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Doctor, what are my options? A prospective cohort study of an individualized care plan for patients with gastrointestinal cancer

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ABSTRACT

Background For cancer patients, information about their disease and its treatment is often delivered within a short time period, potentially leading to patient misunderstanding, which can impede optimal patient care. In this 3-part clinical study, we investigated the utility of an individualized care plan for patients with gastrointestinal (GI) cancer starting a new treatment.

Methods In part 1, a comprehensive literature search identified items for potential inclusion in the care plan. Those items were formatted into a questionnaire. The questionnaire was then administered to patients as a structured interview. In part 2, health care professionals involved in the care of patients with GI cancer evaluated the resulting care plan for content and relevancy. In part 3, a 20-week prospective cohort study (10 weeks using standard of care, 10 weeks using individualized care plans) was conducted. Outcomes were assessed at baseline and at 2–4 weeks after administration of the care plan.

Results In part 1, a 73-item questionnaire was developed and completed by 20 patients in semi-structured interviews. In part 2, long and short versions of the care plan were created. Most health care professionals preferred the long version. Based on their comments, a final version of the care plan was created. The part 3 study enrolled 104 patients. Overall satisfaction scores were significantly higher in the intervention group at baseline ($p = 0.010$) and follow-up ($p = 0.005$). Compared with control patients, the intervention cohort also reported significantly higher overall quality of life ($p = 0.044$) and fewer symptoms of anxiety ($p = 0.048$) at follow-up.

Conclusions Provision of an individualized care plan resulted in improvements in outcome measures at both baseline and follow-up. Future studies are needed to confirm these findings.

Key Words Gastrointestinal cancer, care plans, communication, quality of life, patient satisfaction

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INTRODUCTION

The Canadian Cancer Society estimates that gastrointestinal (GI) cancers account for approximately one fifth of new cancer cases and cancer-related deaths in both men and women[1]. However, mortality rates for certain GI cancers, such as colorectal cancer, continue to decline in both groups, likely as a result of improvements in treatment, such as chemotherapy. Early detection through provincially supported screening initiatives might also contribute to this decline in mortality[1].

Cancer care today often incorporates a multidisciplinary approach, including medical, surgical, and radiation therapies. For example, patients with locally advanced rectal cancer—as well as patients with gastric and pancreatic cancer—often receive multimodality therapy, including the use of novel therapies with narrow therapeutic windows. Information about the cancer itself, the treatment schedule, potential side effects of treatment, and management of those side effects is often delivered within a short period of time. Given the complexity of care in some instances, there is a risk of the patient misunderstanding the illness and treatment plan, which could impede optimal patient care[2]. A wide range of information about prognosis, treatment, and side effects is provided to patients from multiple sources, including doctors, nurses, and pharmacists.

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Hence, information provision might not always be tailored to the specific needs of an individual patient.

Despite advances in early diagnosis and treatment, cancer is commonly viewed as a fatal illness[3,4]. The uncertainty experienced as a reaction to the disease has been suggested to be itself linked with lower patient-reported quality of life (QOL)[3,5–7]. Appropriate informational support can potentially lead to improvements in both informed decision-making and adherence to treatment recommendations. With increased involvement in decision-making and care, patients have experienced increased satisfaction and improved communication with the medical team. Adequate information provision can also help to decrease fear and anxiety, increase hope and empowerment, and perhaps reduce cancer morbidity[8–11]. The provision of individualized care plans for patients with cancer might therefore serve to improve communication between the patient and the health care team, resulting in improved QOL and satisfaction with care, and reduced anxiety and depression. Unfortunately, based on a review of the medical literature, use of written individual care plans in GI cancer is limited. In 2003, a small study investigating the experience of patients being diagnosed with colorectal cancer identified uncertainty as one of the key elements affecting a patient's ability to cope with his or her disease. Uncertainty was found to be triggered by insufficient information[3,12].

Given the decrease in mortality rates for certain GI cancers, survivor care plans have demonstrated considerable utility and are recommended by the U.S. Institute of Medicine[13]. We believe that there is an opportunity for development of a cancer care plan that could improve patient satisfaction and limit anxiety at an earlier stage of GI disease and treatment, facilitating an easier transition from active treatment to remission.

OBJECTIVE

This three-part clinical study investigated the utility of a patient-centred, individualized care plan as a communication tool for patients with GI cancer starting a new treatment. In the development and testing of this communication tool, we hope to increase patient understanding, improve QOL and satisfaction with care, and minimize the psychological distress related to uncertainty about the illness, the treatment plan, or both.

METHODS

Patients with GI cancer who were scheduled to start a new treatment at Sunnybrook Health Sciences Odette Cancer Centre, a specialized comprehensive cancer care centre, were invited to participate in the evaluative portion of the study. Patients were accrued in medical, radiation, and surgical oncology clinics.

The study followed parts 1–3 of the module development guidelines from European Organization for Research and Treatment of Cancer[14]. Ethics approval for the study was obtained from our hospital's research ethics board. The prospective cohort portion of the study (part 3) was completed between 26 March 2012 and 10 August 2012.

Eligibility Criteria

The inclusion criteria were a pathologic diagnosis of GI cancer; receipt of any one or a combination of chemotherapy, radiotherapy, and surgery as treatment for GI cancer; and the provision of written informed consent.

The exclusion criteria were an inability to communicate in English and the current treatment modality being received for a prior malignant diagnosis.

Part 1: Item Generation

During part 1 of the study, potentially relevant items were identified during a comprehensive literature search and were formatted into a questionnaire. We aimed to accrue 20 patients attending a cancer centre clinic for follow-up. Using one-on-one interviews with patients who consented to participate, we set out to determine the information that patients considered important to include in the care plan.

Participants used a 4-point system (1, not at all important; 2, somewhat important; 3, quite important; 4, very important) to rank each of the items according to appropriateness and utility. For each item, patients also indicated whether the item should be included in the final care plan ("yes" or "no"). Patients then listed their top 10 items for inclusion in the care plan. Patients also commented on the wording of items and indicated whether any items were upsetting, confusing, or irrelevant. At the end of the interview, patients were given an opportunity to itemize any pertinent information that was not recognized in the literature search, but that would be important to include in the care plan.

The mean score for each item (>3.75, 3.51–3.75, 3.26–3.50, or ≤3.25), the proportion of patients indicating that the item should be included in the final questionnaire ("yes" responses ≥75% vs. <75%), and the frequency with which each item appeared in the top 10 list were used to quantitatively rank each item.

Part 2: Operationalization

Using the part 1 results, two provisional versions of the care plan were constructed (a short version with 13 items, and a long version with 20 items). Both versions were administered as a survey to 20 health care professionals (physicians and nurses) directly involved in the care of patients with GI cancer to determine which version was preferable. The survey also provided an opportunity to add, remove, or modify items to establish content validity and to facilitate easier completion, increased uptake, and improved understanding of the care plan.

Part 3: Prospective Cohort Study

The prospective cohort portion of the study aimed to enrol 100 patients. During the first 10-week period, enrolled patients received the standard of care (control group). During the subsequent 10-week period, enrolled patients received the care plan (intervention group). Patients meeting the inclusion criteria were identified during their first appointment with the oncologist.

Because treatment is often not initiated until the second or third appointment, patients were flagged by the study investigators. Once a treatment plan was in place, the patient was approached to participate in the study.

During enrolment of the intervention cohort, the care plan was completed and administered by the nurse and physician. To eliminate coercion, patients who were seen during enrolment of the intervention cohort were provided a copy of an individualized care plan regardless of study participation. For patients providing consent, baseline questionnaires were completed before commencement of the scheduled treatment.

Outcomes in both groups were assessed at between 2 and 4 weeks after the baseline interview. The assessment was performed by telephone or in clinic (if the patient was scheduled to see the treating oncologist at the time of the assessment). Outcomes of interest included QOL [measured using the Functional Assessment of Cancer Therapy–General scale (FACT-G)], patient satisfaction (measured using the Functional Assessment of Chronic Illness Therapy–Treatment Satisfaction–Patient Satisfaction questionnaire (FACIT-TS-PS)], and anxiety and depression (using the Hospital Anxiety and Depression Scale).

The 27-item FACT-G QOL assessment tool has been validated in patients with cancer. It has four subscales: physical, functional, emotional/family, and social well-being. Items are scored using a 5-point system (0, not at all; 1, a little; 2, somewhat; 3, quite a bit; 4, very much). The tool has been shown to effectively differentiate patients based on disease stage, performance status, and hospitalization status. It has also demonstrated sensitivity to change over time and the ability to validly measure separate dimensions of QOL when applied to groups known to vary across the subscales[15].

The FACIT-TS-PS is a newly developed treatment satisfaction instrument that aims to measure the health care experience during therapy for chronic illness. The questionnaire is composed of 9 subscales: explanations, interpersonal, comprehensive care, technical quality, decision-making, nurses, trust, and overall satisfaction. As with the FACT-G, items are scored using a 5-point system (0, not at all; 1, a little; 2, somewhat; 3, quite a bit; 4, very much).

The Hospital Anxiety and Depression Scale consists of statements relevant to generalized anxiety and depression[16]. Each item is scored using a 4-point system. The possible overall score ranges from 0 to 21 for both the Anxiety and Depression scales. For either subscale, a score of 0–7 is considered within the normal range, a score of 11 or higher indicates the probable presence of a mood disorder ("abnormal"), and a score of 8–10 suggests the presence of the associated state ("borderline abnormal")[16].

Each questionnaire has been validated in our population of interest[15,17–21], except for the FACIT-TS-PS questionnaire, which required a separate validation study that was completed before initiation of part 3 of our study (data not shown).

Statistical Analysis

Continuous data are reported as mean ± standard deviation, and categorical data, as numbers and percentages. Categorical data were compared using the chi-square test. Quantitative variables were compared using the Student t-test or analysis of variance. Results were considered significant at the 5% critical level (2-tailed for comparison of demographic variables, 1-tailed for comparison of study outcomes: $p < 0.05$).

The FACT-G and the FACIT-TS-PS questionnaires were both completed in accordance with the published scoring and interpretation guidelines[22]. A mean score and average overall scores for each subscale were calculated and compared between the control and intervention cohorts.

Based on patient responses to the Hospital Anxiety and Depression Scale, patients were categorized as normal, borderline abnormal, or abnormal on each of the two subscales[16]. In the analysis, the proportion of patients falling into the normal category were compared with the proportions falling into the borderline abnormal and abnormal subgroups combined.

RESULTS

Part 1: Item Generation

The comprehensive literature search identified 73 possible information items, and 20 patients completed the structured interview about the items. Most patients had colon (35%) or rectal (20%) cancer. Median age of the cohort was 63 years. All 73 items were ranked based on the criteria described in the Methods section. Based on the ranked list, short (13-item) and long (20-item) versions of the care plan were created. The inclusion of 20 items increased the breadth of information coverage in the care plan and encompassed all highly-ranked items from the patient perspective, but whether health care professionals would, in practice, be willing to complete a care plan of this length was unclear. In a survey, both versions of the plan were therefore presented to the professionals who would be completing the care plan during the prospective trial.

Part 2: Operationalization

Of the 12 health care professionals who completed the survey, more than half preferred the long version of the care plan (7 of 12, 58%). Participants provided comments, clarifications, content modification, and formatting changes. Based on the comments, a final version of the care plan was created (Table I).

Part 3: Prospective Cohort Study

The study enrolled 104 patients in all. Between 26 March and 1 June 2012, 54 patients were enrolled into the control cohort. Between 4 June and 10 August 2012, 50 patients were enrolled into the intervention cohort (Table II). Of the 104 enrolled patients, 25 were not evaluable, including 13 in the control cohort and 12 in the intervention cohort. Reasons for exclusion included incomplete baseline assessments (n = 11), treatment not initiated (n = 8), non-malignant diagnosis (n = 3), and withdrawal of consent (n = 3).

Baseline Assessments

At baseline, overall QOL scores were higher in the intervention cohort, but the difference was not statistically significant (84.5 vs. 78.3, $p = 0.071$, Table III). Overall satisfaction scores were significantly higher in the intervention group than in the control group (82.0 vs. 76.0, $p = 0.010$). Compared with the control group, the group receiving the intervention reported significantly higher satisfaction in the nursing subscale (7.4 vs. 4.8, $p = 0.008$, Table IV).

TABLE I Items included in the final care plan

1.	The physician or physicians medically responsible for the patient
2.	The members of the gastrointestinal oncology nursing team
3.	Important telephone numbers (that is, main hospital line, nursing team, chemotherapy suite)
4.	An image of the digestive system with an X marking the location of the cancer
5.	The medical name for the cancer
6.	The stage of the cancer and the significance of that stage
7.	Presence or absence of distant metastases
8.	Symptoms that might be experienced as a result of the cancer itself
9.	Tests that will be needed in the future (blood tests, imaging, and so on)
10.	Treatment or treatments that will be given for the cancer
11.	When the treatment or treatments will start and finish (approximately)
12.	The ultimate goal of the treatment (that is, curative vs. palliative)
13.	The possible side effects of treatments
14.	The options if initial treatment is not successful
15.	Side effects the patient should report to the doctor or nurse (fever, sores on the hands and feet, nausea and vomiting, diarrhea, and so on)
16.	Techniques that the patient can use at home to minimize treatment-related side effects
17.	Other techniques that can be used at home to help the patient recover (gentle exercise, fluid intake, dietary suggestions, stress management, and so on)
18.	How the illness could affect the patient's life during the subsequent few months and where they can turn for support
19.	Space for the patient to write comments and to note questions to ask at the next appointment

Fewer depressive symptoms ($p = 0.020$) were reported in the intervention group than in the control group, but the two groups showed no difference in symptoms of anxiety at baseline ($p = 0.237$, data not shown).

Follow-Up Assessment

At follow-up, the overall QOL score was significantly higher in the intervention cohort than in the control cohort (84.02 vs. 77.16, $p = 0.044$, Table III). The score on the functional well-being subscale was significantly higher in the intervention group than in the control group.

The overall satisfaction score was also significantly higher in the intervention group than in the control group (85.76 vs. 77.43, $p = 0.005$). The scores on the comprehensive care and decision-making subscales were both significantly higher among patients receiving the care plan (Table IV).

Patients who received the care plan reported fewer symptoms of anxiety ($p = 0.048$) and depression ($p = 0.067$) at follow-up, although the difference in depressive symptoms was not statistically significant (data not shown).

TABLE II Patient demographics

Variable	Patient group		*p* Value[a]
	Control	Intervention	
Patients (*n*)			
Enrolled	54	50	
Evaluable	41	38	
Age (years)			0.909
Median	67	68	
Range	33–90	32–92	
Sex (% men)	61	58	0.549
Primary cancer site [*n* (%)]			0.152
Colorectal	19 (47)	25 (66)	
Pancreatic	7 (17)	3 (8)	
Stomach	6 (15)	1 (3)	
Esophagus	2 (5)	2 (5)	
Liver	3 (7)	2 (5)	
Other	4 (10)	5 (13)	
Median time since diagnosis (days)	61.5	45.0	0.074
Stage of disease			0.052
I	7	1	
II	9	6	
III	13	17	
IV	12	14	

[a] Quantitative variables were compared using the Student t-test or analysis of variance. Categorical data were compared using the chi-square test. Results were considered significant at the 5% critical level (2-tailed $p < 0.05$).

DISCUSSION

The U.S. National Cancer Institute has published a framework for effective patient-centred communication and outcome assessment in cancer care. The framework is based on 6 core principles[23]:

- Exchange of information
- Response to patients' emotions
- Management of uncertainty
- The process of deliberation in decision-making
- The ability to foster healing patient–clinician relationships
- Patient self-management

Our study discusses the design and implementation of an individualized care plan for patients newly diagnosed with GI cancer. There is no standard of practice with respect to information provision for patients at the beginning of

TABLE III Quality of life scores[a]

Subscale	Baseline			Follow-up		
	Subscale average			Subscale average		
	Control (*n*=37)	Intervention (*n*=37)	*p* Value[b]	Control (*n*=34)	Intervention (*n*=36)	*p* Value[b]
Physical well-being	20.72	22.36	0.282	19.42	20.77	0.192
Social and family well-being	23.15	24.10	0.433	23.88	24.10	0.428
Emotional well-being	16.42	18.04	0.205	18.46	19.70	0.108
Functional well-being	18.01	20.01	0.195	15.94	19.45	0.017
AVERAGE OVERALL SCORE	78.29	84.51	0.071	77.16	84.02	0.044

[a] Measured using the Functional Assessment of Cancer Therapy–General scale.
[b] Quantitative variables were compared using the Student t-test or analysis of variance. Results were considered significant at the 5% critical level (one-tailed $p < 0.05$).

TABLE IV Patient satisfaction scores[a]

Subscale	Baseline			Follow-up		
	Subscale average			Subscale average		
	Control (*n*=37)	Intervention (*n*=36)	*p* Value[b]	Control (*n*=33)	Intervention (*n*=36)	*p* Value[b]
Explanations	10.95	11.33	0.136	10.42	11.19	0.063
Interpersonal	8.30	8.42	0.476	8.36	8.55	0.266
Comprehensive care	13.11	14.98	0.176	14.27	17.39	0.010
Technical quality	8.47	8.74	0.156	8.41	8.74	0.084
Decision-making	11.26	12.02	0.421	9.62	12.45	0.001
Nurses	4.81	7.42	0.008	6.88	8.08	0.060
Trust	11.66	11.48	0.307	11.36	11.71	0.164
Overall	7.40	7.63	0.255	7.58	7.65	0.344
AVERAGE OVERALL SCORE	75.97	82.02	0.010	77.34	85.76	0.005

[a] Measured using the Functional Assessment of Chronic Illness Therapy–Treatment Satisfaction–Patient Satisfaction.
[b] Quantitative variables were compared using the Student t-test or analysis of variance. Results were considered significant at the 5% critical level (one-tailed $p < 0.05$).

their cancer journey; the strategies used differ from oncologist to oncologist and can be specific to the institution and unique to the cancer type. Although the literature investigating the utility of survivorship care plans is increasing, information needs at the time of diagnosis are quite different, limiting the generalizability of that literature to our patient population[24–26].

In our study, QOL was increased at the follow-up assessment in patients who received the care plan. The influence of information provision and its effect on QOL has been partially attributed to its dispelling uncertainty[3]. "Uncertainty" is a multidisciplinary concept that has been found to comprise three main themes: uncertainty because of inadequate information provision, uncertainty about disease-specific treatment choices, and uncertainty related to everyday activities and coping with the disease[3]. Uncertainty can arise secondary to limited details about the disease itself or inadequate information about the nature of cancer-specific treatment and associated side effects[27], as has recently been demonstrated in research involving patients with breast cancer[28]. It has been reported that approximately one third of the variance in QOL can be attributed to social support and uncertainty[3,29].

The concept of a patient's locus of control has also been discussed as a determinant of the degree of uncertainty. That locus of control has been stated to be a balance between intrinsic (independent decision-making) and extrinsic forces (reliance on guidance from a health care professional, assistance with decision-making, trust). In a study of patients with breast cancer, patients took a positive view of any opportunity to discuss their various therapeutic options, including the associated benefits and risks. By doing so, patients felt better equipped to weigh the implications of each decision. In the absence of such discussions, patients have reported feelings of distress[28]. Thus, interventions providing education and individualized cancer- and treatment-specific information could increase the internal locus

of control for patients and reduce the negative effects of uncertainty on QOL.

In our study, patient satisfaction was higher in the intervention group than in the control group at both assessment points. Previous studies have reported similar findings. Women with breast cancer who received more informational support expressed significantly higher satisfaction over time than did women who received the standard of care[8].

In our analysis, patients who received a care plan reported fewer depressive symptoms at baseline and fewer symptoms of anxiety at follow-up. In a mixed-methods study conducted by Dubois *et al.*[8] in 2009, women with breast cancer who received more informational support reported significantly fewer symptoms of anxiety over time. Anxiety decreased when women knew what to expect and how to prepare for each step of their treatment. In addition, the enhanced informational support allowed patients to address their questions to health care professionals.

Our study's two groups had differences at baseline—namely, stage of disease at the time of enrolment. The intervention cohort contained more patients with stage III and IV disease. That difference might have translated into differences in study outcomes, because the initial cancer journey for the intervention cohort was likely different and perhaps more complex than that for patients with stage I or II disease. For example, patients with more advanced disease at the time of diagnosis could have had more appointments with several oncologists, given that their initial care is often multidisciplinary. In contrast, other studies have shown that the quality of communication can be worse for patients with a palliative treatment goal than for patients with a curative treatment goal[29]. Thus, the effect of the differing demographics on outcomes in our patients is difficult to predict.

The difference in the study cohorts could have been reduced by using a randomized study design. However, randomization of the patients would have been likely to result in contamination of the two arms because of (necessary) unblinded physician involvement. Enrolment of a patient assigned to the intervention group followed by enrolment of a subsequent patient randomized to the control group would prime the physicians to discuss additional issues with control patients, thus leading to study contamination. As an alternative design, randomization was planned to be performed based on physician (block randomization design). However, at our centre, physicians within the same disease site group often have very different scopes of practice. For example, certain oncologists treat more complex curative cases; others have a more palliative focus to their practice. As a result, the populations treated by each physician are quite different, limiting the intervention design at our centre.

Given the risk for study contamination and the differences in scope of practice for the treating oncologists, the investigators elected to proceed with a prospective cohort design. Theoretically, the population of patients seen by a given physician from one 10-week period to the next should not be inherently different. Contamination was minimized by enrolling control patients first. Physicians were thus not administering care plans until control group enrolment was complete.

The care plan used in our study was by no means comprehensive. We attempted to keep it as brief as possible, while still including the highly rated items identified during the part 1 interviews. We hypothesized that this design would facilitate easier uptake of the care plan by participating health care professionals, patients, and caregivers. Additionally, patients have reported negative associations with treatment encounters in which they are given a multitude of details that are "impossible to understand in their particular situation" or "more information than was helpful"[30]. Patients with breast cancer have reported that they are able to manage only small amounts of information because they are still coming to terms with their diagnosis and are not ready to process many treatment or disease-specific details. Thus, restricting the individualized care plan to a manageable length was an important consideration in the present study[31].

The study is limited both by sample size and its consideration only of patients with GI cancers. The improvements observed with the intervention in this study were modest, and it is likely that the study was underpowered. Given that no similar studies have been published, it was difficult to determine how best to measure the study outcomes in question. The chosen tools were based on use and validation in similar patient populations.

An additional consideration is the issue of external experimental validity as it pertains to the actual uptake of the care plan in clinical practice. The care plan was designed in a way (check boxes and pre-fabricated lists when possible) that facilitated easy completion by the treating team. Nevertheless, during a busy clinic, the implementation of such care plans can fall to the wayside in favour of increased clinic efficiency[32,33].

The strength of the evidence in favour of individual care plans might provide the incentive necessary to aid in the uptake of such documents in clinical practice. Additional studies are therefore needed to further characterize the relationship between individualized information provision and QOL, satisfaction with care, and psychological distress.

CONCLUSIONS AND RECOMMENDATIONS

Survival care plans have been recognized as a valuable tool and are now recommended by the U.S. Institute of Medicine. There is some evidence that the development and administration of a care plan for patients with cancer at the beginning of their treatment journey could also reduce anxiety and depression, and increase QOL and satisfaction with care. The current study suggests that provision of a standardized care plan to patients with GI cancer can improve outcome measures, although the overall effects of the intervention in this particular study were modest and whether such differences in outcome measures achieve clinical significance is unclear. Future studies, including randomized controlled trials, are needed to confirm our findings. Studies investigating the utility of care plans in other cancer-site cohorts are also warranted.

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CONFLICT OF INTEREST DISCLOSURES
We have read and understood *Current Oncology*'s policy on disclosing conflicts of interest, and we declare that we have none.

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