

Original Article

# Relationship between the Physical and Psychosocial Conditions of Postoperative Gastrointestinal Cancer Patients and their Responses to an Informational Material

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## ABSTRACT

**Objective:** Postoperative patients with gastrointestinal (GI) cancer have multiple adaptation tasks and care needs to improve their quality of life (QOL). Whether their supportive care needs differ according to their physical and psychosocial conditions is unclear. This study investigated patients' (1) physical and psychosocial conditions (QOL, fatigue, anxiety, cognitive plight, and resilience) and (2) responses to an informational booklet describing cancer patients' problems and adaptation tasks, and examined the association between the two factors. **Methods:** A questionnaire survey was conducted to postoperative patients with GI cancer. **Results:** The mean age of the 69 respondents was 63 years; 59.4% of the respondents were men. Nine patients who did not read the booklet showed high fatigue and cognitive plight and low QOL. The patients (36.2%) who chose "I vaguely understood

the content" showed low scores for resilience and cognitive plight while those (8.5%) who chose "I will deal with my tasks as described in the scenarios" showed high scores for both of these variables. **Conclusions:** The condition of some patients continued to be highly affected by their cancer. In terms of understanding the contents of the booklet, resilience was significant, and cognitive plight did not necessarily have a negative impact. The provision of information by means of a booklet might not be suitable for patients who are highly affected by their cancer. Patients may need additional support to be able to make good use of the information provided in such a booklet.

**Key words:** Anxiety, cognitive plight, fatigue, postsurgical cancer patients, quality of life, resilience

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## Introduction

Gastrointestinal (GI) cancer is the leading cause of cancer-related mortality in Japan.<sup>[1]</sup> In most cases, abdominal surgery is the most effective curative treatment. After surgery, patients face multiple adaptation tasks as cancer survivors and need additional supportive care to improve their quality of life (QOL). The availability of illness-related information services may be useful to these cancer patients. To determine the types of supportive care they may need, we enquired the needs of GI cancer patients after returning home by investigating (1) their physical and psychosocial conditions and (2) their responses to an informational booklet describing cancer patients' problems and adaptation tasks and by examining the association between these two factors.

After completing primary cancer treatment, patients have multiple adaptive tasks and need to be aware of the importance of actively participating by themselves in their recuperation. In a cohort study of colorectal cancer patients in Taiwan, the impact of diagnosis and treatment on QOL and symptom burden tended to improve from diagnosis to 6 months post-treatment.<sup>[2]</sup> However, when patients return home after treatment, they face a broad range of adaptation tasks in their daily lives and recuperation. Foster and Fenlon argue that cancer survivors may struggle to self-manage following primary cancer treatment and, therefore, support is important to facilitate recovery of health and well-being.<sup>[3]</sup>

Because the online setting is not restricted by time and place, it may be useful to prompt and support cancer patients' self-management after their return to home. Several types of self-management support were developed, and their usability and effects have been examined and discussed.<sup>[4-8]</sup> In web-based self-management support, information plays an important role. Provision of information that is relevant to the patient's illness, situation, and problems may be useful to his/her in understanding and coping with his/her recovery. Within a cognitive assessment model, patients were portrayed as actively seeking, selecting, and using internal and external information in the process of constructing their perspective on reality.<sup>[9]</sup> The information needs of cancer patients are high.<sup>[10-13]</sup> Davies *et al.*<sup>[14]</sup> found that after controlling for demographic and illness factors, information satisfaction explained 21% of the variance in global QOL in hierarchical regression analyses. Moreover, a systematic review showed that providing information that is congruent with patients' needs is an important determinant of patient satisfaction.<sup>[15]</sup>

However, information needs and preferences differ according to individual physical and psychosocial conditions.<sup>[16-19]</sup> Shortly, after discharge from the hospital,

patients who are physically weak and mentally dominated by anxiety may not seek additional information that would help them understand their problems and adaptation tasks. In a study of adult cancer patients from an outpatient clinic, patients who were in a poor state of health and elderly patients expressed negative attitudes toward information seeking.<sup>[18]</sup> Moreover, in a study of breast cancer patients in Indonesia, a considerable number of patients were dissatisfied with the information provided, and satisfaction was associated with a more positive perception of their general health and better psychological health conditions.<sup>[19]</sup> Meanwhile, the need for information is also affected by patients' disposition and appraisal of their situation. Some patients may seek realistic information despite the difficulty of their situation whereas others may not. In a study about cancer patients' reasons for their information preferences, sense of control was the most common reason for the need to be fully informed while optimism was most often mentioned as a reason to refrain from seeking out available information.<sup>[17]</sup>

The current study included fatigue, anxiety, cognitive plight, QOL, and resilience as indicators of the physical and psychosocial conditions that affect individual needs for information. Fatigue and anxiety are highly prevalent among cancer patients. In a cohort of ambulatory cancer patients in Ontario, Canada, fatigue/tiredness was the most prevalent symptom (75%), followed by anxiety (59%).<sup>[20]</sup> Because QOL expresses an individual's subjective evaluation of his/her life including physical and psychosocial functioning, a patient's QOL may continue to be affected by his/her cancer experience even after he/she returns home. Moreover, Weisman and Worden reported that a cancer diagnosis imposes existential plight on patients, and that it continues for 2–3 months into the illness.<sup>[21]</sup> Patients may encounter various difficulties and may experience a high cognitive plight. However, most individuals have some degree of natural resilience. Highly resilient individuals are apt to view problems in a positive way and to undertake effective solutions despite exposure to stressful circumstances and/or internal distress.<sup>[22,23]</sup> Study findings of cancer patients showed that resilience contributed to low emotional distress and buffered depression.<sup>[24-26]</sup> Therefore, resilience can act as an indicator of a patient's psychosocial condition.

In this study, we prepared an informational booklet describing the problems and adaptation tasks faced by postoperative cancer patients. The response and approach to such a booklet's information differ according to the individual and the patient's physical and psychosocial conditions. In this study, we identified the responses to an informational booklet from patients who had just been discharged from the hospital after undergoing surgery for GI cancer. The association between the physical

and psychosocial conditions of the patients and their responses to the booklet was examined. The results of this investigation may represent the first step to consider the needs related to adaptation in patients who have returned home after primary cancer treatment.

## Methods

### Patients and procedures

Patients who had undergone surgery for newly diagnosed GI cancer in Japanese General Hospitals were recruited over 4 months starting from October 2009 by hospital nurses. The inclusion criteria included age  $\geq 20$  years and awareness of cancer diagnosis, and the exclusion criteria included a history of psychiatric disorder or affective disqualification based on a primary nurse's judgment. All participants were recruited before discharge from the hospital and were provided with the booklet and questionnaire. They completed the questionnaire anonymously within 1 week of hospital discharge and returned it to the hospital by post. All participants provided written informed consent to participate in the study, and approval for the study was obtained from the Research Ethics Committee of the institution with which the first author is affiliated, as well as from those of the hospitals in which the survey was conducted.

### Informational material

A booklet containing scenarios about cancer-related problems was created to help patients understand their illness and recovery process. It is important that the information provided in such materials reflects the patient's actual situation. The scenarios described in the booklet were based on data gathered through an investigation of postoperative patients with GI cancer in Japan<sup>[27]</sup> and were categorized by adaptation tasks [Table 1]. They were constructed to be effective in enabling patients to recall their own cancer experience, recognize their feelings, and think about their experience. The booklet was written at a ninth-grade reading level and in a style oriented toward middle-aged readers.

The data form asked about the use of the booklet and the responses to it. First, patients were asked whether they had read the booklet. If they answered yes, they were asked to choose one of the following four options regarding their thoughts about the booklet: "I vaguely understood the content;" "The scenarios reflect my situation;" "My situation doesn't correspond to the content;" or "I will deal with my tasks as described in the scenarios."

### Study measures

Five variables (fatigue, anxiety, cognitive plight, QOL, and resilience) were assessed in the questionnaire. The

**Table 1: Adaptation tasks for post-surgical cancer patients**

Sharing feelings about the cancer
Letting family know how to be supportive
Dealing with the unpredictable nature of the illness
Dealing with feelings of loss
Managing changes in self-image
Handling symptom concerns
Talking more effectively with the doctor
Obtaining and managing medical information
Managing fatigue
Reprioritizing and negotiating day-to-day activities
Getting assistance with physical tasks
Talking about the illness with family/friends
Dealing with concerns about sexuality
Dealing with thoughts of "Why did this happen to me?"

participants' demographic and clinical information was gathered using a self-administered data form.

Fatigue was measured by the cancer fatigue scale (CFS), which was developed in Japan as a scale to specifically reflect the nature of fatigue experienced by cancer patients.<sup>[28]</sup> The CFS contains 15 items assessed using a 5-point scale and comprises three subscales: physical, affective, and cognitive. A higher score indicates more severe fatigue. The internal consistency reliability was 0.88 in 307 cancer patient samples.<sup>[29]</sup>

Anxiety was measured by the state anxiety subscale of the Japanese version of Spielberger's State-Trait Anxiety Inventory-Form Y-Scale (STAI-JYZ).<sup>[30]</sup> The state anxiety scale includes 20 items rated on a 5-point scale and evaluates current feelings of apprehension, tension, nervousness, and worry. A higher score indicates increased anxiety. The internal consistency reliability (Cronbach's alpha) was 0.91 or above in undergraduate and population samples.<sup>[30]</sup>

Cognitive plight was measured using three items developed for the current study: "I ask why this is happening to me;" "I am aware that I have been trying to avoid thinking about my feelings;" and "I notice that my emotions and thoughts are disordered." The three items were rated on a 5-point scale; they represent searching for causality, defense mechanisms, and perplexity of mind. In ambiguous, extraordinary, unpredictable, or uncontrollable situations such as the cancer experience, attribution theory assumes that people are motivated to explain, interpret, and understand their causal environments.<sup>[31]</sup> However, some patients may not seek out information related to their difficulties because their defense mechanisms may obstruct their consideration of the cancer experience. Patients who avoid seeking information and thinking about it even though they are unconscious of their mind wanting answers may be suffering perplexity of the mind. A higher score indicates increased cognitive plight. In the factor analysis using the

principal component analysis, the cumulative contribution of those items was 76.68 and the Kaiser normalization was 0.72, indicating the validity of this factor.

QOL was measured using the Japanese version<sup>[32]</sup> of the World Health Organization (WHO) QOL-26. The WHO<sup>[33]</sup> defines QOL as “an individual’s perception of his or her position in life in the context of the culture and value systems in which he or she lives and in relation to goals, expectations, standards, and concerns.” The WHO QOL-26 comprises 26 questions assessed using a 5-point scale and measures QOL in four domains: physical, psychological, social, and environmental, with an additional two questions assessing overall QOL. A higher score indicates higher levels of perceived QOL. The validity of using the WHO QOL-26 for cancer patients was verified by Tazaki *et al.*<sup>[34]</sup> The internal consistency reliability of the four domains ranged from 0.66 to 0.84 in community and population samples.<sup>[32]</sup>

Resilience was measured with part one of the Sukemune–Hiew Resilience Test<sup>[22]</sup> (S-H resilience). The S-H resilience test contains 27 items rated on a 5-point scale and comprises three factors: social support, self-efficacy, and sociability. It evaluates the perception of the ability to perform adaptation tasks effectively despite exposure to stressful circumstances and/or internal distress. A higher score indicates increased resilience. The internal consistency reliability for social support, self-efficacy, and sociability were 0.85, 0.81, and 0.77, respectively, in community and population samples.<sup>[22]</sup>

### Statistical analysis

The descriptive statistics for each study variable were determined, and differences in each study variable according to the demographic or clinical state were assessed by the two-tailed *t*-test or analysis of variance. Because of the small sample size in this study, when significant homogeneity of variance between the variables was not shown, nonparametric methods (Mann–Whitney U-test or Kruskal–Wallis rank test) were used. Correlations between the study variables were assessed using Pearson’s product moment correlation coefficient.

The association between the variables identifying patients’ conditions and responses to the booklet, including whether or not it had been read, was examined. Raw scores in each variable were transformed into Z-scores, which express deviations from the mean (reference scores) in terms of standard deviation (SD) units. The mean score expressed as a Z-score is 0, and the SD of the Z-score is 1. The means of each variable determined by response to the booklet, including the option of not reading the booklet, were calculated using Z-scores and were compared among the responses. Differences were assessed by nonparametric methods.

Statistical analyses were performed using SPSS software (version 18; IBM, Armonk, NY, USA).  $P < 0.05$  was considered statistically significant.

## Results

### Characteristics of the study population

A total of 247 surgeries for GI cancer were performed during the survey period, but only 120 patients received the questionnaire (distribution rate, 48.6%). The remaining patients did not fulfill the inclusion criteria or else did not wish to participate. Questionnaires returned after the due date or that were nonresponsive regarding the usage of the booklet were excluded from the analysis. One respondent who chose “My situation doesn’t correspond to the content” and whose data sheet informed us that he/she had cirrhosis of the liver was also excluded from the analysis. Of the 120 questionnaires distributed, 69 were evaluable (valid response rate, 57.5%). The mean age of the respondents was 63 years (SD, 11.4 years); 59.4% were men. The cancer types were mainly colorectal and gastric. The demographic and clinical characteristics of the study population are shown in Table 2.

The descriptive statistics and internal consistency of reliability for this study’s variables are shown in Table 3. The coefficient alpha of each variable showed a high score. Patients without a spouse had significantly greater fatigue and cognitive plight and significantly lower resilience than did patients with a spouse (all  $P < 0.05$ , Mann–Whitney U-test). No other significant associations were found between the study variables and the participants’ demographics or clinical states.

The correlation coefficients between the variables excluding resilience ranged from 0.40 to  $-0.70$  (all  $P < 0.001$ ) whereas resilience correlated significantly only with QOL ( $r = 0.49$ ,  $P < 0.001$ ) and anxiety ( $r = -0.39$ ,  $P < 0.001$ ).

### Responses to the booklet and association with study variables

Nine patients (13.0%) had not read the booklet. Twenty-nine patients (42.0%) chose “The scenarios reflect my situation;” 25 patients (36.2%) chose “I vaguely understood the content;” and six patients (8.5%) chose “I will deal with my tasks as described in the scenarios.” All patients who chose “I will deal with my tasks in the scenarios” had a spouse, and only one of them was male. No other significant differences were seen in the participants’ demographics or clinical states among the four responses (i.e. not reading the booklet and “The scenarios reflect my situation;” “I will deal with my tasks as in the scenarios;” and “I vaguely understood the content”).

**Table 2: Demographic and clinical characteristics of the study population**

Variable		n	%
Age (years)		Mean: 63.0 (SD, 11.4)	
Gender	Male	41	59.4
	Female	28	40.6
Cancer site*	Colorectal	33	47.8
	Gastric	31	44.9
	Other site <sup>a</sup>	4	5.8
Comorbidity*	Present	30	43.5
	Absent	38	55.9
Employment status*	Employed	33	47.8
	Not employed	35	50.7
Marital status*	Married	56	81.2
	Single	12	17.4
Duration after surgery for completion of questionnaire (days)		Mean: 22.64 (SD, 15.47)	

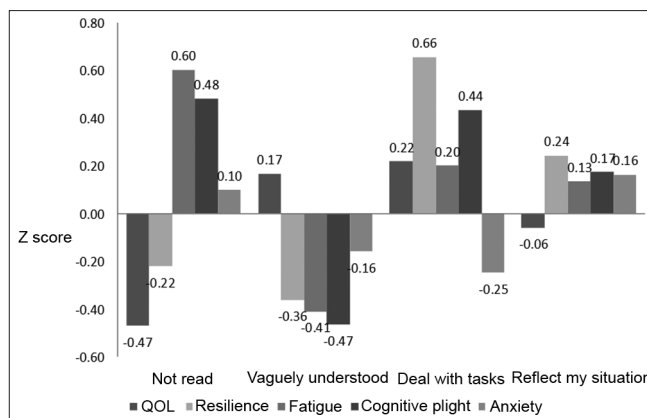
\*: Missing data: 1 (1.4%), <sup>a</sup>Esophagus and pancreas

**Table 3: Descriptive statistics and reliability of study variables**

Study variable/Scale (range)	n	Mean	SD	Median	α
QOL/WHO QOL26 (1-5) 26 items	68	3.22	0.55	3.19	0.92
Fatigue/CFS (0-60) 15 items	67	20.39	10.51	19.00	0.82
Anxiety/STAI JYZ (20-80) 20 items	68	45.99	11.01	45.00	0.93
Cognitive Plight (1-5) 3 items	67	3.20	1.20	3.33	0.84
Resilience/SH Resilience (27-135) 27 items	69	101.70	13.65	104.00	0.89

Note. α=Cronbach's alpha

A significant difference in the mean scores of each variable among the four kinds of patient responses was observed only for cognitive plight ( $P < 0.05$ , Kruskal–Wallis rank test). The mean Z-scores for each variable were compared among the four kinds of patients' responses [Figure 1]. In patients who had not read the booklet, the means for fatigue and cognitive plight were 0.60 and 0.48, respectively, and these scores were the highest among the four responses; the mean for QOL in these patients was  $-0.47$  and was the lowest among the four responses. In contrast, in patients who read the booklet and chose "I vaguely understood the content," the means for the former variables were  $-0.41$  and  $-0.47$ , respectively, and these scores were the lowest among the four responses; the mean QOL for this group was near the average (0.17). These two response groups showed opposite mean scores for all variables but resilience; the mean scores for resilience were low in both groups ( $-0.22$  and  $-0.36$ , respectively). Patients who chose the statement "I will deal with my tasks as described in the scenarios" had the highest mean resilience score (0.66) among the four responses. The mean for these patients' QOL, fatigue, and anxiety were near the average, ranging from  $-0.25$  to 0.22, but the mean for their cognitive plight was high (0.44). In patients who chose the



**Figure 1:** Comparison of mean Z scores for each variable among responses to the booklet. Note: Vaguely understood = I vaguely understood the content; Deal with tasks = I will deal with my tasks as described in the scenarios Reflect my situation = The scenarios reflect my situation

statement "The scenarios reflect my situation," the means of most variables were near the average.

## Discussion

The patients' physical and psychosocial conditions in this study's sample seemed to have been affected by their cancer. The mean scores showed that the patients' QOL was significantly lower than that seen in a general population sample;<sup>[34]</sup> their fatigue was a little higher than that seen in a study of patients with hetero-cancer sites and stages;<sup>[29]</sup> and their anxiety and resilience were standard compared with that seen in a university student sample<sup>[30]</sup> and that seen in a general population sample,<sup>[22]</sup> respectively.

The provision of information in the form of a booklet might not be suitable for patients who are highly affected by their disease. Patients who showed obviously higher fatigue and cognitive plight and lower QOL than this study's average did not read the booklet. Therefore, we could not identify the impressions that patients who were highly affected by their cancer had of the scenarios. Meanwhile, it seemed that the scenarios were congruous with the actual cancer experience that the average patients perceived in this study's sample because patients who showed any variables' score close to the average of this study's sample chose "The scenarios reflect my situation."

In terms of understanding the contents of the booklet, cognitive plight might not necessarily have had a negative impact, but resilience seemed to be significant. Although the scenarios illustrated the common problems and general adaptation tasks faced by cancer patients, 8.5% of all patients chose "I will deal with my tasks as described in the scenarios." They showed obviously higher resilience and higher cognitive plight than this study's average. It was reported that people with high resilience tend to think of

themselves as being able to solve problems despite exposure to internal distress.<sup>[22]</sup> The reason those individuals showed not only high resilience but also high cognitive plight might be that they were faced with difficult realities and, therefore, could recognize their own adaptation tasks. A meta-analysis suggested that individuals with cancer who appraise their illness as a threat are likely to use more problem-focused coping strategies.<sup>[35]</sup> Individuals who recognize the difficult realities associated with their cancer tend to use problem-focused coping to solve their tasks. The height of cognitive plight in the present study might signify the patients' perception of the threat.

Patients who chose "I vaguely understood the content" might have preferred not knowing the content in full, or else the serious illness-related scenarios might not have fit their needs. They showed low cognitive plight as well as low resilience, and the desire to avoid clearly understanding the content of the booklet may have worked for them. Mulcare *et al.*<sup>[36]</sup> showed that high levels of the adjustment style of "cognitive avoidance" were related to low need for information about disease and treatment (e.g. survival rates and treatment side effects). Patients who chose "I vaguely understood the content" might also have had a low need for illness-related information. Another reason why they did not clearly understand the contents of the booklet might be that these patients were optimistic about their condition and might have preferred not to have any serious information. They showed low resilience but stability in the other physical and psychosocial conditions. In a study about cancer patients' reasons for their information preference, optimism was most often mentioned as a reason to prefer limited information about disease and treatment.<sup>[17]</sup> In the present study, the patients' stable condition might have made them optimistic and influenced their understanding of the booklet.

## Nursing implication

The results of the present study suggest that if informational materials related to illness are available, most GI cancer patients who return home after surgery can approach the materials even if the information contained therein is only one way. In particular, patients who had high resilience and cognitive plight seemed to be able to make good use of the information by having a sort of individual semantic attachment to the general scenarios about cancer-related problems and adaptation tasks. The components of resilience used in this study were self-efficacy, social support, and sociability.<sup>[22]</sup> If nursing interventions compensating for these elements are provided for patients with low resilience, they may also come to make good use of the illness-related information. In a study about a support intervention providing newly

diagnosed cancer patients with recordings of their initial treatment consultations, approximately two-thirds of the patients listened to their recorded consultations and most of them assigned high values to the benefits for anxiety reduction, enhanced retention of information, better informed decision-making, and improved communication with their families.<sup>[37]</sup> Many cancer patients would like to understand illness-related information adequately. However, patients who show particularly high fatigue and cognitive plight and low QOL may need support other than the provision of one-way information because they have already experienced the severe impact of cancer and because of the low possibility that they will approach such information.

Although the patients who chose "The scenarios reflect my situation" or "I will deal with my tasks as described in the scenarios" could recognize the contents of the scenarios on their own, those who chose "I vaguely understood the content" would need additional support to understand the illness-related information and to notice their own adaptation tasks. If we had planned codesigned programs with patients in which they engaged in finding the necessary information resources and making the really necessary decisions for themselves, we might have obtained different results. Not everybody can necessarily draw on the information provided directly. Nurses need to plan appropriate ways for individual patients to take advantage of the provision of information. For patients to be able to make the most use of the illness-related information, nurses should plan psychoeducational supports. At that time, nurses need to form a picture of how the patients understand the information provided. The present study suggested that it was necessary to think of patients' fatigue, anxiety, cognitive plight, QOL, and resilience when providing them with an informational material, because those factors related to their responses to the information.

## Limitations

The small sample size and the fact that we restricted participants to those with GI cancer make it difficult to generalize the results of this study to other populations. In addition, our findings were based on data from only a small portion of all patients who had undergone surgery for GI cancer. Patients' responses to the booklet were assessed using close-ended instead of open-ended questions. The choices identified only a limited number of the characteristics of the images that patients took in through the booklet. Thus, a study using an inductive method is necessary to fully understand the responses that patients have to information resources. Furthermore, we cannot deny the possibility that the patients' fatigue was compounded by the burden of having to complete five instruments with so

many question items. In this analysis, the explanation of the association between patients' conditions and responses to the booklet was made by comparing Z- scores but was not based on statistical testing. In addition, although the impact of cancer changes over time, the state of the cancer patients in the present study was elicited by the scores of each study variable at one point after surgery. A longitudinal comparison of each variable is necessary to truly assess their conditions.

## Conclusion

After returning home following surgery for GI cancer, patients were affected physically and psychosocially by their cancer. Patients who did not read the informational booklet showed high fatigue and cognitive plight and low QOL. In terms of the patients understanding the contents of the booklet, their resilience seemed to be significant while cognitive plight may not necessarily have had a negative impact. Most patients could approach illness-related information, and many of them seemed to need some additional support to make good use of the information provided.

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## Conflicts of interest

There are no conflicts of interest.

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