SUPPORTIVE CARE NEEDS OF NEWLY DIAGNOSED ADVANCED COLON CANCER PATIENTS AT MANSOURA UNIVERSITY HOSPITAL

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Abstract:
Newly diagnosed advanced colon cancer(ACC)patients reported high levels of unmet needs related to issues such as provision of information, psychosocial support, practical assistance, and sexual issues. **Aim of the study:**Assess supportive care needs(SCNs) of newly diagnosed ACC patients at Oncology Centre Mansoura University. **Method:** A descriptive researchdesign was used. **Subjects**:Convenient sample (50) of newly diagnosed ACC patients during six months duration. **Tools:** Three tools were used for data collection, Tool I:Socio-demographic Characteristics and Clinical Data of the Patients Questionnaire, Tool II: Short-form Supportive Care Needs Survey (SCNS-SF34) of ACC Patients, and Tool III: Functional Assessment of Cancer-Therapy Colorectal Subscale (FACT-C).**Results:** The highest levels of unmet SCNs of the studied patients were related to psychological well-being needs (90.56%) , followed by health system and information needs (82.60%), then physical and activities of daily living needs (71.82%), but sexual domain represented the lowest needs (50.96%).**Conclusion**:The most reported unmet need was "fear from cancer spreading". **Recommendation**:Most unmet SCNs of colon cancer patients in the study are from the perspective of the psychological and health system and information domains. Therefore, educating colon cancer patients and meeting their psychological needs should be considered as a fundamental part of the supportive care programs.

Key words:supportive care needs, newly diagnosed, advanced colon cancer

Introduction:
Colon cancer is the third most common cancer in the world, contributing 8.9% of all cancers,whereas, in Egypt it contributes 6.5% of all cancers [2].

In 2013, the American Cancer Society estimates that there will be approximately 142820 new cases of colorectal cancer, including 102480 new cases of colon cancer with 50830 deaths expected in the United States, Approximately 39% of these patients will have locally advanced disease and 19% will be diagnosed with metastatic disease[3].

Advanced colon cancer means that, the cancer has metastasis to other parts of the body from where it started in the colon. The colon cancer cells have travelled through the lymphatic system or bloodstream to another part of the

body. The cells have then settled and started to grow there[1].

The diagnosis of cancer is associated with various psychological and emotional reactions, including shock, anger, anxiety, confusion, and depression. These reactions may be heightened by an advanced cancer diagnosis. In addition, patients recently diagnosed with cancer may have significant needs related to existing co-morbidity, uncertainty about their prognosis, and the stigma associated with cancer [4].

Helping a person with cancer and their family deal with cancer and its treatment, from pre-diagnosis through the process of diagnosis and treatment to cure, continuing illness or death and into passing is known as SC [5].

Supportive care needs(SCNs) include many domains such as patient care and support, physical and daily living ,psychological, health system and information, and sexual domains[6].Cancer patients have informed high levels of unmet needs such as providing information, psychosocial support, practical help, and sexual concerns[7].Physical and psychological distress could increase the level of unmet SCNs, and high levels of unmet needs may decrease quality of life [8].

Aim of the Study:

The study aimstoassessthe Supportive Care Needs of newly diagnosed advanced colon cancer patients.

Research Question:

1-What are the types of supportive care needs of newly diagnosed advanced colon cancer patients?

2-Is there any relation between socio -demographic characteristics and supportive care needs?

Subjects& Method

Study Design:

A descriptive research design was used in this study.

Setting:

This study was carried out in Medical and Surgical Departments at Oncology Center-Mansoura University (OCMU) and in Medical Departments at Clinical Oncology & Nuclear Medicine.

Subjects

Convenient sample of (50) newly diagnosed advanced colon cancer patients during six months duration who accepted to participate voluntary in the study, gave consents, age (20-60)years old, newly diagnosed with advanced colon cancer, with stage III or IV confirmed by pathology or biopsy,and before starting medical

and surgical treatment (surgery, chemotherapy or radiotherapy).

Tool:

Three tools were used for data collection:-

Tool I: Socio-demographic Characteristics and Clinical Data of the Patients Questionnaire: This tool was developed by the researcher based on reviewing recent relevant literature. It consists of the following:

A-Socio-demographic characteristics of the patients such as: age, sex, marital status, educational level, occupation, and smoking habit, it includes (6 items).

B-Clinical data of the patients, it includes past medical history (2 items), family history (2 items), and present history of the patients(3 items).

Tool II: Short-form Supportive Care Needs Survey Questionnaire (SCNS-SF34) of Advanced Colon Cancer Patients: The Supportive Care Needs Survey (SCNS) was adopted from *Campbell et al(2014)&Molassiotis et al ,2014*andmodified by the researcherto assess SCNsof cancer patients. The SCNS-SF34, a revised version of SCNS Long Form 59. It involves 34 items and includes five domains of needs:

health system and information (11 items), psychological (10 items), physical and daily living (5 items), patient care and support (5 items), and sexuality (3 items).

There are five response choices that patients were specified the level of their needs for help since they know that they have colon cancer [1, no need (not applicable); 2, no need (satisfied); 3, low need; 4, moderate need; 5, high need].

Tool III: Functional Assessment of CancerTherapy Colorectal Subscale (FACT-C): The FACT-C was adopted from*Wong et al (2014)*and modified by the researcher to assess the health-related quality of life (HRQOL) during the past 7 days in patients with colon cancer. As the SCNS-SF questionnaire does not contain specific colon cancer related needs, a seven-items related to colon cancer patients were incorporated into the survey.

Each item of the FACT-C is rated by a five-point Likert scale (not at all, a little bit, somewhat, quite a bit, very much).The scores of the raw are calculated to give standard scores of(0–28). FACT-C subscale were 0= Not at all, 1= A little bit, 2= somewhat, 3= Quite a bit, 4= Very much. Items that are negatively stated such asI have swelling/cramps in my stomach area ,I am losing weight, and I have diarrhea were reversed before

calculating the mean scores, so that higher subscale scores reflect a better HRQOL.

Method:

1- Official approvals for conducting the study were obtained from Faculty of Nursing of Mansoura University as well as the ethical committee of Faculty of Nursing of Mansoura University.

2- Official approval for conducting the study obtained from the responsible administrative personnel of the previously mentioned settings.

3-Tool II and III were modified by the researcher.

4-Tools were translated into simple Arabic language andvice versa.

5-Tools were tested for content-related validity by 5 experts from Mansoura University(two professors from surgical department faculty of medicine, three assistant professor of medical- surgical nursing)who reviewed the English and Arabic tool for clarity, relevance, understanding, and applicability for implementation. According to their opinions minor modifications were done.

6-Each patient was interviewed individually by the researcher using the previously mentioned tools thenverbal explanation of the aim and the nature of the study were explained to all

patients to gain their cooperation in data collection.

7-A pilot study was carried out on 10% of newly diagnosed advanced colon cancer patients from the oncology medical and surgical departments atOncology Center-Mansoura University before starting the data collection, to evaluate ambiguity, clarity and applicability of the tool, and the approximate time needed for answering the questionnaire. Those patients were excluded from the study.

8-Based on the results obtained from the pilot study, necessary modifications were done.

9-Patients were interviewed before starting any medical or surgical treatment.

Human rights and ethical consideration:

1. Verbal and written consents were obtained from patients who accepted to participate voluntarily in this study after illustrating the aim and nature of the study

2. Privacy of the patients was assured and confidentiality of the collected data was maintained.

Reliability of the tools

The reliability of the developed tools was estimated using the Cronbach'sAlpha test to

measure the internal consistency of the tools. It was foundthat, the reliability for the supportive care needs questionnaire using Cronbach'sAlpha equation was (r = 0.815) and for functional assessment of cancer therapy-colorectal was (r = 0.763).

Statistical analysis:

Data was computed, tabulated, and statistically analyzed using spss version 16 (statistical package of social sciences).The descriptive table represent data in number and percentages, while data for comparisons presented in average ± standard deviation (continuous variables).Student t test was used when comparing two groups, while one-way ANOVA (f test) was used when comparing more than two groups .The difference is considered significance when p ≤ 0.05.

Limitations of the study:

The limitations of this study are that, the sample size was relatively small and study findings represent the views of patients with colon cancer in two regional cancer centre. This may limit the generalization of the results beyond the study population.

Results:

The data collected were analyzed statistically and the results are categorized into 4 main parts which are: socio – demographic characteristics of the studied patients, supportive care needs according to physical, sexual, psychological, patient care and support, and health system and information domains, priority needs arrangement,comparison of the mean scores of different domains of supportive care needs according to socio – demographic characteristics.

Table (5.1): Distribution of the Studied Patients according to their Socio-demographic Characteristics (n = 50):

Items	No	%
Sex:		
- Male	28	56%
- Female	22	44%
Age (years):		
-20-30	4	8%
- 31-40	7	14%
- 41-50	12	24%
- 51-60	27	54%
Marital status:		
- Married	45	90%
- Single	5	10%
Educational level:		
- Not able to read and write	18	36%
-Primary education	8	16%
-Secondary education	20	40%
-University education	4	8%
Work:		
-Working	29	58%
- Not working	21	42%
Type of work: (n=29)		
- Employee	9	31%
-Worker	8	27.6%
- Craftsman	6	20.7%
- Farmer	6	20.7%
Smoking:		
-Yes	7	14%
-No	38	76%
-Ex-smoker	5	10%
Cigarette No: (n=7)		
- < 20	2	28.6%
- ≥ 20	5	71.4%
Duration of smoking: (n=7)		
- < 15y	2	28.6%
- 15 - 30	2	28.6%
- > 30	3	42.8%

Table 5.1: It was observed from the table that,(56%)of the studied patients were males, (54%) were in age ranged from 51 to 60 years old, (40%) were

secondary educated , (90%)were married, (58%)were working, and (31%)of them were employees.

Regarding the cigarettesmokingbehavior. It wasobservedfrom the table that, more than half (76%) of the studied patients never smoked cigarette, (71.4%)were smoking 20 cigarettes or more, and(42.8%) of them weresmoking more than 30 years.

Table (5.2): Supportive Care Needs according to Physical and Activities of Daily Living Domain (n = 50)

Physical and Activities of Daily Living Domain	Not Applicable 1		Satisfied 2		Low Need 3		Moderate Need 4		High Need 5	
	No	%	No	%	No	%	No	%	No	%
Pain	-	-	2	4%	12	24%	8	16%	28	56%
Lack of energy (tiredness)	-	-	1	2%	8	16%	6	12%	35	70%
Feeling sick a lot of the time	-	-	-	-	3	6%	9	18%	38	76%
Daily work	-	-	-	-	2	4%	13	26%	35	70%
Not being able to do the things you used to do	-	-	1	2%	2	4%	6	12%	41	82%

Table 5.2: It was observed from the table that,inability to do the things used to do represented the highest need (82%), followed by feeling sick a lot of the time (76%), then lack of energy as well as daily work represented (70%) of the studied patients.

Table (5.3): Supportive Care Needs according to Sexuality Domain (n= 50)

Sexual Domain	Not Applicable 1		Satisfied 2		Low Need 3		Moderate Need 4		High Need 5	
	No	%	No	%	No	%	No	%	No	%
Changes in sexual feelings	22	44%	7	14%	5	10%	3	6%	13	26%
Changes in sexual relationships	21	42%	7	14%	5	10%	2	4%	15	30%
To be given information about sexual relationships	24	48%	4	8%	7	14%	3	6%	12	24%

Table 5.3: It was observed from the table that, changes in sexual relationships represented the highest need (30%), followed by changes in sexual feelings (26%).

Table (5.4): Supportive Care Needs according to Psychological Domain (n = 50)

Psychological Domain	Not Applicable 1		Satisfied 2		Low Need 3		Moderate Need 4		High Need 5	
	No	%	No	%	No	%	No	%	No	%
Fears about the cancer spreading	-	-	2	4%	-	-	1	2%	47	94%
Worry that the results of treatment are beyond your control	-	-	3	6%	1	2%	3	6%	43	86%
Concerns about the worries of those close to you	-	-	9	18%	2	4%	-	-	39	78%
Uncertainty about the future	-	-	2	4%	3	6%	8	16%	37	74%
Anxiety	-	-	10	20%	1	2%	6	12%	33	66%
Learning to feel in control of your situation	3	6%	1	2%	5	10%	19	38%	22	44%
Feeling down or depressed	-	-	20	40%	6	12%	16	32%	8	16%
Feelings of sadness	-	-	10	20%	4	8%	5	10%	31	62%
Feelings about death and dying	3	6%	25	50%	1	2%	4	8%	17	34%
Keeping appositive outlook	1	2%	12	24%	1	2%	7	14%	29	58%

Table 5.4: It was observed from the table that, fears from cancer spreading represented the highest need (94%), followed by the worry of the patients that the results of treatment were beyond their control (86%), then concerns about the worries of those close to patient (78%), followed by uncertainty about the future (74%).
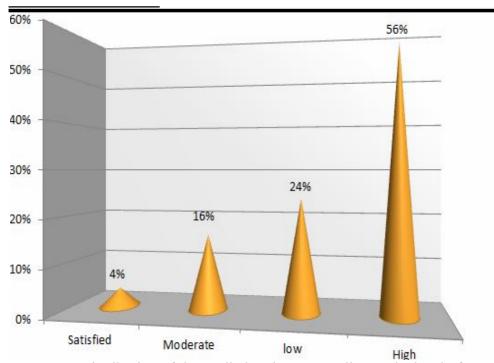
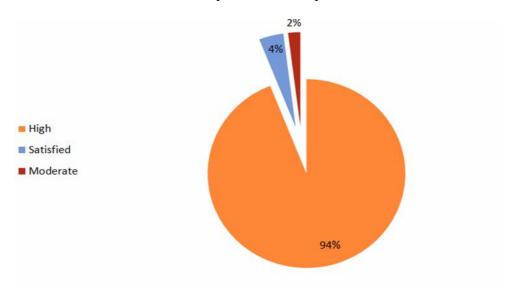**Figure 1:** Distribution of the studied patients according to the level of need for help in relation to pain.

Figure 2: Distribution of the studied patients according to the level of need for help in relation to fear about cancer spreading.

Table (5.5): Supportive Care Needs according to Patient Care and Support Domain (n = 50)

Patient Care and Support Domain	Not Applicable 1		Satisfied 2		Low Need 3		Moderate Need 4		High Need 5	
	No	%	No	%	No	%	No	%	No	%
Reassurance by medical staff that the way you	-	-	46	92%	-	-	-	-	4	8%
More choice about which cancer specialists	-	-	1	2%	-	-	4	8%	45	90%
Hospital staff attending	-	-	47	94%	-	-	-	-	3	6%
Hospital staff acknowledging, and showing sensitivity to,	-	-	46	92%	-	-	-	-	4	8%
More choice about which hospital you	-	-	1	2%	-	-	4	8%	45	90%

Table (5.5): It was observed from the table that ,more choice about which cancer specialists to see as well as more choice about which hospital attends represented the highest need (90%) of the studied patients

Table (5.6): Supportive Care Needs according to Health System andInformation Domain (n = 50)

Health System and Information Domain	Not Applicable 1		Satisfied 2		Low Need 3		Moderate Need 4		High Need 5	
	No	%	No	%	No	%	No	%	No	%
Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow up	6	12%	17	34%	-	-	6	12%	21	42%
Being informed about things you can do to help yourself to get well	2	4%	-	-	2	4%	4	8%	42	84%
Being informed about your test results as soon as feasible	8	16%	-	-	-	-	1	2%	41	82%
Being adequately informed about the benefits and side-effects of treatments before you choose to have them	6	12%	-	-	-	-	-	-	44	88%
Being given explanations of those tests for which you would like explanations	7	14%	4	8%	-	-	-	-	39	78%
Having access to professional counseling	5	10%	6	12%	4	8%	8	16%	27	54%
Being treated in a hospital or clinic that is as physically pleasant as possible	-	-	48	96%	1	2%	1	2%	-	-
Being given written information about the important aspects of your care	48	96%	-	-	-	-	-	-	2	4%
Being treated like a person not just another case	-	-	49	98%	1	2%	-	-	-	-
Being given information about aspects of managing your illness and side-effects at home	1	2%	2	4%	2	4%	-	-.	45	90%
Being informed about cancer which is under control or diminishing	2	4%	2	4%	4	8%	-	-	42	84%

Table (5.6): It was observed from the table that , to be given information about aspects of managing their illness and side-effects at home represented the highest need (90%) ,followed by to be adequately informed

about the benefits and side-effects of treatments before they choose to have them (88%), then to be informed about things they

can do to help themselves to get well as well as to be informed about cancer which is under control or diminishing represented (84%) of the studied patients.

Table (5.8): Comparison of Mean Score of Different Domains of Supportive Care Needs as Regard to Sex (n=50)

Items	Males (n=28) Mean ± SD	Females (n=22) Mean ± SD	Significance Test
Physical Score	22.5 ± 2.9	22.81 ± 2.9	t = 0.382,p = 0.704
Psychological Score	43.14 ± 6.8	39.4 ± 6.9	t =1.906,p = 0.063
Health System and Information Score	41.0 ± 6.6	38.54 ± 6.3	t =1.331, p = 0.19
Patient Care and Support Score	16.6 ± 2.5	16.1 ± 2.5	t = 0.634 ,p = 0.474
Sexual Score	6.92 ± 4.34	8.59 ± 5.43	t =1.203,p = 0.235
Total Score	130.2 ± 13.5	125.4 ± 14.5	t = 0.19,p = 0.218

Table (5.8): shows the distribution of the mean scores of different domains of supportive care needs according to sex, it was observed from the table that, there is no statistical significant difference of the mean score of different domains of supportive care needs between males and females

Table (5.9): Comparison of Mean Score of Different Domains of Supportive Care Needs according to Age Groups (n = 50)

Items	18-30 (n=4) Mean ± SD	31-40 (n=7) Mean ± SD	41-50 (n=12) Mean ± SD	51- 60 (n=27) Mean ± SD	Significance Test
Physical Score	24.2 ±1.5	23.4 ± 2.4	22.3 ± 1.5	22.3 ± 3.5	F= 0.717,P=0.547
Psychological Score	43.3 ±5.5	44.4 ± 3.0	45.3 ± 5.4	38.8 ± 7.7	F=3.332,P=0.027 *
Health System and Information Score	40.8 ± 4.4	41.4 ± 6.3	41.9 ±5.7	38.5 ±7.1	F= 0.932,P=0.433
Patient Care and Support Score	19.0 ± 4.2	16.0 ± 0.0	16.4 ± 2.8	16.07 ± 2.3	F=1.731,P=0.174
Sexual Score	7.3 ± 5.67	7.57 ± 5.3	8.58 ± 5.3	7.33 ± 4.68	F= 0.185,P=0.906
Total Score	134.5 ± 12.2	132.8 ± 9.6	134.5 ± 11.0	123.1 ± 2.9	F= 2.828,P=0.049*

Table (5.9):shows the distribution of the mean scores of different domains of SCNs according to age, it was observed from the table that, there is a statistical significantdifference in the mean score of psychological and total scores among the different age groups, while there is no significant difference in the mean score of the physical, health system and information, patient care and support, and sexual scores among the different age groups**.**

Discussion:

Colon cancer patients experience many problems including negative physical symptoms, social isolation, spiritual suffering, and often psychological distress[13].

The present study revealed that, themajority of patients are between 51-60 years of age. These findings are in line with*Hokkam et al (2013) &Velciov et al (2013)*[14,15]whom stated that the highest incidence of colon cancer patients occurs in the age of 50-60 years.

In relation to gender the findings of the present study represented that, males constituted more than half of the studied patients. This result in the same line with*Glavić et al (2014*[16]*)*who found that incidence of colon cancer among males was higher than that of females.

As regard to supportive care needs (SCNs)of the studied patients, the present study clarified that, patients with newly diagnosed ACC experience high levels of unmet SCNs across a range ofdomains. Thehighest levels of unmetSCNs were related to psychologicalwell-being, followed byhealth systemand information needs ,then physical needs ,followed by patient care and support needs, then sexual needs. This might berelated to their shock of their disease.

This finding is in accordance with*Harrison et al (2011)*[17]who mentioned that psychological domain was the most prevalent domain in patients with cancer.

This also comes in agreement with*Boyes et al (2012)&Harrison et al (2009)*[18, 19]whom reported that the majority of the unmet supportive care needs were psychological. This finding is in accordance with*Fielding et al (2013)*[20]who stated that psychological and health systems and information domains were most prevalent among Japanese patients.

In relation to the FACT-C, the present study clarified that more than two thirds of the studied patients were losing weight and more than half of them had swelling or cramp in stomach area, this may be due to disease

consequences , little appetite and constipation. However, these results contradicting with ***Puts et al (2012)***[21]who found that, the most severe concerns were related to body appearance and bowel control.

Concerning SCNs and sex, the findings of the present study represented that, there is no significance of the mean score of different domains of supportive care needs between males and females. This finding is in disagreement with ***Jorgensen et al (2012)***[22]who reported that, supportive care needs were higher for female's patients than males.

In relation to SCNs and age, the findings of the present study represented that, there is a statistical significance in the mean score of psychological and total scores among the different age groups. This finding is in line with***Barg et al (2007)&Butow et al (2012)***[23, 24]whom found that SCNs, principally psychological needs remain high especially among younger patients.

These findings were also in agreement with ***Jorgensen et al (2012)***[22]who found that, older patients have lower levels of unmet needsthanyounger patients, across a range of cancer types.

However, these results contradict the results of***Fielding et al (2013)***[20]who clarified that, Age was marginally non-significantly associated with psychological need.

In relation to SCNs and marital status, the findings of the present study represented that, there is a significant increase in the mean of physical, psychological, patient care and support, and total scores among single patients to married ones .This finding is in line with***Puts et al (2012)***[21]who found that married patients need physical, psychological and sexual needs more than single patients.

Concerning SCNs and educational level, the findings of the present study represented that, there is a statistical significant difference in the mean of psychological and total scores between working and not working patients. This finding is in agreement with ***Puts et al (2012)***[21]who reported that, unmet needs were found to be greatest in those of low educational status.

Conclusion:
The results of this study clearly indicate that, patients with newly diagnosed ACC experience high levels of unmet SCNs across a range of domains. The highest levels of unmet SCNs were related to psychological well-being and the most reported unmet need was "fear from cancer spreading".

8-Recommendation
Based on the results of the present study the following

recommendations are suggested:-

- Replication of the study using a large number of sample and various settings in Egypt to assess the SCNs of newly diagnosed ACC patients.
- More studies are needed to assess the SCNs of newly diagnosed colon cancer patients during and after intake of chemotherapy.
- Most unmet SCNs of colon cancer patients in the study are from the perspective of the psychological and health system and information domains. Therefore, educating colon cancer patients and meeting their psychological needs should be considered as a fundamental part of the supportive care programs.
- There are needs for further studies that investigate the SCNs, using other data collection methods including private interviews may increase the validity of results in sexual domain of SCNs.

Acknowledgments:

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