Original Article

Unmet Supportive Care Needs of Jordanian Patients with Colorectal Cancer: A Cross-Sectional Survey

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ABSTRACT

Objective: Colorectal cancer (CRC) is ranked the second most common cancer diagnosed in both men and women in Jordan. This paper aims to explore the unmet supportive care needs (USCNs), and their predictors among Jordanian survivors with CRC. **Methods:** A cross-sectional descriptive correlational research design with a convenience sample of 180 patients with CRC was conducted. Participants completed the Supportive Care Needs Survey-Short Form 34. **Results:** Jordanian patients with CRC reported their highest perceived level of need in the information and psychological domains. Multiple linear regression revealed that income and the number of chemotherapy sessions were significant predictors in the physical and daily living domains. Age, type of surgical treatment, and type of clinical setting were significant predictors of USCN in the psychological, patient care and support, and the health system and information domains. **Conclusions:** The health-care systems should work to meet all the supportive care needs for patients with CRC, particularly the informational and psychological needs domains where patients express unmet needs. Special care should be given according to age, type of surgery, and the doses of chemotherapy received. This study further confirms a disparity in the care and support provided to Jordanian cancer patients with different health-care settings in the country.

Key words: Cancer survivors, colorectal neoplasms, Jordanian, supportive care need survey-short form 34, supportive care needs

Introduction

In Jordan, colorectal cancer (CRC) is ranked the second most common cancer among both men and women.[1] The overall 5-year and 10-year survival rates of CRC among Jordanians were 58.2% and 51.8%, respectively.[2] Living with cancer requires managing a broad range of supportive care needs (SCNs), resulting from either the illness or its treatment.[3-6] Provision of effective, high-quality cancer care necessitates not only providing medical care (e.g., surgery, chemotherapy, etc.) but also identifying patients' SCN and interventions that meet these needs.[7]

Supportive care is the provision of essential services/interventions that satisfy cancer patients' physical, psychological, social, informational, sexual, and spiritual needs throughout their entire illness and ultimately improving their well-being and health-related quality of life.[8] Provision of supportive care to cancer patients has been found to have a beneficial impact on patients'

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ability to regain emotional stability, social adjustment, cognitive function, body image, future perspective, physical strength, and the ability to make informed treatment choices.[9-11] Unmet SCNs (USCNs), defined as discrepancies between needed support and support provided to the patient, were found to negatively influence health-related outcomes (e.g., psychosocial health and health-related quality of life).[12,13]

Studies of USCN among CRC patients in the international literature have shown that these patients reported a wide array of USCN including physical, psychological, sexual, informational, financial, and health system navigation needs.[12,14,15] USCN among CRC patients was found to be influenced by several demographic, clinical, and psychosocial factors including level of education, having positive cancer-related thoughts, presence of stoma, symptom distress, psychological distress, social support, and chemotherapy treatment.[15,16] Further, USCN among CRC patients was found to change as the patient progressed in the illness trajectory (i.e., SCN at the time of diagnosis was different from those at 6 months after diagnosis).[14]

Studies of Jordanian cancer patients reported that informational needs (especially about cancer, the cancer diagnosis, diagnostic tests, cancer treatment, and treatment side effects) are the most frequently reported USCN among these patients.[17,18] Although supportive care is a priority research topic in other countries, there is a paucity of studies that have specifically investigated the USCN among CRC patients in Jordan, even though they represent the highest proportion of cancer survivors in the country. Further, Jordanian CRC patients have a different cultural background and availability of resources which create different SCN.[2] Thus, to provide high-quality care to patients with CRC in Jordan, meet their SCN, and improve future service interventions, there is a need to explore their perceived USCN, and the interventions they believe will be the most helpful to meet those needs. Therefore, the purpose of this study was to explore the USCN of Jordanian survivors with CRC. More specifically, this study aimed to answer the following research questions:

1. What is the prevalence of unmet physical, psychological, practical, informational, and sexual SCN among CRC survivors in Jordan?
2. What are the predictors of USCN among Jordanian survivors with CRC?

Methods

Study design

A cross-sectional descriptive correlational research design was used to answer the study's research questions.

Recruitment and sampling

Recruitment of the participants took place in three major hospitals in Jordan. The first was a cancer specialty center. The second was one of the largest hospitals affiliated with the Jordan Ministry of Health (MOH). The third was one of the largest hospitals affiliated with the Royal Medical Services. These hospitals were selected because they are the primary settings where the majority (almost 80%) of Jordanian patients are treated for cancer in general and CRC particularly. Convenience sampling techniques were used to recruit participants for the study. Inclusion criteria were as follows: any Jordanian adult (over 18 years) with a confirmed first-time diagnosis of CRC, diagnosed 6 months 5 years before the time of the data collection, the patient is currently receiving treatment/care at one of the three aforementioned clinical settings, the patient is mentally and physically able to participate, able to communicate in Arabic, has complete disclosure about his/her diagnosis, can give informed consent, and is willing to participate in the study. Exclusion criteria included patients with recurrent disease or metastatic cancer, because these patients have different SCN.

The sample size was calculated using G*Power 3.0 software (Heinrich-Heine-University Düsseldorf, Düsseldorf, Germany, 2020). Using a conventional power estimate of 0.80 with alpha set at 0.05 and medium effect size, it was estimated that, for a multiple linear regression based on 10 predictors (e.g., age, marital status, education, employment status, income, type of surgery, type of treating facility, stage of cancer, time since diagnosis, and chemotherapy doses received if any), 118 patients would need to be approached. To allow for a minimum of 75% response rate, a total of 200 potentially eligible participants were approached.

Data collection procedures

This study was approved by the Institutional Review Boards at the researchers' university and each of the three hospitals. Data were collected from January 2018 to October 2019. Recruitment of the participants took place in the radiotherapy departments, outpatient surgery and chemotherapy clinics, and inpatient surgical units of the three hospitals. The investigator met with the head nurses of the units involved at each hospital and explained the purpose, significance, and inclusion and exclusion criteria for participation and asked them for help in the identification and recruitment of eligible participants. The researchers then approached the possible participants and explained the purpose of the study and asked them to participate. After answering their questions related to the study, participants who met the study eligibility criteria and agreed to participate were asked to complete a written consent form and the study questionnaires. Participants completed the study questionnaires as they waited for their clinic appointments.

Study measures

Data collection was performed using a study packet that included a demographic data sheet that was developed by the researchers and the SCNs Survey-Short Form (SCNS-SF34). Demographic data collected from study participants included age, gender, educational level, marital status, type of health insurance, religion, average monthly income, occupation, number of children if any, and type of treating facility. Clinical data included time since diagnosis, stage at diagnosis, type of surgical treatment (e.g., total colectomy, hemicolectomy with/without a stoma, etc.), chemotherapy doses received if any, and radiation therapy doses received if any. Clinical data were validated by reviewing patients' medical records with their permission. The SCNS-SF34 is an instrument originally developed for assessing the perceived needs of patients diagnosed with cancer. SCNS-SF34 consists of 34 items covering the following five domains: psychological needs, health system, physical and daily living, patient care and support, and sexuality.[19] For each item, the participants are asked to indicate their perceived level of need using a Likert scale ranging from 1 (not applicable) to 5 (high need). Total crude scores were based on the scale range from 34 to 170, with higher scores indicating a higher level of need for the individual participant. The survey has been extensively used in studies of SCN among cancer patients globally, with satisfactory validity (convergent and construct validity) and reliability with a Cronbach's alpha ranging from 0.87 to 0.97 for the five domains.[8,19-21] In this study, the scale has a reliability coefficient of 0.96. The survey has been previously translated into Arabic and used in measuring SCN among Arab cancer patients.[22] Completion of the study questionnaires took about 15 min.

Results

Sample description

A total of 200 questionnaires were distributed, of these, 191 questionnaires were returned (96% response rate). Due to the condition of their illness and time constraints, nine potentially eligible patients declined participation. Further, 11 questionnaires were excluded from the analysis due to incomplete data, leaving a total of 180 complete questionnaires. As shown in Table 1, the mean age of the participants was 54.3 (±12.5) years. Most of the participants were male (62%), Muslim (96%), had high school education (60%), had medical insurance (91%), and underwent hemicolectomy (57%) as a primary surgical treatment.

Table 1: Demographic and clinical characteristics of the sample (n=180)

Characteristics	Categories	Frequency, n (%)*
Gender	Male	112 (62.2)
	Female	68 (37.8)
Religion	Muslim	172 (96.0)
	Christian	8 (4.0)
Education	Up to high school	109 (60.5)
	Diploma	29 (16.2)
	Bachelor degree	42 (23.3)
Occupation	Employed	54 (30.0)
	Unemployed	74 (41.0)
	Retired	52 (29.0)
Monthly income (JD)	<500	128 (71.2)
	500-1000	43 (23.9)
	>1000	9 (5.0)
Children	<5	72 (40.0)
	≥5	108 (60.0)
Insurance	Yes	165 (91.7)
	No	15 (8.3)
Time since diagnosis (years)	<1	109 (60.6)
	1-3	47 (26.1)
	More than 3	24 (13.3)
Stage of cancer	First	63 (35.0)
	Second	30 (16.7)
	Third	31 (17.2)
	Fourth	31 (17.2)
	Not known	25 (13.9)
Type of surgery	None	33 (18.3)
	Tumor resection	38 (21.1)
	Hemicolectomy	65 (36.1)
	Hemicolectomy with stoma	34 (18.9)
	Total colectomy with stoma	10 (5.6)
Radiotherapy dose	Not received	21 (11.7)
	<5	89 (49.4)
	≥5	70 (38.8)
Chemotherapy treatment	Not received	21 (11.7)
	Received<5 doses	89 (49.4)
	Received 5-10 doses	53 (29.4)
	Received more than 10 doses	17 (9.4)
Clinical setting	MOH-affiliated hospital	54 (30.0)
	RMS-affiliated hospital	84 (46.7)
	Specialty cancer center	42 (23.3)

*Percentages are based on valid cases. MOH: Ministry of health, RMS: Royal medical services

Perceived supportive care need

Overall, about 81% of the participants reported SCN. As illustrated in Table 2, participating Jordanian CRC survivors perceived their highest level of need in the domain of information provision (33.95 ± 11.58) followed by the psychological domain (26.27 ± 9.75). Items in the domain of sexuality were perceived to be of the lowest need by the participants (7.40 ± 3.14).

Further, six of the top ten perceived needs (i.e., items with moderate to high need) across the supportive care domains were related to the health system and information domain. Fear of cancer spreading, being treated in a hospital or clinic that is physically as pleasant as possible, being treated like a person, pain, and being informed about cancer that is under control or diminishing were the most prominent USCN perceived by many of the participants [Table 3].

The scale is the SCNS-SF34 and not USCNS-SF34 as stated in the results of the bivariate analysis section.

Results of the bivariate analysis

The assumptions of regression analysis tests that are not robust to violation are linear, homoscedastic, and normal. Our data are approximately normally distributed in terms of skewness and kurtosis based on histogram and the Skewness Z value, and all kurtosis Z values were between −1.96 and 1.96 and based on Shapiro–Wilk test ($P > 0.05$). Predictors of the SCN were identified through the use of one-way analysis of variance to determine the variables that can enter the regression analysis. Each variable from the demographic and clinical variables that were significantly related to the total mean score of the SCN was selected as shown in Table 4. Clinical setting, age, marital status, employment status, cancer stage, type of surgery, and the number of chemotherapy sessions received had significant associations with participants' total scores in the SCNS-SF34. Moreover, differences were assessed according to each domain in the SCNS-SF34. Participants who underwent treatment at the specialty cancer center were more likely to report lower levels of perceived SCN in the health system and information domain compared to those who underwent treatment at the other two clinical settings ($F = 13.56$, $P = 0.00$). Furthermore, participants who underwent a hemicolectomy or total colectomy with a stoma were more likely to report higher levels of perceived SCN in the health system and information domain than those who underwent no surgical treatment ($F = 4.36$, $P = 0.00$). In contrast, participants were more likely to report lower levels of perceived SCN in the psychological, sexual, physical, and patient care and support domains if they fell under the following categories: received treatment at the specialty cancer center ($F = 9.55$, $P = 0.00$), received more than 10 sessions of chemotherapy ($F = 4.43$, $P = 0.01$), were older than 60 years of age ($F = 6.49$, $P = 0.00$), and underwent no surgical treatment ($F = 6.00$, $P = 0.00$).

Table 2: Means and standard deviations on the five domains in the SCNS-SF34 (*n*=180)

Domain	Mean	SD	Median	Actual Range	Possible Range
Physical	14.76	4.87	15.00	20.00	5-25
Psychological	26.27	9.75	25.50	37.00	10-50
Sexual	7.40	3.14	7.00	12.00	5-15
Patient care and support	13.25	5.00	14.00	20.00	5-25
Information and health system	33.95	11.58	34.00	49.00	11-55
Total SCNS-SF34 score	95.70	29.13	95.00	125.00	34-170

SD: Standard deviation, SCNS-SF34: Supportive care needs survey-short form 34

Results of multivariate statistical analysis

Variables found to have significant associations (i.e., age, education, employment status, type of clinical setting, type of surgical procedure, and the number of chemotherapy sessions received) with the SCN from the bivariate statistical analysis were entered into the regression models.

As shown in Table 5, multiple linear regression revealed that only monthly income ($B = 0.187$) and the number of chemotherapy sessions received ($B = 0.160$) were significant predictors of USCN in the physical and daily living domains. Age ($B = 0.156$), type of surgical treatment ($B = 0.207$), and type of clinical setting ($B = 0.187$) were significant predictors of USCN in the psychological domain. Moreover, age ($B = 0.178$), type of clinical setting ($B = 0.280$), and type of surgical

Table 3: Top ten reported unmet needs across the supportive care domains (*n*=180)

Rank	Items	Domain	*n* (%)
1	Fears about cancer spread	Psychological	82 (45.6)
1	Being treated in a hospital or clinic that's physically pleasant as possible	Health systems and information	82 (45.6)
2	Being treated like a person not just another case	Health systems and information	79 (43.9)
3	Pain	Physical	77 (42.8)
3	Being informed about cancer which is under control or diminishing (i.e., remission)	Health systems and information	77 (42.8)
4	Not being able to do the things you used to do	Physical	74 (41.1)
5	Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	Health systems and information	72 (40.0)
6	Being informed about your test results as soon as feasible	Health systems and information	71 (39.4)
7	Being informed about things you can do to help yourself to get well	Health systems and information	69 (38.3)
8	Lack of energy/tiredness	Physical	68 (37.8)
9	Anxiety	Psychological	65 (36.1)
10	Worry that the results of treatment are beyond your control	Psychological	63 (35.0)

treatment ($B = 0.143$) were significant predictors of USCN in the patient care and support domain. In the sexual domain, age ($B = 0.183$), marital status ($B = 0.243$), and type of surgical treatment ($B = 0.149$) were the significant predictors. Finally, in the health system and information domain, type of surgical treatment ($B = 0.162$) and type of clinical setting were the significant predictors ($B = 0.234$).

Table 4: Comparison of participants' sum scores on supportive care needs survey-short form 34 by their demographic and clinical characteristics (*n*=180)

Variable	Mean±SD	*F*	*P*
Clinical setting			
MOH-affiliated hospital	2.79±0.93	13.336	0.000
RMS-affiliated hospital	2.97±0.70		
Specialty cancer center	2.20±0.76		
Age (yr)			
20-40	3.11±0.98	7.496	0.001
41-60	2.82±0.77		
61-80	2.42±0.79		
Marital status			
Married	2.48±1.16	6.303	0.000
Single	2.00±0.68		
Widow	1.23±0.43		
Divorced	1.80±1.06		
Employment status			
Employed	2.82±0.85	3.163	0.026
Not employed	2.49±0.84		
Cancer stage			
Stage 1	2.50±1.02	2.648	0.035
Stage 2	2.68±0.98		
Stage 3	2.73±0.96		
Stage 4	3.02±1.26		
Type of surgery			
Hemicolectomy	2.67±0.75	5.950	0.000
Total colectomy with stoma	3.29±0.81		
Chemotherapy dose			
<5 doses	2.18±0.77	5.950	0.000
More than 5 doses	2.80±0.77		

*Only variables that had significant associations with participants' total scores on SCNS-SF34 are presented in the table. SD: Standard deviation, SCNS-SF34: Supportive care needs survey-short form 34, MOH: Ministry of health, RMS: Royal medical services

Discussion

This study revealed that, among patients with CRC in Jordan, the most prevalent USCN is related to the health system and information domain followed by the psychological domain. In comparison to other studies that used the SCNS-SF34, this finding demonstrates that Jordanian CRC survivors share some of the USCN with CRC patients from other cultural backgrounds.[14,16,17] Results of this study are also consistent with findings among Jordanian patients with other types of cancer.[16] This study further revealed that USCN among the study participants greatly varied depending on the type of clinical setting where the participants underwent treatment. Participants who received treatment at the specialty cancer center were less likely to report a high level of USCN in three of the five domains of the SCNS-34SF (e.g., health system and information, psychological, patient care, and support) compared to those who had treatment at the other two clinical settings, which were public hospitals. This finding is consistent with previous studies of Jordanian cancer patients[23] and further highlights the disparity in cancer care provided to Jordanian patients by the type of treatment

Table 5: Predictors of unmet supportive care needs in the five domains of the supportive care needs survey-short form 34 (*n*=180)

Variable	B	SE	β	*t*	*P*
Physical domain					
Income more than 1000 JD	−4.163	1.65	−0.187	−2.552	0.012
Number of chemotherapy sessions: More than 10 sessions	−2.660	1.209	−0.160	−2.200	0.029
Psychological domain					
Type of clinical setting: Specialty cancer center	−4.296	1.817	−0.187	−2.364	0.019
Type of surgical treatment: No surgery	−5.214	1.845	−0.207	−2.826	0.000
Age	−0.123	0.056	−0.156	−2.187	0.030
Sexual domain					
Marital status: Married	1.966	0.574	0.243	3.423	0.001
Type of surgical treatment: No surgery	−1.210	0.604	−0.149	−2.004	0.047
Age	−0.047	0.020	−0.183	−2.389	0.018
Patient care and support domain					
Type of clinical setting: Specialty cancer center	−3.310	0.913	−0.280	−3.625	0.000
Type of surgical treatment: No surgery	−1.846	0.927	−0.143	−1.991	0.048
Age	−0.072	0.028	−0.178	−2.554	0.012
Health system and information domain					
Type of clinical setting: Specialty cancer center	−6.432	2.166	−0.234	−2.969	0.003
Type of surgical treatment: No surgery	−4.820	2.179	−0.162	−2.212	0.028

SE: Standard error

setting (specialty cancer center vs. public hospitals). This disparity could be attributed to the difference in the models of care and supportive cancer services available between the three clinical settings. For instance, most of the health-care institutions in Jordan, except for the specialty cancer center, lack structured psychosocial support programs and patient care coordinators.[24] Jordan started the palliative care initiative in 2001. King Hussein Cancer Centre located in Amman provides comprehensive palliative care for inpatients, outpatients, and patients at home. However, the other public hospitals still lack structured palliative care that can meet the needs of a large segment of cancer patients.

One possible solution to alleviate some of the disparity in care between the specialty cancer center and the public health-care settings is to provide the health-care team with adequate education and awareness about the SCN of patients with cancer, specifically focusing on palliative care education and early palliative care referral and implementing a nurse coordinator program. These strategies would assist cancer patients to navigate the complex health-care system and meet their SCN, especially in the health systems and information domain.

Patients who have undergone a surgical treatment reported higher levels of perceived USCN in the psychological and health system and information domains compared to patients who did not undergo a surgical treatment. This finding is not surprising, given that undergoing surgical treatment places patients under greater psychological stress (e.g., changes in body image and self-esteem) and a greater need for information related to the surgery as reported in previous studies among CRC survivors.[15] Unmet informational needs have been found to negatively affect patients' psychological health and quality of life.[15,25,26] Thus, health-care providers must assess the informational needs of cancer patients on an individualized and ongoing basis throughout their illness trajectories. This helps providers to update the patient with tailored information to meet their needs and help them cope with and endure the burden of the disease and its different treatment modalities.

Consistent with other studies among CRC survivors from other cultural backgrounds,[15,27] fearing about cancer spread was ranked as the top perceived USCN across all domains of the SCNS-34SF. This finding is expected as cancer patients in general usually fear about cancer progression and/or reoccurrence.[28,29] However, these feelings might become overwhelming in cancer patients and negatively affect their health, response to treatment, and quality of life.[29] Thus, it is essential to identify those at risk of developing overwhelming feelings of fear about cancer progression/reoccurrence and provide them with psychosocial support programs to manage these feelings.

SCN related to pain symptoms was ranked the third of all USCN among Jordanian CRC survivors in this study. This finding is discordant with findings among CRC survivors from other cultural backgrounds, in which pain was beyond the top 10 ranked USCN and ranked at the last among all top needs.[15,27] One potential explanation for this is the time differences following diagnosis for the participants in this study and those in other studies. For instance, about 61% of the participants in our study were diagnosed <1 year before data collection, compared with the CRC survivors from other studies whose samples were collected 15 and 24 months after surgery.[15] Another possible explanation for this difference could be the difference in the culture of the health-care system between our study and other studies. For instance, the insufficient assessment and management of pain in the Jordanian health-care system, especially in public health-care settings, owing to deficient knowledge and poor attitudes among health-care providers, is a frequently reported issue in the literature.[30,31] This finding stresses the importance of providing Jordanian health-care providers, especially those working in the public health-care sector, with continuing education on pain management.

Consistent with other studies of both CRC patients and those with other types of cancer,[15,17,27] Jordanian CRC survivors in this study ranked USCN in the sexual domain as the least important, though a higher level of sexual needs was expressed by married participants. In general, Jordanians are conservative by nature and thus topics such as sexuality are not openly discussed. This cultural difference may explain the low prevalence of USCN among CRC survivors in this study. Another possible explanation for the low prevalence of sexual needs among the study participants could be that these patients were preoccupied with other topics of higher priority to them, such as cancer metastasis, managing treatment side effects, and survival. Therefore, health-care providers should ensure that clinical encounters are conducive to patient–provider conversations and information exchange. Providers should encourage their patients, especially young and married ones, to freely express their sexual concerns.

Strengths and Limitations

The main strength of this study is the recruitment of diverse and representative samples of Jordanian CRC survivors from the three clinical settings where more than 80% of CRC survivors in the country are treated. Strength of this study is the use of the SCNS-34SF survey form used globally. However, the results of this study should be interpreted considering several limitations. The cross-sectional research design and the convenience sampling used in this study limit our ability to conclude any causal relationships between USCN and the demographic and clinical characteristics of the participants. Further, the self-reported data collected in this study are associated with the possibility of reporting bias. Thus, to provide robust evidence on the long-term impact of CRC on Jordanian patients, future research should involve longitudinal research designs, random sampling techniques, and direct observation of clinical encounters.

Conclusions

This study confirms that Jordanian CRC patients have a range of USCN. The health systems and information and the psychological domains are particular areas where patients express unmet needs. This study further confirms a disparity in the care and support provided to Jordanian cancer patients at different health-care settings in the country. Patients treated at a specialty cancer center perceived a lower level of USCN compared to those treated at the public hospitals. Thus, our findings should raise the attention of stakeholders (e.g., MOH officials and health-care professionals) to the necessity of developing quality improvement programs that aim to bridge the disparity in cancer care among different health-care settings in the country. Special consideration should be given to younger patients and patients with certain types of surgical interventions such as stomas.

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Conflicts of interest

There are no conflicts of interest.

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