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**Supportive care needs, quality of life and psychological morbidity of advanced colorectal cancer patients**

**This is a pre print version of the following article:**

*Original Citation:*

*Availability:*

This version is available <http://hdl.handle.net/2318/1730023> since 2020-02-22T22:09:15Z

*Published version:*

DOI:10.1016/j.ejon.2019.09.009

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(Article begins on next page)

Manuscript Number:

Title: Supportive care needs, quality of life and psychological morbidity  
of advanced colorectal Italian cancer patients

Article Type: Full Length Article

Keywords: Supportive care needs; Colorectal cancer; Psycho-oncology;  
Quality of life; Anxiety; Depression

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with no needs or low needs.

Conclusions: The findings of this study suggest that meeting supportive  
care needs seems to improve psychological morbidity, functions and  
symptoms of CRC patients.

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Great experience on psychosocial aspects of cancer care



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Turin, 15 May 2019

Addressed to: *European Journal of Oncology Nursing* Editor-in-Chief

Dear Professor Alex Molassiotis, RN, PhD

I'm submitting to you a manuscript titled “*Supportive care needs, quality of life and psychological morbidity of advanced colorectal Italian cancer patients*” to be considered for publication as Full Length Article in your prestigious journal.

The manuscript reports the study I conducted together with my colleagues to describe the features of the supportive care needs of Italian colorectal cancer patients and to study their relations with patients' psychological morbidity and quality of life. We are currently doing research on this topics among patients with colorectal cancer and other cancers and we believe that publishing this study into your journal could emphasize the importance of assessing supportive care needs in all the different cancer populations and could sensitize health care providers to not underestimate and manage unmet needs. Furthermore, we hope to encourage other researchers to address their interest toward this area.

I confirm to you that the present manuscript has not been published previously and it is not being considered for publication elsewhere. All the co-authors are qualified for authorship and are listed as authors on the byline. Each author has approved the final version of the manuscript, as well as its submission to *European Journal of Oncology Nursing*. This study was supported by a grant from Rete Oncologica del Piemonte e della Valle d'Aosta (12/2016). All the authors declare that they have no conflict of interest (financial or other).

The present manuscript represents original material and I hope you find it adequate and interesting to your journal. I declare our complete availability and willingness to review the text, or make any other changes requested for publication.

Together with my co-authors, I thank you for your attention and look forward to hearing from you.

Best Regards.  
Sincerely,

Marco Miniotti, PhD student  
*Corresponding author*

On behalf of all my co-authors

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**Supportive care needs, quality of life and psychological morbidity of advanced colorectal Italian cancer patients**

**Short title:** Quality of life in colorectal cancer

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**Funding:** The study was supported by a grant from Rete Oncologica del Piemonte e della Valle d’Aosta (12/2016)

**Conflict of interest:** All authors declare that they have no conflicts of interest

**Acknowledgments:** The authors would like to thank the original SCNS-SF34 developers, particularly Allison Boyes, for authorizing the use of the questionnaire and Alix Hall for assisting us. The authors would also like to thank Racca Patrizia, MD and Bertetto Oscar, MD, for discussing the final version of the paper.

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*Purpose:* This study describes the supportive care needs in a consecutive sample of Italian colorectal cancer (CRC) patients, evaluating their quality of life and psychological morbidity.

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*Results:* Approximately the 80% of the patients experienced one or more moderate- or high-level unmet need, notably regarding psychological concerns (approximately the 20% presented also signs of anxiety and depression). Functional roles and cognitive functioning were low. Symptoms of fatigue, nausea and vomiting and financial issues were frequent. The severity of anxiety, depression and quality of life impairment was significantly different across different levels of needs according to a unique linear relation. Patients with moderate or high needs had more severe anxiety and depression and a lower quality of life (i.e., lower level of functioning and more severe symptoms) than those with no needs or low needs.

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### **Keywords**

Supportive care needs, Colorectal cancer, Psycho-oncology, Quality of life, Anxiety, Depression

**Supportive care needs, quality of life and psychological morbidity of advanced colorectal Italian cancer patients**

**Highlights**

- **Colorectal cancer patients have anxiety, depression and need for psychological support**
- **Physical symptoms of colorectal cancer affect the health-related quality of life**
- **Supportive care needs are significantly associated with anxiety and depression**

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## **Introduction**

Supportive care is defined as a global person-centred approach to care that includes a wide range of attention and care for physical needs related to pain, nausea and fatigue as well as psychosocial needs related to anxiety, depression, fears of cancer spreading or returning, feelings of being a burden to others, isolation or social stigma, spiritual needs and needs linked to a perceived lack in the health care apparatus or in delivery of information on the disease and treatment or even needs about sexual functions (Hui, 2014). This approach to care focuses on relieving suffering and maximizing the quality of life of patients with life-threatening or advanced disease and their families from the time of diagnosis and is used in combination with curative life-extending treatments or palliative interventions. Although supportive care refers to the management of all highly disabling illnesses, it has been historically more closely linked to cancer care (Hui, 2014). Over the past decade, there has been an international recognition of the importance of supportive care in enhancing patient outcomes in cancer settings (National Institute for Clinical Excellence [NICE], 2004; Jordan et al., 2018). The growing literature also supports its cost-effectiveness and cost-utility (Jansen et al., 2016).

The need for supportive care interventions by cancer patients has become urgent in recent years because of several factors. On the one hand, the number of long-term cancer survivors is likely to continue to grow in response to the increased incidence of cancer, the ageing of the general population and the implementation of new treatment options, both intensive and prolonged (Global Burden of Disease Cancer Collaboration, 2017). On the other hand, the increased public expectation with respect to the standards of care provided by health professionals works together with the growing desire of the patients to actively participate in the care and treatment processes throughout the trajectory of their disease (Kaasa et al., 2018). Despite these factors, a gap in the provision of supportive care in cancer is still generally

acknowledged throughout most of the world (Harrison et al., 2009; Smith et al., 2015), albeit with differences between low- and middle-income countries (Hannon et al., 2016).

Colorectal cancer (CRC) is a common disease and a leading cause of cancer death worldwide. It was the most frequent cancer in males and the second most frequent cancer in females, with more than 1,65 million new cases and approximately 835.000 deaths in 2015 (Global Burden of Disease Cancer Collaboration, 2017). In Italy, CRC is the first most common neoplasm in the whole population (14%) and the second most common neoplasm in men (16%, after prostate cancer) and women (13%, after breast cancer) (Associazione Italiana di Oncologia Medica-Associazione Italiana Registro Tumori [AIOM-AIRTum], 2017). In January 2015, there were approximately 120,000 people diagnosed with CRC in Italy. In 2016, more than 52,000 new cases of large bowel cancer were diagnosed (approximately 8,800 in men and 6,500 in women). In 2017, the prevalence of CRC exceeded 460,000 cases (Associazione Italiana di Oncologia Medica-Associazione Italiana Registro Tumori [AIOM-AIRTum], 2017). Recent advances in the early identification and management of CRC have led to more people surviving the disease and living with outcomes that might affect their psychological health and various aspects of their quality of life (Börjeson et al., 2012; Kotronoulas et al., 2017). Thus, the advances in diagnosing and treating CRC are linked to an increased need of this patient population for clinical care and an even greater need for supportive care throughout the illness trajectory (Kotronoulas et al., 2017; Ekholm et al., 2013).

Are colorectal units or cancer centres dealing with CRC adequately equipped to address this demand and meet the needs of these patients?

This question seems to be of particular importance since CRC patients must address peculiar physical challenges and restrictions due to the disease (e.g., fatigue, nausea, lack of appetite, gastrointestinal obstruction) and treatment (e.g., stoma care, diarrhoea, vomiting, bowel

dysfunction, neuropathy), which are often sources of embarrassment and distress (Wood et al., 2015). Moreover, although supportive care requirements were generally determined by individual needs rather than age-specific needs (Jorgensen et al., 2012), the older age of CRC patients complicates the outcomes and exacerbates the needs (Wood et al., 2015). A recent systematic review of the supportive care needs of CRC patients and survivors identified 136 unique supportive care needs reported by this cancer patient population and found that the need for emotional support and reassurance when trying to deal with fears of the cancer returning or spreading is the most frequent desire (up to 6 out of 10 patients), followed by the need for more information about diet, nutrition and long-term self-management of symptoms and complications at home (Kotronoulas et al., 2017). An increasing amount of literature has identified that distress in CRC patients is related to symptoms in several domains, quality of life impairment and unmet needs regarding supportive care at the end of treatment (Russell et al., 2015), following discharge from the hospital (Harrison et al., 2011), during follow-up (Wieldraaijer et al., 2017) or during long-term survival (Harrison et al., 2011). Moreover, heightened levels of anxiety and depressive symptoms are widely documented in this patient population (Tsunoda et al., 2005; Simon et al., 2009; Alacacioglu et al., 2010; Husson et al., 2013; Braamse et al., 2016). Regarding correlates, female gender and younger age were the most consistent predictors of unaddressed concerns and of greater needs for support (Kotronoulas et al., 2017).

Since there is a complete lack of data about the Italian context and because of the proven importance of investing time and research to investigate issues, concerns and needs related to care in oncology, this study aimed to explore and describe the supportive care needs of Italian CRC patients to provide knowledge for the clinicians who provide care to this cancer population and to enrich the evidence on this matter in the literature.

## **Methods**

### *Study design, participants and setting*

This study used a cross-sectional design and self-assessment procedures for data collection. Possible participants were identified from outpatient treatment lists between January 2017 and January 2018 by an expert data manager with the intent to approach a consecutive sample. Eligibility criteria for this study required that each patient had a diagnosis of stage III-IV colon or rectal cancer, was in active treatment with curative intent in an outpatient setting, was over 18 years of age and was able to understand and complete the questionnaires. Patients were ineligible if they were cognitively impaired, deemed too unwell by the treating team or physically or mentally unable to provide written informed consent and/or complete the written questionnaires.

This study was conducted in an ambulatory setting in the SSD ColoRectal Cancer Unit, Oncology Department, “Città della Salute e della Scienza” hospital in Turin. Patients were approached in person in the waiting room while they were waiting for treatment. Those who were eligible and agreed to participate were accompanied to a reserved room where they were fully informed about the methods and purposes of the study, signed the informed consent form and completed the questionnaires. The study was conducted in accordance with the principles of the Declaration of Helsinki and was approved by the appropriate ethics committee (“Comitato Etico Interaziendale AOU Città della Salute e della Scienza di Torino” N. CS/947, 27 May 2016).

### *Measures and instruments*

Age, gender, marital status, educational level and other socio-demographic information were self-reported. The date of CRC diagnosis, cancer site and stage, type of treatment and other basic clinical information of the patient were collected from clinical records.

Supportive care needs were assessed using the Italian version of the Supportive Care Needs Survey – Short Form (SCNS-SF34) (McElduff et al., 2004; Zeneli et al., 2016). The SCNS-SF34 has a total of 34 items belonging to 5 different domains: Psychological (10 items), Health system & information (11 items), Physical & daily living (5 items), Patient care & support (5 items), and Sexuality (3 items). Patients rated their need for help with each item over the past month based on the following 5-point scale built as follows: 1=not applicable (no need), 2=satisfied (need met), 3=low unmet need, 4=moderate unmet need, and 5=high unmet need; low refers to a need that causes little concern and little desire for additional help; a moderate need causes some concern and some desire for additional help; and a high need causes much concern and a strong desire for additional help.

Quality of life and specific symptoms and concerns related to CRC were assessed using the European Organisation for Research and Treatment of Cancer (EORTC) core questionnaire (QLQ-C30) (Aronson et al., 1993) and its CRC-specific module (QLQ-CR29) (Whistance et al., 2009). The QLQ-C30 provides an index of the general health status of respondents and evaluates five domains of functioning (physical, role, emotional, cognitive and social) and a list of symptoms closely linked to having a cancer. The QLQ-CR29 addresses four domains of functioning (body image, anxiety, weight and sexual interest) and a list of symptoms strictly related to CRC. Higher scores on functional scales indicate higher levels of functioning, whereas higher scores on symptom scales indicate greater intensity of symptoms.

Symptoms of anxiety and depression were assessed using the self-rated Hospital Anxiety and Depression Scale (HADS). The HADS consists of 14 items and yields scores based on two independent subscales measuring symptoms of anxiety (HADS-A) and depression (HADS-D). For each subscale, scores of 8-10 are considered borderline while scores above 11 suggest clinical anxiety or depression (Bjelland et al., 2002).

### *Statistical analyses*

Data were analysed using SPSS software v. 20.0 (IBM, Armonk, New York). Descriptive statistics were used to summarize patients' characteristics and scores generated by study measures. Since normative data are not yet available, scores of the SCNS-SF34 were calculated and transformed to a range of 0-100 to be easily interpreted by the readers. Mean ratings of scale domains were also calculated. Scores of the EORTC-QLQC30 were summed to provide new sums called Function (relative to items concerning functions), Symptom (relative to items concerning symptoms) and Total (a mean value of all the items). The summed scores were calculated and transformed to the 0-100 range following the procedure of Hinz and colleagues (Hinz et al., 2012). Scores of the EORTC-QLQCR29 regarding problems related to stomas and sexuality were differentiated for patients with and without a stoma and for males and females. Independent samples t-tests and one-way ANOVAs, with Bonferroni's correction when appropriate, were used to study between-group differences and to compare the EORTC-QLQC30 scores with the reference values (Scott et al., 2008) and the EORTC-QLQCR29 scores with the data of the large sample international validation study (Whistance et al., 2009). Cohen's d was used to calculate effect sizes. The proportion of patients who designated each item of the SCSN-SF34 as a moderate to high level was calculated, and the ten most prevalent items were isolated, as other authors did in previous studies (Boyes et al., 2012). The proportion of patients who reported "no needs" (i.e., selected response option 1 or 2 to all the items of the SCSN-SF34), "low needs" (i.e., selected response option 3 to at least one item but did not select response option 4 or 5 to any options), and "moderate to high needs" (i.e., selected response option 4 or 5 to at least one item) was calculated. SCNS-SF34 scores for each domain were recoded to discrete variables comprising three categories (no need, low need, moderate/ high need); relative frequencies for each category were calculated. Then, to study characteristics of the categories with different levels

of need, they were compared on levels of anxiety, depression and quality of life through multivariate analysis of variance (MANOVA) with alpha set at 0.01.

## **Results**

### *Participants*

A total of 250 patients were approached, and 235 expressed their consent to participate in the study and were recruited. Of those, 20 patients were excluded from the study because of their cancer stage (patients in stages I-II were not enrolled), and 12 were not able to adequately complete the questionnaires. The final sample included 203 patients. Detailed demographic and clinical characteristics of the participants are reported in Table 1.

**- Table 1 about here -**

### *Supportive care needs*

Detailed standardized scores of the SCNS-SF34 by scale domains are shown in Table 2. The mean ratings for the scale domains were as follows: Psychological= $2.5\pm 0.9$ , Physical & daily living= $2.4\pm 1.1$ , Sexuality= $1.8\pm 1.1$ , Health system & information= $2.4\pm 0.9$ , and Patient care & support= $2.0\pm 0.8$ . More than three-quarters of the patients surveyed (76.8%) experienced at least one or more moderate- or high-level unmet need. The top ten most prevalent moderate- or high-level unmet needs are listed in Table 3. The top three unmet need belonged to the psychological domain, followed by the physical & daily living and health system & information domains.

**- Table 2 and 3 about here -**

Females showed higher scores than males in the psychological ( $t=3.277$ ,  $p=0.001$ ,  $d=0.5$ ) and physical & daily living ( $t=2.585$ ,  $p=0.010$ ,  $d=0.4$ ) domains. Patients with stage IV cancer had higher scores than patients in stage III cancer in the patient care & support domain ( $t=2.582$ ,

$p=0.011$ ,  $d=0.4$ ). No differences emerged by age group, age of leaving school, time since diagnosis, type of tumor or treatment or between patients with or without colostomy.

### *Quality of life*

Detailed standardized scores of the EORTC QLQ-C30 and QLQ-CR29 by scale domains are shown in Table 2. P-values, effect sizes and interpretation of the comparisons between the observed scores and the reference values are also reported (see Table 2). Females showed lower scores than males on the QLQ-C30 total score ( $t=-2.672$ ,  $p=0.008$ ,  $d=0.4$ ), and the difference was mainly in the Function score of the scale ( $t=-3.187$ ,  $p=0.002$ ,  $d=0.5$ ). Females were also more worried about future health ( $t=2.652$ ,  $p=0.009$ ,  $d=0.4$ ). Patients with stage IV cancer had lower scores in physical functioning ( $t=-2.402$ ,  $p=0.017$ ,  $d=0.4$ ) and were more concerned about dry mouth ( $t=2.594$ ,  $p=0.010$ ,  $d=0.4$ ) and hair loss ( $t=3.024$ ,  $p=0.003$ ,  $d=0.5$ ) than patients with stage III cancer. Patients over seventy years old had more problems with urinary incontinence than younger patients ( $p=0.002$ ,  $d=0.5$ ). Patients with primary tumors were worried about future health ( $t=2.846$ ,  $p=0.005$ ,  $d=0.4$ ). Patients with colostomy had more problems with faecal incontinence ( $t=2.961$ ,  $p=0.003$ ,  $d=0.4$ ) and felt more embarrassed ( $t=5.242$ ,  $p<0.001$ ,  $d=0.8$ ). Relative to patients who had undergone surgery and/or chemotherapy, those who had also undergone radiation reported more pain ( $p=0.011$ ,  $d=0.5$ ). No differences emerged by age of leaving school or time since diagnosis.

### *Anxiety and depression*

The HADS mean scores were also under the cut-off values also for subthreshold symptoms of both anxiety and depression. Clinical anxiety was found in approximately 13% of the patients. Clinical depression affected approximately 11%. More than 20% showed signs of borderline anxiety and depression. Females were more anxious ( $t=3.527$ ,  $p=0.001$ ,  $d=0.5$ ) and depressed ( $t=2.858$ ,  $p=0.005$ ,  $d=0.4$ ) than males. No differences emerged by age group, age of leaving

school, time since diagnosis, type or stage of tumor or treatment or between patients with or without colostomy.

#### *Quality of life, anxiety and depression across different levels of need*

The MANOVA results showed significant effects of anxiety, depression and quality of life on all the domains of supportive care needs. Patients with moderate or high needs had more severe anxiety and depression and lower quality of life (i.e., lower functional capacity and more severe symptoms) than those with no needs or low needs. Significance values of test statistics and descriptive statistics are reported in Table 4.

**- Table 4 about here -**

### **Discussion**

Although the SCNS-SF34 mean scores reported might suggest that the study population had a substantial absence of need or, at most, a slight unmet need, the findings of this study still suggest a gap in the provision of adequate supportive care for CRC patients, notably regarding needs in the psychological domain. First, most of the patients (just under 80%) experienced at least one or more moderate- or high-level unmet need. Moreover, fears about cancer spreading and anguish about the future were frequent and reported by approximately 40% of the participants. Concern about the worries of loved ones was observed in just under 50% of participants. These data suggest that due to their psychological issues, most CRC patients feel like a burden to others. Patients' self-perceived burden was defined as "an empathic concern engendered from the impact on others of one's illness and care needs, resulting in guilt, distress, feelings of responsibility and diminished sense of self" (McPherson et al., 2007) (p 425). Cancer patients frequently worry about being a burden to their families (Simmons, 2007), and this condition has been shown to be associated with diminished will to

live (Chochinov et al., 2005), desire for hastened death (Filiberti et al., 2001), and avoidance of a home setting for end-of-life care (Thomas et al., 2004). Thus, this may complicate patient decision making and might lead to refusal of the most appropriate treatment. The frequency of psychological unmet needs that emerged in this study is not substantiated by an equally high frequency of psychological morbidity. Approximately 40% of the participants showed a moderate or high psychological unmet need, but only approximately 20% presented signs of anxiety and depression, and that percentage dropped to 11-13% if we considered symptoms at a clinical level. This finding suggests that psychological supportive care needs could be a different construct from anxiety and depression and thus confirms the importance of supportive care needs assessment to capture the complex nature of the psychological suffering experienced by cancer patients. The between-group differences in supportive care needs were not surprising. Moreover, the size of their effect was small. Gender was associated with reporting some unmet needs in the psychological domain, with females reporting higher levels of unmet need than males. This result is consistent with previous research (Sanson-Fisher et al., 2000; Boyes et al., 2012). Similarly, cancer stage was associated with reporting some unmet needs in the patient care & support domain, with patients with stage IV cancer reporting higher levels of unmet needs than patients with stage III cancer. Additionally, this result is in keeping with other studies that found that patients with advanced disease have higher levels of need than patients in remission or with localized disease (Sanson-Fisher et al., 2000; Boyes et al., 2012).

Concerning cancer-related quality of life, the study population showed lower functional roles and cognitive functioning when compared to the reference values for advanced CRC patients (Scott et al., 2008). The study participants also experienced more disabling symptoms of fatigue, nausea and vomiting. They were also more concerned about financial difficulties. Except for the differences in financial concerns, the effect size of these differences was

moderate. These findings are very similar to those observed in previous studies of CRC patients (Arndt et al., 2004; Russell et al., 2015). As observed in those studies, symptoms of fatigue, nausea and vomiting are particularly disabling during treatment and tend to decline after treatment. The patients we examined in this study were all in active treatment (i.e., chemotherapy) during the assessment; some of them had also undergone surgery and/or radiation in the past. This factor is probably the reason why patients encountered problems in concentrating and remembering (i.e., cognitive functioning) and in performing daily activities and hobbies (i.e., functional roles). Notably, the patients who also had radiation reported more pain. Financial problems were also a greater issue for the participants in this study. Perhaps, treatment symptoms may prevent patients from returning to work, and this could add financial concerns. This result was also observed in other studies on CRC patients (Russell et al., 2015) and has also been found in other cancer populations (Timmons et al., 2013). Except for women, patients with primary tumor and patients over seventy years old, the study population reported fewer concerns about future health, weight and body image and also fewer problems with urinary incontinence and blood and mucus in the stool than the patients from the large multi-center validation study of the EORTC CRC-specific module (Whistance et al., 2009). The effect sizes of these comparisons ranged from medium to large. However, the patients we examined had more severe problems with urinary frequency, abdominal pain and related bloating, they reported frequent taste disturbances, and men showed lower sexual interest. Effect sizes for these comparisons were mainly small or medium. Particularly, patients with stage IV cancer were more physically compromised and concerned about physical symptoms (i.e., dry mouth and hair loss) than those with stage III cancer, whereas stoma patients were more embarrassed and concerned about faecal incontinence. Taken together, the findings from EORTC QLQ-C30 and its CRC-specific module seem to suggest that the CRC-related quality of life of the study population was more physically rather than psychologically compromised

and must be investigated and interpreted by considering the presence of subsets of patients determined by both demographic and clinical factors.

Beyond the above distinction between anxiety, depression and psychological supportive care needs, the frequency of anxious-depressive symptoms observed in this study seems to be relevant, since the 1-month prevalence of anxiety and mood disorders in the Italian general population is approximately 2.2% and 1.5% respectively (de Girolamo et al., 2006), versus the 11-13% experiencing clinical symptoms in the study population.

The severity of anxious-depressive symptoms and quality of life impairment was significantly different across the different levels of supportive care needs according to a unique linear relation in all the need domains. That is, the severity of anxiety and depression together with the impairment of quality of life increases as the intensity of the need rises from low to moderate to high. This could mean that meeting supportive care needs has a significant positive impact on psychological morbidity, functions and symptoms. Anxiety, depression, and the different components of quality of life (i.e., functions and symptoms), even individually considered, had a significant effect on the domains of supportive care needs. However, the analysis of the sum of squares and cross products (SSCP) matrix of the MANOVA provided an interesting insight into the pattern of the data since it suggests that there might be a relationship between anxiety, depression and quality of life that it could be more important than these individual variables alone. Future studies could benefit from deepening this understanding through further analyses to shed further light on the relationships between these variables.

This study includes important limitations. First, the analyses were based on a single time-point which prevents the observation of the pattern of supportive care needs, quality of life and psychological morbidity over time throughout the CRC trajectory. For this reason, the findings of this study do not allow us to establish causal links between the variables. Second,

this study was conducted at a single site and examined only patients with advanced disease (i.e., stage III-IV) in active treatment. This limits the generalizability of the results, not only to the cancer population in general but also to the whole CRC population. Third, in examining the effect of quality of life, anxiety and depression on supportive care needs, this study did not consider other subjective variables as possible covariates, such as personality characteristics, strategies for coping and adjustment or other factors linked to the history of the disease.

## **Conclusion**

In summary, the study population reported specific unmet supportive care needs, mainly related to psychological concerns. Psychological morbidity was present in a small subset of patients. Functional roles and cognitive functioning were significantly impaired, and disabling CRC- and treatment-related symptoms were reported. Meeting supportive care needs seems to improve psychological morbidity, functions and symptoms. These findings could have implications for clinical care. Patients and clinicians should know that psychological issues and concerns, specific symptoms and functional impairments might be expected throughout the CRC trajectory. Referring to supportive care appears to be a feasible way to quickly plan adequate interventions to relieve suffering or to prevent suffering as much as possible. Future research should test the effectiveness of supportive care-based interventions in different cancer settings.

## References

- Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J. et al. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute* 85, 365-376.
- Alacacioglu, A., Binicier, O., Gungor, O., Oztop, I., Dirioz, M., Yilmaz, U. (2010). Quality of life, anxiety and depression in Turkish colorectal cancer patients. *Supportive Care in Cancer* 18, 417-421.
- Arndt, V., Merx, H., Stegmaier, C., Ziegler, H., Brenner, H. (2004). Quality of life in patients with colorectal cancer 1 year after diagnosis compared with the general population: a population-based study. *Journal of Clinical Oncology* 22, 4829-4836.
- Bjelland, I., Dahl, A. A., Haug, T.T., Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *Journal of Psychosomatic Research* 52, 69-77.
- Börjeson, S., Starkhammar, H., Unosson, M., Berterö, C. (2012). Common symptoms and distress experienced among patients with colorectal cancer: a qualitative part of mixed method design. *The Open Nursing Journal* 6, 100-107.
- Boyes, A. W., Girgis, A., D'Este, C., Zucca, A. C. (2012). Prevalence and correlates of cancer survivors' supportive care needs 6 months after diagnosis: a population-based cross-sectional study. *BMC Cancer* 12, 150.
- Braamse, A. M., van Turenhout, S. T., Terhaar Sive Droste, J. S., de Groot, J. H., van der Hulst, R. W., Klemm-Kropp, M., et al. (2016). Factors associated with anxiety and depressive

symptoms in colorectal cancer survivors. *European Journal of Gastroenterology & Hepatology* 28, 831-835.

Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., Harlos, M. (2005). Understanding the will to live in patients nearing death. *Psychosomatics* 46, 7-10.

de Girolamo, G., Polidori, G., Morosini, P., Scarpino, V., Reda, V., Serra, G., et al. (2006). Prevalence of common mental disorders in Italy: results from the European Study of the Epidemiology of Mental Disorders (ESEMeD). *Social Psychiatry and Psychiatric Epidemiology* 41, 853-861.

Ekholm, K., Grönberg, C., Börjeson, S., Berterö, C. (2013). The next of kin experiences of symptoms and distress among patients with colorectal cancer: diagnosis and treatment affecting the life situation. *European Journal of Oncology Nursing* 17, 125-130.

Filiberti, A., Ripamonti, C., Totis, A., Ventafridda, V., De Conno, F., Contiero, P., et al. (2001). Characteristics of terminal cancer patients who committed suicide during a home palliative care program. *Journal of Pain and Symptom Management* 22, 544-553.

Global Burden of Disease Cancer Collaboration, Fitzmaurice, C., Allen, C., Barber, R. M., et al. (2017). Global, Regional and National Cancer Incidence, Mortality, Years of Life Lost, Years with Disability, and Disability-adjusted Life-years for 32 Cancer Groups, 1999-2015: A Systematic Analysis for the Global Burden of Disease Study. *JAMA Oncology* 3, 524-548.

Guidance on Cancer Services: Improving supportive and palliative care for adults with cancer. The manual. National Institute for Clinical Excellence (NICE).

<https://www.health.govt.nz/system/files/documents/publications/supp-care-guidance-mar2010.pdf>. Accessed June 2018.

Hannon, B., Zimmermann, C., Knaul, F. M., Powell, R. A., Mwangi-Powell, F. N., Rodin, G. (2016). Provision of palliative care in low- and middle-income countries overcoming obstacles for effective treatment delivery. *Journal of Clinical Oncology* 34, 62-68.

Harrison, J. D., Young, J. M., Auld, S., Masya, L., Solomon, M. J., Butow, P. N. (2011). Quantifying postdischarge unmet supportive care needs of people with colorectal cancer: a clinical audit. *Colorectal Disease* 13, 1400-1406.

Harrison, J. D., Young, J. M., Price, M. A., Butow, P. N., Solomon, M. J. (2009). What are the unmet supportive care needs of people with cancer? A systematic review. *Supportive Care in Cancer* 17, 1117-1128.

Harrison, S. E., Watson, E. K., Ward, A. M., Khan, N. F., Turner, D., Adams, E., et al. (2011). Primary health and supportive care needs of long-term cancer survivors: a questionnaire survey. *Journal of Clinical Oncology* 29, 2091-2098.

Hinz, A., Eienkel, J., Briest, S., Stolzenburg, J.U., Papsdorf, K., Singer, S. (2012). Is it useful to calculate sum scores of the quality of life questionnaire EORTC-QLQC30? *European Journal of Cancer Care* 21, 677-683.

Hui, D. (2014). Definition of supportive care: does the semantic matter? *Current Opinion in Oncology* 26, 372-379.

Husson, O., Thong, M. S., Mols, F., Smilde, T. J., Creemers, G. J., van de Poll-Franse, L. V. (2013). Information provision and patient reported outcomes in patients with metastasized colorectal cancer: results from the PROFILES registry. *Journal of Palliative Medicine* 16, 281-288.

I numeri del cancro in Italia 2017. Associazione Italiana di Oncologia Medica-Associazione Italiana Registro Tumori (AIOM-AIRTum).

[http://www.aiom.it/C\\_Common/Download.asp?file=/\\$Site\\$/files/doc/AIOM-Fondazione/2017\\_numeri\\_del\\_cancro\\_ed\\_pazienti.pdf](http://www.aiom.it/C_Common/Download.asp?file=/$Site$/files/doc/AIOM-Fondazione/2017_numeri_del_cancro_ed_pazienti.pdf). Accessed June 2018.

Jansen, F., van Zwieten, V., Coupé, V. M., Leemans, C. R., Verdonck-de Leeuw, I.M. (2016). A review on cost-effectiveness and cost-utility of psychosocial care in cancer patients. *Asia-Pacific Journal of Oncology Nursing* 3, 125-136.

Jordan, K., Aapro, M., Kaasa, S., Ripamonti, C. I., Scotté, F., Strasser, F., et al. (2018). European Society for Medical Oncology (ESMO) position paper on supportive and palliative care. *Annals of Oncology* 29, 36-43.

Jorgensen, M. L., Young, J. M., Harrison, J. D., Solomon, M. J. (2012). Unmet supportive care needs in colorectal patients: differences by age. *Supportive Care in Cancer* 20, 1275-1281.

Kaasa, S., Knaul, F. M., Mwangi-Powell, F., Rodin, G. (2018). Supportive care in cancer: new directions to achieve universal access to psychosocial, palliative, and end-of-life care. *The Lancet Global Health* 6, S11-12.

Kotronoulas, G., Papadopoulou, C., Burns-Cunningham, K., Simpson, M., Maguire, R. (2017). A systematic review of the supportive care needs of people living with and beyond cancer of the colon and/or rectum. *European Journal of Oncology Nursing* 29, 60-70.

McElduff, P., Boyes, A., Zucca, A., Girgis, A. (2004). *Supportive Care Needs Survey: A guide to administration, scoring and analysis*. Newcastle: Centre for Health Research & Psycho-Oncology.

McPherson, C. J., Wilson, K. G., Murray, M. A. (2007). Feeling like a burden: exploring the perspectives of patients at the end of life. *Social Science & Medicine* 64, 417-427.

Russell, L., Gough, K., Drosdowsky, A., Schofield, P., Aranda, S., Butow, P. N. et al. (2015). Psychological distress, quality of life, symptoms and unmet needs of colorectal cancer survivors near the end of treatment. *Journal of Cancer Survivorship* 9, 462-470.

Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., Cook, P. (2000). The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer* 88, 226-237.

Scott, N. W., Fayers, P., Aaronson, N. K., Bottomley, A., de Graeff, A., Groenvold, M., et al. (2008). *EORTC Quality of Life Group. EORTC QLQ-C30 Reference Values Manual (2<sup>nd</sup> ed.)*. Brussels, Belgium: EORTC Quality of Life Group.

[http://groups.eortc.be/qol/sites/default/files/img/newsletter/reference\\_values\\_manual2008.pdf](http://groups.eortc.be/qol/sites/default/files/img/newsletter/reference_values_manual2008.pdf).

Accessed June 2018.

Simmons, L. A. (2007). Self-perceived burden in cancer patients: validation of the Self-perceived Burden Scale. *Cancer Nursing* 30, 405-411.

Simon, A. E., Thompson, M. R., Flashman, K., Wardle, J. (2009). Disease stage and psychosocial outcomes in colorectal cancer. *Colorectal Disease* 11, 19-25.

Smith, A., Hyde, Y. M., Stanford, D. (2015). Supportive care needs of cancer patients: a literature review. *Palliative & Supportive Care* 13, 1013-1017.

Thomas, C., Morris, S. M., Clark, D. (2004). Place of death: preferences among cancer patients and their carers. *Social Science & Medicine* 58, 2431-2444.

Timmons, A., Gooberman-Hill, R., Sharp, L. (2013). The multidimensional nature of the financial and economic burden of a cancer diagnosis on patients and their families: qualitative findings from a country with a mixed public-private healthcare system. *Supportive Care in Cancer* 21, 107-117.

Tsunoda, A., Nakao, K., Hiratsuka, K., Yasuda, N., Shibusawa, M., Kusano, M. (2005). Anxiety, depression and quality of life in colorectal cancer patients. *International Journal of Clinical Oncology* 10, 411-417.

Whistance, R. N., Conroy, T., Chie, W., Costantini, A., Sezer, O., Koller, M., et al. (2009). European Organisation for the Research and Treatment of Cancer Quality of Life Group. *European Journal of Cancer* 45, 3017-3026.

Wieldraaijer, T., Duineveld, L. A., van Asselt, K. M., van Geloven, A. A., Bemelman, W. A., van Weert, H. C., et al.; ICARE study group. Follow-up of colon cancer patients; causes of distress and need for supportive care: results from the ICARE study. *European Journal of Surgical Oncology* 43, 118-125.

Wood, C., Lawton, S., Downing, A., Morris, E., Glaser, A. W., Thomas, J., et al. (2015). Quality of life of colorectal cancer survivors in England: report of a national survey of colorectal cancer survivors using patient reported outcome measures (PROMs). Project Report. NHS England. 2015; <https://www.england.nhs.uk/wp-content/uploads/2015/03/colorectal-cancer-proms-report-140314.pdf>. Accessed June 2018.

Zeneli, A., Fabbri, E., Donati, E., Tierney, G., Pasa, S., Berardi, M. A., et al. (2016). Translation of Supportive Care Needs Survey Short Form 24 (SCNS-SF34) into Italian and cultural validation. *Supportive Care in Cancer* 24, 843-848.

Table 1. Patients' characteristics (N=203).

	n(%)
<b>Age</b>	
≤59 years	52(25.6)
60-69 years	78(38.4)
≥70 years	73(36.0)
<b>Gender</b>	
Male	115(56.7)
Females	88(43.3)
<b>Marital status</b>	
Married/ defacto	150(73.9)
Single/ widowed	53(26.1)
<b>Age leaving school</b>	
≤11 years	113(55.7)
12-14 years	62(30.5)
15-19 years	25(12.3)
≥20 years	3(1.5)
<b>Current employment</b>	
Paid work	56(27.6)
Not working	23(11.3)
Retired	124(61.1)
<b>Time since diagnosis</b>	
≤12 months	102(50.2)
13-49 months	62(30.5)
≥50 months	39(19.2)
<b>Cancer site</b>	
Colon	145(71.4)
Rectum	58(28.6)
<b>Tumor</b>	
Primary	140(69.0)
Relapsed	63(31.0)
<b>Cancer stage</b>	
III	70(34.5)
IV	133(65.5)
<b>Treatment</b>	
Chemotherapy	22(10.8)
Surgery+chemotherapy	140(69.0)
Surgery+chemotherapy+radiation	41(20.2)
<b>Chemotherapy</b>	
Adjuvant	75(36.9)
For metastatic disease	128(63.1)
<b>Colostomy</b>	
Underwent	140(69.0)
Not underwent	63(31.0)

Table 2. Supportive care needs and quality of life scores (N=203).

	<b>m±sd</b>	<b>p(d)</b>	<b>+/-</b>
<b>Supportive care needs (SCNS-SF34)</b>			
Psychological	38.9±23.4		
Health system & information	33.9±22.4		
Physical & daily living	37.7±27.1		
Patient care & support	24.4±17.9		
Sexuality	18.9±25.2		
<b>Quality of life (EORTC-QLQ-C30)</b>			
<i>Global Health status</i>	60.5±20.0		
<i>Function</i>	71.5±17.3		
Physical functioning	74.5±21.1		
Role functioning	64.3±26.3	<0.001(0.6)	-
Emotional functioning	69.5±23.2		
Cognitive functioning	77.8±25.0	<0.001(0.6)	-
Social functioning	71.7±27.5		
<i>Symptom</i>	25.3±14.9		
Fatigue	44.4±24.8	<0.001(0.5)	+
Nausea/vomiting	16.8±22.9	<0.001(0.6)	+
Pain	26.6±29.4		
Dyspnoea	17.7±24.9		
Sleep loss	32.7±33.3		
Appetite loss	19.3±28.1		
Constipation	19.1±31.3		
Diarrhoea	26.1±32.1		
<i>Financial difficulties</i>	18.9±28.5	0.001(0.3)	+
<i>Total</i>	71.4±14.2		
<b>Quality of life (EORTC-QLQ-CR29)</b>			
<i>All patients</i>			
Body image	77.7±28.1	<0.001(2.1)	+
Anxiety	54.7±29.5	<0.001(0.5)	+
Weight	81.4±26.3	<0.001(2.2)	+
Urinary frequency	27.5±27.7	<0.001(0.8)	+
Blood and mucus in stool	3.1±9.2	0.002(0.3)	-
Urinary incontinence	5.4±15.5	0.003(0.3)	-
Dysuria	4.6±14.5		
Abdominal pain	22.8±27.1	0.003(0.3)	+
Buttock pain	14.1±25.7		
Bloating	23.3±31.0	0.014(0.2)	+
Dry mouth	29.9±38.0		
Hair loss	14.7±28.0		
Taste	31.1±35.0	<0.001(0.6)	+
<i>Patients without stoma (n=154)</i>			
Stool frequency	16.1±25.3		
Flatulence	21.3±30.8		
Faecal incontinence	4.4±13.7		
Sore skin around anus	13.8±22.5		
Embarrassment by defaecation	9.4±23.1		
<i>Patients with stoma (n=49)</i>			
Stool frequency/ bags change	13.2±19.4		
Flatulence	23.8±29.7		
Faecal incontinence/ leakage	12.2±22.2		
Sore skin around stoma	17.1±25.6		
Embarassment by stoma	32.0±34.0		
Stoma care problems	25.5±36.3		
<i>Males (n=115)</i>			
Sexual interest	68.7±28.4	0.008(0.9)	-
Impotence	28.5±36.9		
<i>Females (n=88)</i>			
Sexual interest	89.8±16.3		

Dyspareunia

8.2±22.1

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*Notes:* Scores were standardized sums of ratings; High score for functional scales indicates better functioning whereas high symptom score indicates more problems;  $p(d)$ , T-tests p-value and Cohen's  $d$ ; +/-, observed score higher (+) or lower (-) than the reference value (Scott et al., 2008; Whistance et al., 2009).

Table 3. Ten most prevalent “Moderate” or “High” level unmet supportive care needs.

<b>Rank</b>	<b>SCNS-SF34 item</b>	<b>n(%)<sup>†</sup></b>
<b>1</b>	Concerns about the worries of those close to you	94(46.3)
<b>2</b>	Fears about the cancer spreading	77(37.9)
<b>3</b>	Uncertainty about the future	74(36.5)
<b>4</b>	Lack of energy/ tiredness	72(35.5)
<b>5</b>	Being informed about things you can do to help yourself to get well	66(32.5)
<b>6</b>	Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	59(29.1)
<b>7</b>	Not being able to do the things you used to do	54(26.6)
<b>8</b>	Being informed about cancer which is under control or diminishing (that is, remission)	50(24.6)
<b>9</b>	Pain	48(23.6)
<b>10</b>	Being informed about your test results as soon as possible	45(22.2)

Notes: <sup>†</sup> number and percentage of “Moderate” or “High” needs.

Table 4. Comparing groups with different levels of needs on anxiety, depression and quality of life: mean HADS and EORTC QLQ-C30 scores by levels of needs.

SCNF-SF34 domains by levels of needs	V	HADS Anxiety	HADS Depression	QLQ-C30 Function	QLQ-C30 Symptom
<b>Psychological</b>	0.410**	$p<0.001$	$p<0.001$	$p<0.001$	$p<0.001$
<b>No</b>		3.4±2.9	3.5±2.8	81.6±13.8	18.9±12.1
<b>Low</b>		5.8±3.7	6.0±3.1	71.6±14.1	25.1±14.6
<b>Moderate/ High</b>		9.0±3.8	8.1±3.7	59.9±16.5	32.8±14.8
<b>Health system &amp; information</b>	0.169**	$p<0.001$	$p=0.001$	$p<0.001$	$p=0.007$
<b>No</b>		4.6±3.8	4.9±3.3	76.5±15.4	22.5±15.5
<b>Low</b>		6.6±3.7	5.8±3.0	69.6±13.9	26.7±12.6
<b>Moderate/ High</b>		8.7±4.3	7.8±5.0	61.1±22.8	31.8±16.2
<b>Physical &amp; daily living</b>	0.469**	$p<0.001$	$p<0.001$	$p<0.001$	$p<0.001$
<b>No</b>		4.3±3.7	4.1±3.0	83.5±11.7	15.8±9.9
<b>Low</b>		6.5±4.3	6.4±3.6	68.6±13.6	28.1±12.6
<b>Moderate/ High</b>		7.9±3.8	7.7±3.8	56.4±15.5	36.1±14.5
<b>Patient care &amp; support</b>	0.160**	$p<0.001$	$p=0.016$	$p<0.001$	$p=0.133$
<b>No</b>		5.0±3.8	5.3±3.2	75.2±14.5	24.0±15.1
<b>Low</b>		7.9±4.1	6.5±4.5	64.5±19.4	27.9±13.3
<b>Moderate/ High</b>		8.1±4.8	7.7±4.8	60.5±22.5	30.0±17.3
<b>Sexuality</b>	0.087*	$p=0.071$	$p=0.001$	$p=0.014$	$p=0.626$
<b>No</b>		5.6±4.4	5.2±3.5	73.2±17.3	25.4±15.2
<b>Low</b>		6.4±3.4	6.0±3.2	71.1±13.3	23.9±12.7
<b>Moderate/ High</b>		7.6±3.8	8.2±4.8	62.1±20.8	27.6±17.0

Notes: V, Pillai-Bartlett trace;  $p$ -values refer to separate univariate ANOVAs on the outcome variables;  $p<0.05$ ; \*\*  $p<0.001$ .