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# Quality of life assessment in patients with a stoma due to rectal cancer in Morocco

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**Abbreviations:** EORTC: European Organization for Research and Treatment of Cancer; QLQ: Quality of Life Questionnaire.

#### Abstract

Colorectal cancer is a major public health problem in Morocco, according to the Moroccan.

Cancer Registry; it represents the first gastro-intestinal cancer and the third most common cancer in Morocco. The aim of this paper is to compare the quality of life of rectal cancer patients with and without permanent colostomy in the course of rectal cancer treatment.

**Methods:** Patients were recruited from the National Institute of Oncology in Rabat – Morocco, during the February 2016 - June 2018 period. The version of the third QLQ-C30 and C29 questionnaire of the European Organization for Research and Treatment of Cancer (EORTC) was translated for the first time in Moroccan Arabic and used to obtained relevant data.

Psychometric properties were measured on patients with colorectal cancer recruited from different regions of the country. Statistical analysis included Cronbach's alpha, correlation, multi-trait scaling and known groups comparisons. p value  $\leq 0.05$  was considered significant.

**Results:** In total, 102 patients with rectal cancer were included in the study and 45 (44 %) patients with stoma. The mean age at diagnosis time was 51 years (+/- 11.4). Stoma patients did not show significant impairment of functioning, which did not negatively influence their quality of life.

Patients with stoma had higher symptom scores related to diarrhea and experienced more financial difficulty as measured by EORTC C-30, in clinically distinct group comparison. With EORTC C-29, this group showed lower Functional scales scores for body image, sexual dysfunction for female patients and higher symptom scores related to urinary frequency, troubles with taste, hair loss, sore skin, psychosocial disturbance in the form of embarrassment due to the frequent need to change the stoma bag compared to patients without a stoma.

**Conclusions:** The experience of stoma has a not large negative impact on Moroccan patients' quality of life. Influence of stoma is most pronounced in the area of symptom and financial difficulty. Financial difficulties are, by far, more present.

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#### Background

The colorectal cancer is a major public health problem in Morocco, according to the Moroccan.

Cancer Registry, it represents the first gastro-intestinal cancer and the third most common cancer in Morocco, as it represents 6.7 % of all cancers in Morocco, as per the standardized rates on the world population, and the Moroccan population was respectively 9.6 and 7.8 for 100,000 inhabitants in 2012. These rates were slightly higher among men compared to women [1]. The European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire core (QLQ-C30 and QLQ-C29) are frequently used in cancer of the colorectal [2-4]. The questionnaire has been validated across many cultures and disease conditions and was found to have adequate acceptable psychometric properties.

In order to develop an integrated modality for assessing the QLQ in patients with colorectal cancer, the EORTC working group on QLQ subsequently developed the QLQ- CR29 [5].

In addition to being more sensitive to novel therapies, the new shorter QLQ- CR29 enables sexual functioning to be assessed over a 4- week period and to be analyzed independently of the other domains [6]. To address the limitations of the EORTC QLQ- CR30, the EORTC QLQ- CR29 is now the specific supplementary module for to be used in a combination with EORTC QLQ- CR30 and should be adapted, and translated into the Moroccan Arabic language in the near future in the Moroccan colorectal cancer population.

The EORTC QLQ-C30 questionnaire was previously translated into the Moroccan Arabic Dialectal version [7]. However, the psychometric properties of QLQ-C30 and C-29 in colorectal cancer have never been examined, especially in Patients with a stoma despite the fact that this cancer represents an important public health burden and there is an increasing need to assess quality of life experienced by patients with this cancer and to release appropriate treatment in Morocco.

The objective of this study was to compare the quality of life in rectal cancer patients with or without permanent colostomy in colorectal cancer patients receiving treatment at the National Institute of oncology in Rabat.

#### **Materials and methods**

#### **Patient's recruitment**

Colorectal cancer patients were recruited from the National Institute of Oncology in Rabat –Morocco during the February 2015 - June 2017 period. These patients were from different regions of the country, as the National Institute of Oncology of Rabat is the main cancer treatment centre in the country. Adult patients (≥18 years) with histologically proven colorectal cancer were eligible to enter the study. Demographic and clinical data were retrieved from the patients' medical records. A written informed consent was required for recruitment in the study. All the patient has received the information's regarding the conditions of the study. This study received Ethical approval from the ethics committees of the Mohamed V Faculty of Medicine and Pharmacy and the National Institute of Oncology in Rabat, Morocco.

#### Instruments and procedures

The Moroccan Arabic version of the EORTC QLQ-C30 and QLQ-C29 was used to obtain relevant data. Participants were requested to complete the questionnaire by themselves or with the help of an interviewer while waiting to see the doctor at the outpatient surgical clinic or immediately after their consultation. Reference values from the literature were used to compare the obtained results [8].

#### Statistical analysis

Descriptive statistics were performed using mean or median and standard deviations. The internal-consistency reliability of the multi-item scales was assessed by Cronbach's a coefficient. A value of 0.70 or greater was considered adequate. Clinically distinct group's validity was examined by comparing the scores of patients with and without stoma as well as localization of cancer in the colon and rectum using Mann Whitney u-test. All statistical analyses were performed using SPSS version 18.

#### Results

#### Patient's characteristics

In total, 102 patients with colorectal cancer were included in the study, of which there were 40 patients (39%) with colon cancer, 62 patients (61%) with rectal cancer. Among them 45 patients (44%) had a stoma. The mean patient age at diagnosis was 51 years (+/- 11.4) (range: 28–76). The male – female sex ratio was 1.48. 71 patients (70%) married were and came from urban areas. (56%) without formal education and had a low-intermediate socio-economic status, and 71 (70%) had no medical insurance.

#### Acceptability of questionnaires and preferences

The average time required to complete the questionnaire was from 9.6 to 17 min and more than 67 patients (56%) could not respond the questionnaire without the help of an interviewer. Patients considered the time of administration, which was immediately after the medical consultation, to be inappropriate.

#### Internal consistency

The internal consistencies of the Moroccan Arabic version of versions of the EORTC QLQ-C30 were acceptable with Cronbach's alpha ( $\alpha \ge 0.70$ ) in the global health status/overall quality of life (GHS/ QOL)(P=0.678), and all of the functioning and multi-item symptom scales.

In all assessed domains, stoma patients did not show significant impairment of functioning, which did not negatively influence their quality of life. All results are shown in Table 1. Mean score of physical functioning, social roles and emotional scale did not show a difference of points compared to the reference. The presence of a stoma also did not significantly influence functions scales with EORTC C-29 group. 
 Table 1: Demographic and clinical features of patients (n=102).

Variable	No	Percentage (%)
Age		
Mean (SD)		51 (11.4)
Range		28-76
Gender		
Male	61	60.0
Female	41	40.0
Marital status		
Single	18	17.6
Married	71	69.6
Other	13	12.7
Educational status		
Illiterate	53	52.0
Primary school and college	37	36.3
High school	12	11.8
Living environment		
Urban	71	69.6
Rural	31	30.5
Socioeconomic status		
Low	57	55.8
Intermediate	39	38.2
high	6	5.9
localization		
Colon	40	39.2
Rectum	62	60.7
Stoma		
Yes	45	44.1
No	57	55.8
Medical insurance		
Yes	31	30.4
No	71	69.6

Table 2: Internal consistencyEORTC QLQ-C30 scores.

scale	Cronbach's alpha				
	overall	With stoma	Without stoma		
Global health status / quality of life					
Global health status / quality of life	0.82	0.87	0.81		
Functioning scales					
Physical	0.79	0.83	0.79		
Role	0.82	0.88	0.81		
Emotional	0.80	0.84	0.80		
Cognitive	0.80	0.85	0.79		
Social and Family	0.83	0.83	0.83		
Multi-item symptoms scales					
Fatigue	0.78	0.83	0.76		
Nausea/Vomiting	0.83	0.86	0.82		
Pain	0.79	0.83	0.79		

Table 3: EORTC QLQ-C30 scores (functional scales).

Conoral quality of life		Cronbach's alpha				
General quality of life	Cronbach's alpha					
	With stoma	Reference value	Difference			
Functioning scales						
Physical	0.83	0.90	0.07			
Role	0.88	0.88	0.00			
Emotional	0.84	0.78	-0.06			
Cognitive	0.85	0.91	0.06			
Social and Family	0.83	0.91	0.08			

#### Clinically distinct group comparison

Patients in version of the EORTC QLQ-C30with stoma had a higher symptom scores related to diarrhea (p=0.013) and more financial difficulty (P=0.035) as compared with patients without stoma (Table 4).

Table 4: EORTC QLQ-C29 scores (functional scales).						
QLQ-CR29 Scales	Without a stoma n=61			With	a stoma n=41	
	Convergent	Divergent	α	Convergent	Divergent	α
Urinary frequency	0.93-0.94	0.03-0.31	0,70	0.88-0.90	0.10-0.53	0,65
Blood and mucus in stools	0.80-0.84	0.14-0.58	0,61	0.83-0.89	0.26-0.54	0,63
Stool frequency	0.92-0.93	0.11-0.50	0,69	0.90-0.97	0.03-0.51	0,62
Body image	0.76-0.84	0.01-0.21	0,77	0.70-0.84	0.01-0.46	0,80

On the other hand, patients with stoma who took the EORTC QLQ-C29 version reported lower functional scores for body image (P=0,004), sexual dysfunction for female (P =0,036) patients and higher symptom scores related to urinary frequency (P=0,045), troubles with taste (P =0,033), hair loss (P =0,001), sore skin (P =0,027), psychosocial disturbance in the form of embarrassment (P =0,032) due to the frequent need to change the stoma bag compared to patients without a stoma (Table 5).

 Table 5: Group comparison version QLQ-C30 between patients

 with and without a stoma.

Stoma=45 No Stoma=57 P- valu					P- value
	Stoma=45		No Stoma=57		P- Value
	Mean / N	/ledian (SD)	Mean / N	ledian (SD)	
GHS/ QOL	66.7	19.8	63.4	21.9	0.678
Physical function	66.1	21.3	70.2	19.5	0.131
Role function	55.5	30.4	60.4	31.4	0.148
Emotional function	65.2	30.7	66.1	25.7	0.907
Cognitive function	83.3	26.5	83.9	23.7	0.419
Social function	79.1	27.6	86.6	25.6	0.151
fatigue	51.8	29.3	44.6	27.3	0.734
Nausea /vomiting	13.8	21.1	9.4	18.3	0.593
Pain	36.1	32.4	40.8	33.3	0.839
Dyspnoea	30.5	41.3	20.2	29.1	0.882
Insomnia	47.2	41.3	40.5	39.6	0.588
Appetite loss	36.1	36.1	26.1	32.8	0.221
Constipation	39.1	37.2	28.6	33.6	0.154
Diarrhoea	32.9	36.3	14.9	21.1	0.013
Financial difficulty	65.1	39.8	54.7	38.7	0.035

 Table 6: Group comparison version QLQ-C29 between patients

 with and without a stoma.

	With a stoma=45	P- value	
	Mean/ (SD)	Mean(SD)	
Functional scales			
Body image	61.3 27.6	77.7 25.8	0,004
Anxiety	63.2 34.8	69.2 32.6	0,398
Weight	67.8 35.0	74.7 30.3	0,306
Sexual function (men)	53.3 39.4	40.1 39.0	0,252
Sexual function (women)	52.3 38.5	73.1 35.4	0,036
Symptom scales			
Urinary frequency	32.1 28.4	46.7 34.9	0, <b>045</b>
Blood and mucus in stool	28.1 31.5	35.5 30.4	0,263
Stool frequency	21.8 31.2	20.5 30.9	0,841
Urinary incontinence	22.9 32.2	26.3 35.3	0,647
Dysuria	34.4 33.9	36.6 35.5	0,775
Abdominal pain	35.6 35.5	40.2 38.6	0,566
Buttock pain	33.3 34.5	37.7 35.2	0,558
Bloated feeling	29.8 37.1	29.6 37.0	0,978
Dry mouth	11.4 22.3	12.8 27.1	0,812
Hair loss	32.1 37.2	16.8 31.9	0,033
Trouble with taste	65.5 36.1	36.2 38.3	0,001
Flatulence	31.0 35.5	23.0 34.6	0,287
Fecal incontinence	36.7 28.6	33.6 37.3	0,684
Sore skin	36.7 37.1	23.8 38.2	0,027
Embarrassment	71.7 27.7	40. 0	0,032
Stoma care problems	46.6 37.3	32.0 36.3	0,177

The aim of this study was to compare quality of life using the EORTC questionnaire: QLQ-C30 and QLQ-CR29 in colorectal cancer patients with or without permanent colostomy receiving treatment at the National Institute of Oncology in Morocco.

The ability of the EORTC QLQ-C30 and QLQ-CR29 to differentiate between the global health status/overall quality of life (GHS/ QOL), symptom, financial difficulty and clinically distinct patient's groups was examined based on the presence or absence of stoma.

The global health status was good and stoma patients did not show significant differences, which did not negatively influence their quality of life. The presence of a stoma also did not significantly influence cognitive and physical functioning, social roles and emotional group comparison version QLQ-C 30. However, in the group comparison with the QLQ-C29 version, the stoma patients showed significant difference in body image and sexual function women, which negatively influenced their quality of life.

Several authors have reported results comparable to those we havereported, namely the lack of difference in quality of life after treatment between the two groups of patients [9,10,11]. Other authors havereported better quality of life scores for the group of patients without stoma and this with a statistically significant difference [4,12,13]. Only one study reported better quality of life scores in the group patients with a permanent stoma. This is a study carried out in Norway and published in 2004 including patients in remission after treatment for rectal cancer in which authors unexpectedly discovered less anxiety, better self-esteem and a better ability to maintain social relationships in the group of patients with permanent stoma [14].

Several studies show that the quality of life of colorectal cancer patients treated with stoma is mostly reduced in the initial post-operative period [15]. The patients have high expectations with respect to surgical treatment, and formation of the stoma may be disappointing to them, but with time the quality of life scores improves. This may explain why stoma patients did not show significant impairment of functioning, which did not negatively influence their quality of life also by the "responsibility change", or reformulation.

Patients suffering from potentially fatal colorectal cancer, realize with time the value of their saved lives, which allows them to have a more positive perception of their daily activities. This in turn leads to better scores in quality of life assessments [16-18]. As a consequence, the assessment of quality of life in stoma patients is not unambiguous, and depends significantly on the time which has passed since the surgical treatment.

On the other hand, this study's allowed to differentiate between patients with and without stoma, by showing higher symptom scores related to diarrhea (p=0.013) and financial difficulty (P =0.035) for patients with stoma. This is consistent with the chinese-malaysian study (Magaji et al. 2016) [19], finding high symptom scores on the financial difficulty scale as well as more impairment in their physical and social/family functioning and less constipation. In fact, the impairment of quality of life for patients with stoma compared to those without has been challenged in many studies that have proved either no difference or even a better quality of life. (Pachler and Wille-Jørgensen 2004). A recent Cochrane review involving thirty-five observational studies representing 5127 patients concluded that even though differences were observed between patients with and without a stoma, such differences were not consistent (Pachler and Wille- Jorgensen, 2012) [20].

In distinct group comparison, patients with a stoma bag presented more financial difficulty. This is because of the lower socioeconomic status of the patients and the shortcomings of the health financing system in Morocco, which does not subsidize all steps of cancer treatment. It is worth noting that the expensive price of stoma bags, transportation costs for care and hospital housing represent heavy financial burdens for patients. The number of studies in Morocco considering cancer-related financial difficulties is limited. More studies are needed to determine whether the publicly funded Moroccan healthcare system is able to protect colorectal cancer patients from financial havoc) [21].

Many studies reported that permanent stoma could significantly alter patients 'quality of life by affecting negatively physical, sexual, social, and psychological aspects of life, especially in Islamic societies like Morocco where religious rituals are considered as an important factor of Social adaptation and improved quality of life. Indeed, daily praying and fasting were altered, since significantly greater number of Muslim who underwent APR stopped daily praying and did not fast during Ramadan [22,23]. In Islamic societies, religious rituals are considered as an important factor of social adaptation and improved quality of life. Kuzu et al. showed that social, physical, sexual, and psychological aspects of life, in addition to religious worship, are severely impaired by sphincter sacrificing surgery in the Islamic population [22].

Distinct group comparison shows a significant difference for the sexual function scale, with female patients with stoma reporting lower sexual function scores. This is due to female patients experiencing rejection or fear of rejection by their sexual partners. This is consistent with the study in which 80% of patients reported that the reason for their inactive sexual life was their spouse's abdominal colostomy, which they found repulsive [23,24]. However, it must be noted that measurement of the sexual function scale was imperfect, as many patients refused to respond to this part of the questionnaire due to the cultural stigma and shame attached to sexuality in Moroccan society. Furthermore, this difference should be nuanced in light of the fact that most Moroccan men and women become sexually active only after marriage.

There are some limitations to our study. Due to the crosssectional nature of the study, we could not estimate the longterm effects of stoma on the quality of life of patients with colorectal patients.

Sexual functions and symptoms are the most difficult scales from which to draw conclusions, as many patients are reluctant to complete the questions or give the truth to doctors. Some studies were unable to evaluate sexual functions due to too many missing values [25].

Another possible limitation for this study is the small sample size of cancer patients in each disease subgroup and cancer location (rectum and colon) making it difficult to perform subgroup analyses. In addition, the majority of patients recruited came from outpatient rather than inpatient units, limiting further statistical analysis especially in assessing responsiveness over time. Finally, the illiteracy of many participants limited the response rate to the questionnaire.

#### Conclusion

To our knowledge, this is the first study focused on the QLQ of patients with colorectal cancer patients using the QLQ-CR30 and QLQ-CR29 in Morocco. Our study was able to provide additional information about patient quality of life in colorectal cancer patients with or without permanent colostomy in Morocco. The creation of a stoma does not negatively impact the global health status of Moroccan colorectal cancer patients.

#### Declarations

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Availability of data and materials: All questionnaires and consents forms are available at National Institute of oncology in Rabat– Morocco where the study was conducted.

The data were pooled and analysed at the Clinical Research and Epidemiological Laboratory; Mohammed V University in Rabat, Morocco, Medical School.

**Authors' contributions:** Y ELA has contributed to conception and design, acquisition of data, analysis and interpretation of data, wrote the manuscript; SB has contributed to conception and design, analysis and interpretation of data, has been involved in revising critically the manuscript for important intellectual content and has given final approval of the version to be published; HOE has contributed to conception and design, analysis and interpretation of data, has been involved in revising critically the manuscript for important design, analysis and interpretation of data, has been involved in revising critically the manuscript for important intellectual content and has given final approval of the version to be published; All authors read and approved the final manuscript.

**Competing interests:** The authors declare that they have no competing interests.

**Ethics approval and consent to participate:** This study N° 79/2017 has been approved by the ethics committee of the Faculty of the medicine and pharmacy - University Mohamed V Rabat – Morocco and the ethics committees in the University Hospital Center Hassan II in Fez- Morocco (Nejjari et al. BMC Research Notes 2014, 7: 228 and all) the subjects were informed of the conditions related to the study and gave their written, informed consent.

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