PATIENT-REPORTED EXPERIENCE IN COLORECTAL CANCER CONTINUUM OF CARE. HOW TO TRANSLATE THEM IN A HELPING PROGRAM FOR PATIENTS AND FAMILY?

EXPERIÊNCIA RELATADA PELOS DOENTES COM CANCRO COLORRETAL SOBRE OS CUIDADOS RECEBIDOS AO LONGO DO TEMPO. COMO TRADUZI-LOS NUM PROGRAMA DE APOIO A DOENTES E FAMILIARES?

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ABSTRACT

Background: Patient-focused interventions recognize the role of patients as active participants in the process of delivering effective, safe and responsible healthcare. When equipped with appropriate knowledge, patients can play an important role in their own care by early diagnosing self-limiting conditions and establishing a beneficial relationship with the healthcare team. The purpose of this study was to identify the main changes in bodily processes and their impact on dependency and self-care during colorectal cancer multimodal treatment to further develop a consistent patient-focused intervention protocol. **Methods:** A prospective longitudinal design was chosen to describe the evolution of the health condition of colorectal cancer patients during multimodal treatment. Patients were assessed (N = 129) in three separate moments, namely: T1 – after multi-disciplinary-team treatment decision; T2 – three months after T1; and T3 – six months after T1. **Results:** The results of this study show that, during treatment, patients with colon or rectal cancer experience significant changes in their health condition. They present a negative evolution on health status related with impairment in the gastrointestinal, circulatory and nervous systems and in psychological, neurovascular and resting processes. Chemotherapy adverse effects significantly reduce the ability to self-care. These patients reveal a higher dependency level in self-care areas, such as: instrumental activities of daily life (IADL) "bathing", "to dress and undress", "rising", "taking medication" and "colostomy". **Conclusion:** The results of this study pose a challenge to health care providers in the sense that these professionals are in a privileged position to help with an appropriate program, patients with colorectal cancer and their family in transition from dependence to supported self-care.

Keywords: *Colorectal Cancer; continuum of care; Patient-reported experience.*

RESUMO

Introdução: Os doentes quando munidos do conhecimento necessário podem desempenhar um papel importante no seu percurso terapêutico, quer pelo reconhecimento precoce das alterações na sua condição de saúde, quer pela relação que podem

https://doi.org/10.34635/rpc.950

estabelecer com os profissionais de saúde. Assim, a prescrição de intervenções focadas no doente e nas suas necessidades individuais torna-os mais participativos no processo de prestação de cuidados, tornando-os mais eficazes e seguros. O objetivo deste estudo foi identificar as principais alterações nos processos corporais e o seu impacto na dependência para o autocuidado durante o tratamento do cancro coloretal para desenvolver um protocolo de intervenção consistente com foco no doente. **Métodos:** Estudo prospetivo longitudinal. Os doentes foram avaliados (N = 129) em três momentos distintos, a saber: T1 – após decisão do tratamento da equipe multidisciplinar; T2 – três meses após T1; e T3 – seis meses após T1. **Resultados:** Os resultados deste estudo mostram que, durante o tratamento, os doentes com cancro do cólon ou reto experienciam mudanças significativas no seu estado de saúde. Apresentam uma evolução negativa da condição de saúde de saúde relacionada com compromissos nos sistemas gastrointestinal, circulatório, nervosa, nos processos psicológicos, neurovasculares e regulador. Os efeitos adversos da quimioterapia reduzem significativamente a capacidade para o autocuidado. Esses doentes revelam maior grau de dependência nas áreas de autocuidado, tais como: atividades instrumentais de vida diária (AIVD) "tomar banho", "vestir-se e despir-se", "levantar-se", "tomar medicamentos" e "colostomia". **Conclusões:** Os resultados deste estudo representam um desafio para os profissionais de saúde no sentido de que esses profissionais estão numa posição privilegiada para ajudar com um programa de intervenção, adequado aos doentes com cancro coloretal e sua família na transição da dependência para o autocuidado com suporte.

Palavras chave: *Cancro Coloretal; Cuidados ao longo do tempo, experiencia relatada pelos doentes.*

BACKGROUND

Cancer is a chronic disease that represents a serious risk to individuals' health and is responsible for disability.[1] The colorectal cancer (CRC) is the second most deadly cancer worldwide, with about 881,000 deaths estimated for 2018[1]. In 2008, 1459 new cases of colorectal cancer (Age-standardised rate using the European Standard Population was 59·2 / 100 000) were diagnosed in Northern Portugal, and this number is estimated to rise in the following years.[2,3] Geographical patterns of the incidence and mortality of colorectal cancer in mainland Portugal municipalities (2007-2011).[4]

Colorectal cancer patient's health status is influenced by multimodal treatment during continuum of care, which may include surgery, chemotherapy, and radiation. Therefore, it is accepted that the level of dependence for self-care may change along the therapeutic course as the disease and treatments impose their burden. For instance, patients undergoing chemotherapy combined with radiation therapy, have a higher incidence of symptoms, which is reflected by their lower functional capacity and care needs.[5] Bodily impairment (bodily process) during treatment includes: skin alterations, sleep patterns changes, taste and swallowing deterioration, weight loss, diarrhoea, constipation, nausea and vomiting, pain and ostomy-related disorders.[5-11] These changes hinder patient's ability to perform activities of daily living and negatively impact their quality of life.[6] Patients' perceptions of their health and experiences are key to providing excellent patient-centred care.[12]

Currently, person-centred care approach is gaining strength, because it recognizes the patient as an active participant on its own process of healthcare.[13] The participation of patients in the care process is extremely important because they provide the information that is the basis for better recognition of health problems and needs over time, and facilitate appropriate care for those needs in the context of other needs.[13,14]

Patients can play a key role in their own care by early diagnosing self-limiting conditions if they have the appropriate knowledge and establish beneficial relationships with the healthcare team and other caregivers, such as their family.[10] Thus, it is important to know how the health condition of the patient with colorectal cancer evolves during the therapeutic course in order to early intervene mitigating its deterioration.

The aim of this study was to identify the main changes in bodily processes and their impact on dependency and self-care during colorectal cancer multimodal treatment to further develop a consistent person-focused intervention protocol.

METHODS

A prospective longitudinal clinical study was chosen to describe the evolution of the health condition of colorectal cancer patients undergoing multimodal treatment (September 2011 to December 2018. The study was conducted at the Gastrointestinal (GI) Unit at the Portuguese Institute of Oncology in Porto, Portugal after its ethical committee approval. The inclusion criteria were a) patients with colorectal cancer; b) older than 18 years of age and c) willing to participate. Patients with liver or lung metastases were excluded from the study because they are submitted to multiple and different treatment approaches (chemotherapy, radiation, surgery).

All eligible patients were invited to take part in this study and to sign an informed consent form before answering the questionnaire. Patient-reported experience measures (PREMs) are questionnaires measuring the patients' perceptions of their experience whilst receiving care. Following this principle, patients completed the questionnaire while waiting for their appointment in the clinic, after being briefed by a research team member.

The questionnaire was developed by the Nursing School of Porto entitled "Families that integrate dependents in self-care" was selected as an outcome measure. This questionnaire is divided in two parts: part one includes socio-demographic variables and part two is composed by different subscales assessing the health status in patients with colorectal cancer that list the presence or absence of a variety of symptoms. Moreover, each subscale considers the level of dependence/self-care regarding: "bathing", "dressing or undressing", "hygiene", "toileting"; "mobility", "feeding", "turning", "transferring"; "lifting" "ostomy", "taking medication" and "instrumentals activities of daily living" (IADL). These items are scored using a 4-point Likert scale ranging from totally dependent (score 1); dependent need help from another person (score 2); requires equipment (score 3); to completely independent (score 4).

All patients were assessed in three different time points of the colorectal cancer continuum of care: T1 – after multidisciplinary treatment decision; T2 – three months after T1 (which generally includes neoadjuvant therapy and surgery in cases of rectal cancer; surgery in colon cancer cases; the beginning of the adjuvant treatment and patients in palliative treatment); and T3 – six months after T1 (which generally includes patients in adjuvant or palliative treatment). The evaluation of patients at T1 was performed after the multidisciplinary treatment decision meeting and after the subsequent nursing appointment. At T2, the assessment was performed after the nursing appointment or related medical oncology or surgery postoperative appointments. At T3, patients were evaluated after the nursing or medical oncology clinical appointments (Figure 1).

The SPSS (Statistical Package for Social Sciences) for Windows v. 21·0 was used to analyze the data. Descriptive statistics (mean, standard deviation, absolute frequencies, and percentages) were used, as well as chi-square paired samples, Pearson and Spearman correlation tests. The results were considered statistically significant for $p< 0{\cdot}05$.

RESULTS

Overall characterization of the sample

From a total of 136 patients initially recruited, 4 patients were lost from T1 to T2 because they

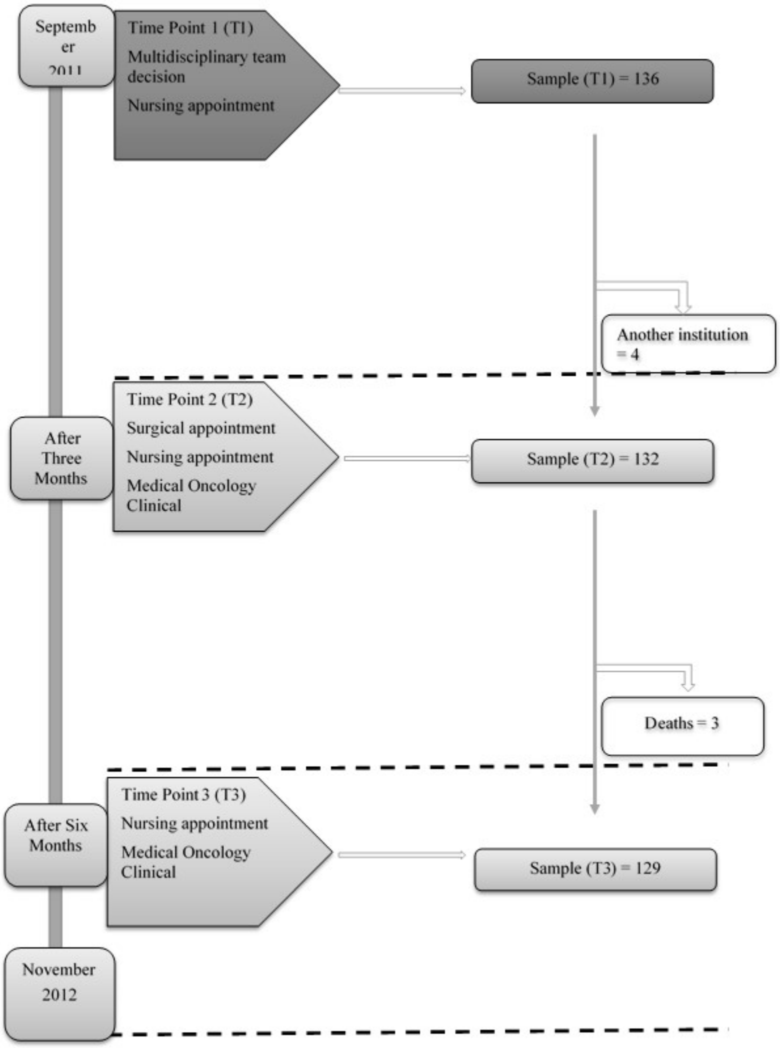

Figure 1 – **Flow diagram**

were transferred to other health facilities. Three patients died from T2 to T3. The patients who died were elderly patients, with other comorbidities and, therefore, with an already extremely poor health condition, in which the cancer disease was one of the conditions presented. We were able to assess 129 patients in the tree moments (T1, T2 and T3). Our sample included 75 males (58·1%) and 54 (41·9%) females. The mean age was 66·16 years (SD = 11·21; range = 39-87). Most patients were married (N=103; 79·8% of the total), 10·9% (N=14) were widowed and 72·4% (N=94) were retired. Only 58·9% (N= 76) completed primary education and 18 (14·0%) never attended school. Regarding the location of cancer, 70 patients (54·3%) had rectal cancer and 59 patients (45·7%) had colon cancer. Surgery was performed in 114 patients (88·4%), neoadjuvant treatment in 61 patients (47·3%), adjuvant treatment in 86 patients (66·6%) and palliative treatment in 15 patients (11·6%) The characterization of patients in each moment is summarised in Table 1.

Symptoms and physical findings reported by patients at T1, T2 and T3

T1 included 129 patients and the main reported symptoms were rectal bleeding (N=86; 66·7%), constipation (N=35; 27·1%), diarrhoea (N=63; 48·8%), fatigue (N=61; 47·3%), pain (N = 60; 46·5%),

Table 1 – **Sample Characteristics at T1, T2 and T3 (N=129)**

Characteristics	N	%
Gender		
Male	75	58·1
Female	54	41·9
Marital Status		
Married	103	79·8
Single	3	2·3
Divorced	9	7·0
Widowed	14	10·9
Age		
Mean	66·12	–
Median	67·0	
Mode	71	
Standard Deviation	11·2	
Minimum	39	
Maximum	87	
Diagnosis		
Colon Cancer	59	45·7
Rectal cancer	70	54.3
Treatment Received		
Surgery alone	29	21·7
Surgery +Neoadjuvant Treatment + Adjuvant Treatment	61	47·3
Surgery + Adjuvant Treatment	24	19·4
Palliative Chemotherapy	15	11·6
ASA Classification		
ASA I	52	40·3
ASA II	61	47·3
ASA III	16	12·4

dizziness (N=60; 46·5%), sleep impairment (N=60; 46·5%) and decreased appetite (N=46; 35·7%) (Table 2).

At T2, the main reported symptoms were fatigue (N = 80; 62·0%), decreased appetite (N=76; 58·9%), taste impairment (N=70; 61·2%), sleep impairment (N=72; 55·8%) and diarrhoea (N=85; 65·9%).

We found significant differences between therapeutic modalities and the signs or symptoms reported (Table 3).

At six months after diagnosis (T3) patients reported more symptoms and especially those undergoing adjuvant chemotherapy. In patients in whom the therapeutic modality was surgery, pain was the most significant reported symptom in T2, that is, still close to the surgical procedure. The age and the presence of comorbidities were not significant variables with respect to different therapeutic modalities. Patients with the highest number of episodes of hospitalization and those most in need of emergency services were those with tiredness, pain, hand-foot syndrome, vomiting, dehydration and dizziness (Table 4).

Table 2 – **Reported Symptoms at T1, T2 and T3**

Reported Symptoms	T1 (N=129)				T2 (N=129)				T3 (N=129)			
	Yes		No		Yes		No		Yes		No	
	n	%	n	%	n	%	n	%	n	%	n	%
Fatigue	61	47·3	68	52·7	80	62.0	49	38.0	72	55.8	57	44.2
Decreased appetite	46	35·7	83	64·3	76	58.9	53	41.1	77	59.7	52	40.3
Taste impairment	32	24·8	97	75·2	79	61.2	50	38.8	69	53.5	60	46.5
Sleep impairment	60	46·5	69	53·5	72	55.8	57	44.2	69	53.5	60	46.5
Constipation	35	27·1	94	72·9	17	13.2	112	86.8	7	5.4	122	94.6
Rectal bleeding	86	66·7	43	33·3	16	12.4	113	87.6	4	3.1	125	96.9
Diarrhea	63	48·8	66	51·2	85	65.9	44	34.1	70	54.3	59	45.7
Pain	60	46·5	69	53·5	54	41.9	75	58.1	25	19.4	104	80.6
Nausea	15	11·6	114	88·4	51	39.5	78	60.5	52	40.3	77	59.7
Dizziness	60	46·5	69	53·5	54	41.9	75	58.1	25	19.4	104	80.6
Palmar-plantar erysthrodysesthesia	0	0·0	129	100	45	34.9	84	65.1	54	41.9	75	58.1
Vomiting	0	0·0	129	100	37	28.7	92	71.3	28	217	101	78.3
Signs of under nutrition	27	20·9	102	79·1	29	22.5	100	77.5	31	98	24.0	76.0

Table 3 – **Association between treatment and reported symptoms (N=129)**

TREATMENT	T1 (N=129)	T2 (N=129)	T3 (N=129)
SURGERY ALONE (N=29)	Constipation Rectal bleeding	Pain (p=0,03)*	No symptoms
SURGERY +NEOADJUVANT TREATMENT OR ADJUVANT TREATMENT (N=61)	Diarrhoea Rectal bleeding	Palmar-plantar erysthrodysesthesia (p=0.009) Impairment of sleep (p=0.004)* Impairment of taste (p<0.001)* Decreased appetite (p=0.01)* Fatigue (p=0.01)* Nausea (p< 0.01)* Diarrhoea (p=0.03)* Constipation (p=0.02)*	Diarrhoea (p=0.007)* Sleep impairment (p=0.002)* Decreased appetite (p<0.001) Taste Impairment (p<0.001)* Fatigue (p<0.001) *
SURGERY OR ADJUVANT TREATMENT (N=24)	Constipation Rectal bleeding	Palmar-plantar erysthrodysesthesia (p=0.009)* Sleep Impairment (p=0.004)* Taste Impairment (p<0.001)* Decreased appetite (p=0.01)* Fatigue (p=0.01)* Nausea (p<0.01)* Diarrhoea (p=0.03)* Constipation	Pain (p=0.02) * Dizziness (p=0.03) * Signs of under nutrition (p=0.01) * Palmar-plantar erysthrodysesthesia (p<0.001) * Sleep Impairment (p<0.001) * Taste Impairment (p<0.001) * Decreased appetite (p<0.001) * Fatigue (p=0.004) Nausea (p < 0.01) * Diarrhoea (p=0.02) * Constipation (p=0.02)
PALLIATIVE (N=15)	Diarrhoea Rectal bleeding Constipation	Fatigue (p=0.02)* Nausea (p=0.03)* Signs of under nutrition (p=0.003)* Vomiting (p=0.01)*	Pain (p=0.02) * Dehydration signs (p=0.01)* Dizziness (p=0.02) Decreased appetite (p<0.01) * Signs of under nutrition (p=0.003) * Fatigue (p=0.01)*

Table 4 – **Association between reported symptoms in the last year and the number of hospitalizations and events in emergency care**

	T2 (N=129)	T3 (N=129)
Number of episodes of hospitalization in the last year> 1.	Pain (x^2= 7.86; p = 0.001) Palmar-plantar erysthrodysesthesia (x^2= 15.96; p = 0.001) Vomiting (x^2= 8.14; p = 0.04)	Pain (x^2= 7.86; p = 0.04) Dizziness (x^2= 7.86; p = 0.04) Dehydration signs (x^2= 8.71; p = 0.03)
Events in emergency care in the last year> 1	Palmar-plantar erysthrodysesthesia (x^2= 15.96; p = 0.001) Pain (x^2= 11.54; p = 0.02) Fatigue (x^2= 10.71; p = 0.03) Vomiting (x^2= 16.50; p = 0.002) Dehydration signs (x^2= 12.64; p = 0.01) Dizziness (x^2= 11.54; p = 0.02)	Sleep Impairment (x^2= 11.64; p = 0.02) Fatigue (x^2= 10.48; p = 0.03) Dehydration signs (x^2= 22.46; p = 0.0001)

Table 5 – **Level of patient dependency considering the therapeutic modalities**

Treatment	T1 (N=129)		T2 (N=129)		T3 (N=129)	
	Dependent In *Self-Care*	Independent In *Self-Care*	Dependent In *Self-Care*	Independent In *Self-Care*	Dependent In *Self-Care*	Independent In *Self-Care*
SURGERY ALONE (N= 29)	27.6% (N=8)	72.4% (N=21)	31.0% (N=9)	69.0% (N=20)	31.0% (N=9)	69.0% (N=20)
SURGERY +NEOADJUVANT TREATMENT + ADJUVANT TREATMENT (N= 61)	29.5% (N=18)	70.5% (N=43)	47.5% (N=29)	52.5% (N=32)	55.7% (N=34)	44.3% (N=27)
SURGERY + ADJUVANT TREATMENT (N=24)	12.5% (N=3)	87.5% (N=21)	33.3% (N=8)	66.7% (N=16)	41.7% (N=10)	50.3% (N=14)
PALLIATIVE (N=15)	33.3% (N=5)	60.7% (N=10)	73.3% (N=11)	26.7% (N=4)	66.7% (N=10)	33.3% (N=5)

Impairment in self-care in patients with colorectal cancer during treatment

We observed that patients were more dependent at T3 than at T2. Patients reported a need for help for self-ostomy (55·5%), self-IADL (31·8%), self-hygiene (24·0%), self-bathing (23·5%), self-dressing and undressing (22·5%) and self-taking medication (31·6%). The level of the dependency according to the treatment was described in Table 5.

Patients treated by surgery alone are mostly independent and maintained the level of dependence over time. The patients with higher dependency level to self-care reported sleep impairment ($x^2= 11{\cdot}54$; $p = 0{\cdot}02$), pain ($x^2= 7{\cdot}14$; $p = 0{\cdot}02$), fatigue ($x^2= 10{\cdot}19$; $p = 0{\cdot}006$), and dizziness ($x^2= 15{\cdot}08$; $p = 0{\cdot}001$). Older patients presented lower scores on the overall level of dependence for self-care, i.e. older individuals are more dependent ($r_S = -\,0{\cdot}45$, $p < 0{\cdot}001$). These patients were the ones presenting more comorbidities ($r_S= 0{\cdot}70$, $p < 0{\cdot}001$).

DISCUSSION

According to our study, during the continuum care of colorectal cancer, patients present important changes in bodily processes. The main symptoms observed were nausea and vomiting, stomatitis, palmar- plantar syndrome, fatigue, and diarrhea. Our results are similar to other studies, where the most frequent symptoms were skin changes, changes in sleep patterns, taste impairment, difficulty swallowing and chewing, weight loss, diarrhea, constipation, nausea and vomiting, pain, changes in bowel movements due to the presence of a colostomy.[5,7,8,11,15-19] The EORTC quality of life questionnaire (QLQ 30) is an integrated system for assessing the health related quality of life (QoL) of cancer patients combined with the EORTC QLQ-CR29 quality of life questionnaire for colorectal cancer allows to know the health situation of these patients with this pathology through patient reported data.[20] Assessing the appointment of these instruments during the continuum of care allows us to know the evolution of the patient's health and to identify its degradation early.[21] Our study suggests that assessments during T1, T2 and T3 and their comparison are crucial. Thus, it is essential to invite patients to join the quality of life assessment program, doing so, as in our institution, through a digital platform accessible to the patient and whose data are recorded in their clinical process.[21]

The level of fragility in cancer patients is considered a major determinant of poor health outcomes.[22] Different health outcomes are associated with the level of fragility[23] including comorbidities, functional dependence, hospitalization, and health care associated complications and cancer specific risks (intolerance to chemotherapy, disease progression or relapse). According to Carneiro and colleagues[23], one in two elderly patients show signs of vulnerability or fragility. These authors argue that a routine assessment of vulnerability risk and comprehensive geriatric assessment would be paramount in providing high quality cancer care in aging populations[23]. This assessment was shown to predict prognosis over time in the health condition of those patients. In our study, the most vulnerable patients were the oldest and most co-morbid and those undergoing adjuvant chemotherapy. The older ones presented higher levels of dependence for self-care and especially those who reported tiredness, pain, sleep impairment, dizziness, and signs of dehydration. Patients undergoing adjuvant chemotherapy report more signs and symptoms after six months. Along the therapeutic course, patients with colorectal cancer who deserve special attention from health professionals are referred to above. The knowledge of the frailties of patients with colorectal cancer during the continuum care is a key-factor in the decision-making process.

The changes in health condition that we observed were fatigue, decreased appetite, sleep impairment, taste impairment and diarrhoea. The level of dependency rose from T2 to T3 phases (namely during adjuvant and palliative chemotherapy). These conditions need an assessment of self-care, another key factor of the program, which includes self-ostomy, IADL, self – taking medication, self-dressing, self-bathing, and self-hygiene.

This gradual deterioration advises us to empower patients and their caregivers before these difficulties emerge (acting preventively instead of reacting). Therefore, a consistent person-focused intervention protocol, namely a colorectal cancer education personalized program, must be developed with each patient and his family (a patient navigation program). This program in our experience must be centralized in the nursing team (patient navigation nursing team) of the unit that follows the patient (figure 2). This team should promote and facilitate communication with the patient and family by establishing a contact schedule. Patients responses (QLQ questionnaire included) should be immediately captured on mobile devices that will fed into a tailored mobile health (mHealth) study management system (an app's mobile interface simple to use could be a solution).[24] The responses and activity of this nursing team shall aim at teaching patients how to get better health outcomes.[25]

In our opinion, the ideal timing for program implementation would be during the transition from T1 to T2 or T2 to T3. The main activities of this education program should include: informing patients and caregivers about key aspects of the colorectal continuum care; motivate them to participate in prehabilitation programs (before

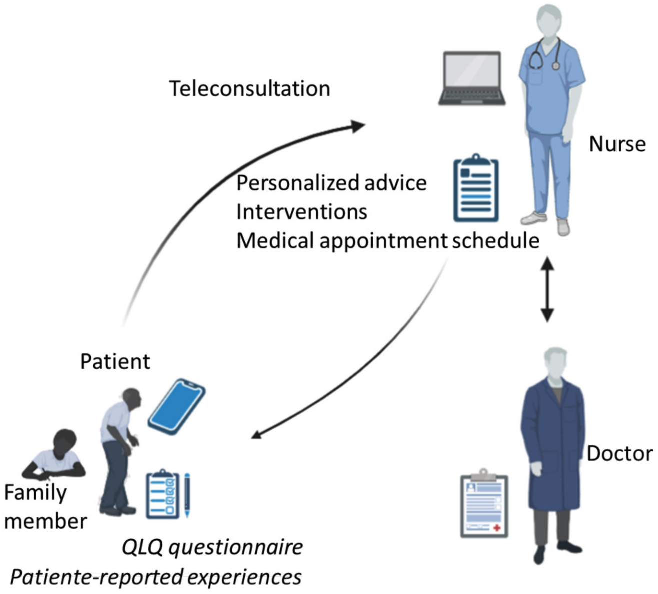

FIGURE 2 – **Patient-navigation program to help patients and families**

surgery); to fill in the quality of life models, and use the teleHealth resources that are made available, alerting for the most frequent signs and symptoms and their meaning; teaching ways to overcome the difficulties that will arise and connect patients to a Patient Navigation team so that they can overcome the barriers they find. All providers at colorectal cancer continuum care must be committed, to implement this program.

CONCLUSIONS

Patients with colorectal cancer in the treatment continuum presented a set of signs and symptoms and decreased capacity for self-care. These changes in the health status of these patients make them more vulnerable and fragile. Thus, we propose the creation of an follow-up program that aims to accompany patients during the colorectal continuum care, promoting their autonomy and proactivity throughout this course based on Patient-reported experiences. With this program, health professionals can provide patients or their families with the knowledge and skills that allow them to be autonomous, proactive and act safely in relation to management of the disease and therapy side-effects and complications.

Conflicts Of Interest

No conflict of interest

Authors' Contributions

CCP and LLS were responsible for the primary conception and design of the article with input from co-authors. Initial drafts of the article were prepared by CCP, LLS, FP, CMS, FT, and DMG. Additions, modifications, and revisions critical for the important intellectual content of the article were performed by CCP, DMG, CMS and LLS. All authors approval the final version to be published.

Acknowledgments

Group of Experimental and Therapeutic Pathology, Department of Surgical Oncology and GI cancer Unit of the Portuguese Oncology Institute of Porto FG, EPE (IPO-Porto) for the possibility of assessing a large series of colorectal cancer patients.

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Data de recepção do artigo:
16/07/2021

Data de aceitação do artigo:
08/11/2021