disease at diagnosis, having undergone radiotherapy, and being a carer were also significant predictors of SD (Table 3 lists all ORs).

SDI Subscales

Regarding the separate subscales, 19.5% of respondents had difficulties with everyday living (score ≥ 5), 15.6% had difficulties with money matters (score ≥ 2), and 18.1% had difficulties with self and others (score ≥ 3). Multivariable analysis demonstrated presence of other LTCs was a strong predictor of difficulties on all three subscales but was strongest on the everyday living subscale (OR, 7.37; 95% CI, 6.36 to 8.55 for $\geq$ three LTCs v none). Unemployment was an important predictor on all three subscales but strongest on the everyday living subscale (OR, 6.02; 95% CI, 4.91 to 7.38 v employed group). Older age (≥ 85 years) was predictive of problems on the everyday living subscale but had a protective effect on the other two subscales. Having carer responsibilities was an important predictor of distress on the money matters and self and others subscales. Women were less likely to have difficulties with money matters but were more likely to have problems on the self and others subscale. Chemotherapy affected the money matters subscale but not the other subscales (Table 4 lists all ORs).

SDI Single Items

Only 0.7% reported difficulties with plans to have a family. Some 2.9% of respondents reported difficulties with where they lived. Difficulties with travel or taking a holiday were reported by 17.5% of respondents; this was higher in those with a stoma (34.6%) than in those with a reversed stoma (19.7%) or no stoma (13.2%; $P < .001$). A further 8.4% reported difficulties in any other aspect of life. Detailed analysis of the question concerning sexual matters has been reported elsewhere.[10] Overall, 16.0% reported difficulties with sexual matters (answered quite a bit or very much).

DISCUSSION

To our knowledge, this is the largest investigation of social outcomes in patients with CRC and, we believe, in patients with any cancer in the early years of survival. Most patients with CRC showed considerable resilience 1 to 3 years postdiagnosis. However, a sizable minority (15%) reported significant SD. Our results demonstrate this is related not only to the CRC diagnosis and treatment but also to additional, readily identifiable clinical and social factors. These factors may or may not be independent of the cancer and cancer treatment (eg, unemployment). When these factors are present and potentially working in combination, they put people at greater risk of SD.

The study design resulted in a large unselected all-comers sample, with good data quality and completeness. The 63% response rate is the same as that reported in a recent survey of supportive care of patients with CRC, in which a similar approach was used (no exclusion criteria).[18] The identification of individuals via the NCRS eliminated hospital or clinical trial selection bias, a limitation of many reported

Table 3. Logistic Regression Model for SD-16 (n = 17,830)

Variable	OR	95% CI	P
Sex			.082
Male	1.00		
Female	1.09	0.99 to 1.20	
Age, years			< .001
< 55	1.00		
55-64	0.42	0.36 to 0.50	
65-74	0.26	0.22 to 0.32	
75-84	0.26	0.21 to 0.32	
$\geq$ 85	0.41	0.31 to 0.53	
Index of Multiple Deprivation			< .001
1 (least deprived)	1.00		
2	1.07	0.93 to 1.23	
3	1.21	1.06 to 1.39	
4	1.29	1.12 to 1.49	
5 (most deprived)	1.45	1.24 to 1.70	
Race/ethnicity			< .001
White	1.00		
Nonwhite	1.70	1.30 to 2.22	
No response	1.55	1.17 to 2.03	
Dukes' disease stage at diagnosis			< .001
A	1.00		
B	1.41	1.21 to 1.64	
C	1.41	1.19 to 1.66	
D	1.69	1.36 to 2.10	
Not known	1.25	1.02 to 1.53	
No. of LTCs			< .001
None	1.00		
1	1.76	1.51 to 2.05	
2	2.69	2.29 to 3.16	
$\geq$ 3	6.64	5.67 to 7.77	
No response	1.99	1.57 to 2.52	
Treatment			
Radiotherapy			< .001
No	1.00		
Yes	1.34	1.18 to 1.51	
Chemotherapy			.295
No	1.00		
Yes	1.07	0.95 to 1.20	
Stoma status			< .001
No stoma	1.00		
Reversed	1.14	0.99 to 1.31	
Present	2.10	1.86 to 2.36	
No response	1.02	0.85 to 1.22	
Disease status			< .001
Remission	1.00		
Other or not known	2.75	2.49 to 3.04	
Current employment status			< .001
Employed	1.00		
Unemployed	5.11	4.21 to 6.20	
Retired	1.04	0.88 to 1.23	
Other or not known	1.52	1.25 to 1.84	
Current living arrangements			.969
Live with spouse or family	1.00		
Live alone	1.01	0.89 to 1.13	
Other or not known	1.02	0.88 to 1.18	
Current carer status			< .001
No	1.00		
Yes	1.30	1.16 to 1.45	

NOTE. Adjusted for all other variables in table. Because of correlations between some variables, tumor site and surgery were omitted from multivariable analyses.
Abbreviations: LTC, long-term condition; OR, odds ratio; SD, social distress.

	Everyday Living			Money Matters			Self and Others		
Variable	OR	95% CI	P	OR	95% CI	P	OR	95% CI	P
Sex			.003			< .001			< .001
Male	1.00			1.00			1.00		
Female	1.15	1.05 to 1.25		0.66	0.60 to 0.73		1.31	1.20 to 1.43	
Age, years			< .001			< .001			< .001
< 55	1.00			1.00			1.00		
55-64	0.58	0.49 to 0.69		0.46	0.40 to 0.53		0.40	0.35 to 0.46	
65-74	0.50	0.41 to 0.61		0.22	0.18 to 0.26		0.21	0.18 to 0.25	
75-84	0.69	0.56 to 0.85		0.16	0.13 to 0.19		0.15	0.13 to 0.19	
≥ 85	1.45	1.13 to 1.88		0.12	0.08 to 0.17		0.18	0.14 to 0.23	
Index of Multiple Deprivation			< .001			< .001			.004
1 (least deprived)	1.00			1.00			1.00		
2	1.03	0.91 to 1.16		1.18	1.04 to 1.35		1.20	1.06 to 1.35	
3	1.16	1.03 to 1.32		1.25	1.09 to 1.43		1.21	1.07 to 1.37	
4	1.31	1.14 to 1.49		1.40	1.22 to 1.62		1.26	1.10 to 1.43	
5 (most deprived)	1.43	1.23 to 1.65		1.39	1.18 to 1.63		1.22	1.05 to 1.42	
Race/ethnicity			< .001			< .001			.396
White	1.00			1.00			1.00		
Nonwhite	1.68	1.29 to 2.19		2.49	1.93 to 3.21		1.11	0.85 to 1.45	
No response	1.37	1.05 to 1.78		1.63	1.25 to 2.14		1.17	0.90 to 1.54	
Dukes' disease stage at diagnosis			< .001			.05			.006
A	1.00			1.00			1.00		
B	1.38	1.20 to 1.59		1.22	1.05 to 1.42		1.21	1.05 to 1.39	
C	1.43	1.23 to 1.67		1.22	1.03 to 1.43		1.29	1.11 to 1.49	
D	1.89	1.55 to 2.32		1.22	0.98 to 1.53		1.40	1.15 to 1.71	
Not known	1.28	1.06 to 1.54		1.04	0.85 to 1.28		1.29	1.08 to 1.55	
No. of LTCs			< .001			< .001			< .001
None	1.00			1.00			1.00		
1	1.71	1.48 to 1.99		1.45	1.27 to 1.66		1.50	1.32 to 1.70	
2	2.90	2.48 to 3.38		1.99	1.72 to 2.31		2.00	1.74 to 2.30	
≥ 3	7.37	6.36 to 8.55		3.32	2.86 to 3.86		4.26	3.71 to 4.89	
No response	1.92	1.51 to 2.43		1.64	1.32 to 2.03		1.59	1.29 to 1.97	
Treatment									
Radiotherapy									
No	1.00		< .001	1.00		.116	1.00		.002
Yes	1.31	1.16 to 1.47		1.10	0.98 to 1.25		1.20	1.07 to 1.34	
Chemotherapy									
No	1.00		.213	1.00		< .001	1.00		.289
Yes	1.07	0.96 to 1.20		1.35	1.20 to 1.52		1.06	0.95 to 1.18	
Stoma status									
No stoma	1.00		< .001	1.00		< .001	1.00		< .001
Reversed	1.08	0.95 to 1.24		1.31	1.15 to 1.49		1.25	1.10 to 1.42	
Present	2.15	1.92 to 2.40		1.57	1.39 to 1.78		2.30	2.05 to 2.57	
No response	1.09	0.93 to 1.28		1.02	0.85 to 1.22		1.17	1.00 to 1.38	
Disease status									
Remission	1.00		< .001	1.00		< .001	1.00		< .001
Other or not known	2.76	2.51 to 3.03		1.82	1.63 to 2.03		2.20	2.00 to 2.42	
Current employment									
Employed	1.00		< .001	1.00		< .001	1.00		< .001
Unemployed	6.02	4.91 to 7.38		3.58	2.98 to 4.29		2.37	1.98 to 2.83	
Retired	1.75	1.47 to 2.09		0.50	0.44 to 0.58		0.95	0.82 to 1.09	
Other or not known	2.22	1.81 to 2.72		1.01	0.85 to 1.20		1.21	1.02 to 1.44	
Current living arrangements									
Live with spouse or family	1.00		.789	1.00		< .001	1.00		.022
Live alone	0.96	0.86 to 1.07		1.28	1.13 to 1.44		1.15	1.03 to 1.28	
Other or not known	1.00	0.87 to 1.15		1.15	0.99 to 1.32		1.13	0.98 to 1.29	
Current carer status									
No	1.00		.009	1.00		< .001	1.00		< .001
Yes	1.15	1.04 to 1.27		1.50	1.35 to 1.68		1.50	1.36 to 1.66	

Table 4. Logistic Regression Models for Subscales (n = 17,830)

NOTE. Adjusted for all other variables in table. Because of correlations between some variables, Dukes' stage, tumor site, and surgery were omitted from multivariable analyses.

Abbreviations: LTC, long-term condition; OR, odds ratio.

outcome studies. Encouragingly, most participants were below the cut point for SD, similar to findings from a Dutch study exploring living in good health after treatment for CRC.[6] However, 15% of respondents reported high SD-16 scores, with an impact across all subscales. The highest levels of SD and subscale distress were seen in patients reporting multimorbidity, not being in remission, having a stoma present, and being unemployed. The cumulative effect of morbidity, with two other LTCs plus cancer being worse than one other LTC plus cancer, is consistent with that seen in previous studies.[19] Although only 4.4% of the sample was unemployed, more than half of participants were socially distressed and not only were at risk of experiencing severe money matters difficulties but also faced problems in the other subscales, especially everyday living, in comparison with employed participants. This may be accounted for in part by the respondents unable to undertake paid work for health reasons, possibly cancer related, and also by those struggling with household chores for similar reasons. This demonstrates the additional burden faced by patients with cancer who cannot find or are unable to work and reinforces the need to provide vocational rehabilitation services.[20] Age, ethnicity, socioeconomic deprivation, being diagnosed with more advanced disease, undergoing radiotherapy, and having caring responsibilities also affected levels of SD. There is literature on carers of patients with cancer, but less is known about patients with cancer who are carers themselves. As the population ages, mutual caring will become commonplace and will need to be addressed.[21] Differences in sex were not seen in overall SD-16 scores, but subscale examination revealed men had more problems with money matters and women with self and others and, to a lesser extent, everyday living subscales, suggesting some traditional gender roles continue to prevail.

The study is limited by the lack of a matched case-control group, baseline data, and general population normative data. Although population-based sampling was used, another limitation is differences in participant and nonparticipant characteristics. However, the large scale of this study, with a response rate of 63%, where almost 18,000 participants had fully complete SD-16 data, has resulted in some of the best evidence to date. The validity of the self-reported disease status data is untested, but, reassuringly, high concordance has been reported between self-report by patients with breast cancer and medical records data.[22]

With cost-limited health and social care services and greater reliance on informal carers and the voluntary sector, new ways of providing appropriate, cost-effective, and timely support for CRC survivors who need it must be found. The primary focus of CRC clinical follow-up care remains detection of recurrence. Guidance in the United Kingdom recommends follow-up be discontinued when the patient and health care professional have discussed and agreed that likely benefits no longer outweigh the risks of additional tests.[23] Although there are national guidelines for incorporating assessment of and support for the social impact of cancer,[24-26] their implementation is patchy. Only 27% of individuals diagnosed with CRC or lower GI cancer reported being offered a written assessment (including psychosocial assessment) or care plan.[27] An obvious time for undertaking assessment would be on completion of primary treatment. On the basis of the survey results, one in six patients is likely to be experiencing SD. However, to allow for response bias, with the characteristics of nonparticipants likely being associated significantly with SD (older age, minority ethnicity, and more deprivation), and for those who did

not survive long enough to be surveyed, the prevalence of SD in patients with CRC overall may be higher.

Some cancer services routinely perform risk-based screening of patients with the SDI-21 using touchscreen technology, which provides an efficient and effective way to identify patients with problems.[28] However, where access to electronic systems is limited, a simple checklist derived from the identified factors associated with development of SD could be used to identify patients in high-risk groups. This would ensure the sizeable minority (2,688 of 18,830 in this cohort) at risk of experiencing SD can be targeted by appropriate health and social care staff.[29] Primary care follow-up has been shown to be satisfactory for many patients with CRC, but for those identified as being at greater risk of poorer outcomes, multiple-provider care (eg, primary, secondary, social) may be more appropriate.[30] Although in the critical early years postdiagnosis, when recurrence is most likely to occur, the CRC team must play a primary role, generalists with a remit to care for people with multiple LTCs (eg, general practitioners, nurses, care managers, or geriatricians) may be best placed to support disease-free CRC survivors with complex problems.[31,32] A model of supportive care for survivors at completion of primary CRC treatment might include: assessment with the SDI-21 (or shorter form, if one could be derived using psychometric approaches) or a simple checklist, associated care planning, access to up-to-date supportive care information and services to aid individual self-management, and, for those with non-CRC complex problems, referral to key generalists.

The use of patient-reported outcome measures to drive change in health care organization and delivery has been advocated.[33] By assessing patient-reported outcomes, we have defined easily identifiable cancer- and non–cancer-related factors for the minority who experience higher levels of SD. This strong evidence base may be drawn on to inform change to enable the delivery of robust risk-stratified targeted support for those at risk of experiencing poor social outcomes.

How outcomes of patients with CRC compare with those experienced by other cancer survivors, people living with LTCs, and healthy individuals from the general population is unknown. Similar surveys of individuals living with and beyond other cancers should be undertaken, if possible incorporating matched control groups. Health economic evaluation of the implications of providing health and social care support for those at highest risk should be a focus for future research.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Disclosures provided by the authors are available with this article at www.jco.org.

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■■■

GLOSSARY TERMS

comorbidity: having two or more diseases at the same time.

health-related quality of life (HRQoL): a broad multi-dimensional concept that usually includes self-reported measures of physical and mental health.

patient-reported outcomes: questionnaires used in a clinical setting to systemically collect information directly from the patient.

psychosocial: the psychological (emotional) and social aspects of a disease and its treatment. Some of the psychosocial aspects of cancer are its effects on patients' feelings, moods, beliefs, the way they cope, and relationships with family, friends, and coworkers.

risk-based screening: screening for long-term and late cancer and cancer treatment–related effects that considers health risks related to the patient (age at treatment, attained age, sex, race, genetics, health behaviors, etc) and cancer (histology; involved sites; specific treatment like surgery, radiation, chemotherapy, hematopoietic cell transplantation, transfusion, etc).

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Identifying Social Distress: A Cross-Sectional Survey of Social Outcomes 12 to 36 Months After Colorectal Cancer Diagnosis

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