Longitudinal Study on Quality of Life and Psychosocial Conditions in Light of Responses to Illness-Related Information in Postoperative Cancer Patients

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ABSTRACT

Objective: Illness-related information can be significant for cancer patients after gastrointestinal (GI) surgery in terms of their performing adaptive tasks. This study longitudinally investigated the health outcomes of Japanese patients who read a booklet about cancer patients’ problems and adaption tasks and evaluated the association between the responses to the booklet and the patients’ health outcomes. Methods: A questionnaire survey about quality of life (QOL), fatigue, anxiety, cognitive plight, and resilience was administered to postoperative patients with GI cancer 1 week after their discharge from hospital and 6 months after surgery. The questionnaires were returned by email. Results: The mean age of the 32 patients at 1 week was 60.9 years; nearly 68.8% of them were men. As a whole, only two variables, QOL and anxiety, were significantly improved at 6 months over those at 1 week. Three statements were taken to gauge the responses to the booklet. In the two-way ANOVA that took QOL and responses to the booklet as independent variables, the post hoc test found that QOL was significantly improved in patients who agreed with the statement “I vaguely understood the content” or “I will deal with my tasks as described in the scenarios” but not in patients who agreed with the statement “The scenarios reflect my situation.” The anxiety in patients who agreed with the statement “The scenarios reflect my situation” was high at both survey points. Conclusions: This study suggests that associations between the responses to the informational booklet and patients’ health outcomes partially indicate the directional property of how to support their information usage.

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

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Introduction

Illness-related information can be significant for cancer patients in terms of their performing multiple adaptive tasks after surgery. However, responses to such information highly depend on the patient. How patients deal with the information affects their quality of life (QOL), healing, and long-term outcomes. Our research team preliminarily investigated, in a cross-sectional manner, the physical and psychosocial conditions of gastrointestinal (GI) cancer patients after their return home and their responses to an informational booklet describing cancer patients’ problems and adaptation.1 GI cancer continues to be the highest morbidty in Japan.2 In a prospective study of 465 gastric cancer patients, whereas some problems of fatigue, digestive symptoms, body image disturbance, and cognitive functioning after gastrectomy did not improve until 12 months, most functions or symptoms gradually improved.3 Moreover, a study of 134 patients with colorectal cancer found that other than for females and stage-IV patients who had more severe physical symptoms, the QOL and symptoms significantly improved over the 6-month treatment period.4 However, some kinds of patients do not get to the point where their symptoms, functions, and QOL improve after surgery. Their improvement may be affected not only by their disease condition and personal background but also by their responses to illness-related information. In this study, we longitudinally investigated the health outcomes of the patients who had read the booklet, and we evaluated the relationship between the responses to the information and the patients’ health outcomes.

Background

Although the global health status of cancer patients after treatment improves with time, it is also true that some patients continue to be impacted by considerable problems even after the end of cancer treatment.5 In a cohort study of 16,850 individuals taken after a 2-year interval, the cancer survivors continued to have poorer health-related QOL than did the no-cancer group, and the newly diagnosed cancer patients had poorer QOL than did the long-term cancer survivors or the no-cancer group.6 Illness-related information may exert an important influence on the adaptation process in which cancer patients manage physical and psychosocial problems.

Information seeking/usage and adaptation style

Studies have shown that cancer patients had great information needs after diagnosis.7,8 Although one study found that information-seeking among patients with colorectal cancer was lower than among patients with breast or prostate cancer,9 this does not necessarily mean that colorectal cancer patients have lower information needs than patients with other forms of cancer. Studies showed that cancer patients’ information needs did not necessarily predict their information-seeking but that their adjustment style was related to their information needs and information-seeking.10,11 If patients think that information lends itself to their own adaptation, they may show a ready intent to seek it. A study using the integrative model of behavioral prediction as the study framework explored the psychosocial determinants of cancer patients’ intentions to seek information about their cancer from sources other than a physician.12 Attitudes, perceived normative pressure, and perceived behavioral control were predictive of information-seeking intentions, although attitudes emerged as the primary predictor. Patients’ responses to illness-related information may express the path of their future adaptation in some part.

Information usage and perceptions of illness

Some kinds of health conditions may lend themselves to cancer patients using information effectively. In a study about the benefit of providing cancer patients with tailored information to promote social comparison of illness-related issues, only patients with a high perceived life threat and negative health expectations benefited from the social comparison information: it increased their life satisfaction and QOL, respectively.13 Even if information tailored to each patient is provided, not everyone can necessarily use it usefully. Patients’ perception of illness and their perspective seemed to affect whether they could use the information provided effectively. Perceptions of illness and recognitions about one’s own health condition may be tied to information usage in cancer patients.

Responses to illness-related information and health outcomes

Responses to illness-related information of cancer patients are related to their health conditions in their many forms. In our study, about postoperative patients with GI cancer that investigated relationships between patients’ responses to an informational booklet and health outcomes, nine of the 69 patients (13%) did not read the booklet and had high scores for fatigue and cognitive plight and a low score for QOL.14 The booklet was developed to introduce problems and adaptation tasks that could arise in the context of having cancer. Twenty-nine patients (42%) who read the booklet and agreed with the statement “The scenarios reflect my situation” showed average scores for all health outcomes; twenty-five of those who read the booklet (36.2%) who agreed with the statement “I vaguely understood the content” showed low scores for cognitive plight; and six of those who read the booklet (8.5%) who agreed with the statement “I will deal with my tasks as I want” showed high scores for resilience. In this study, “cognitive plight” meant the cognitive
condition consisting of “causal attribution,” “cognitive disorder,” and “cognitive decline.” Thus, patients who showed low scores for cognitive plight might be apt not to think hard about their illness-related problems. In addition, it has been reported that highly resilient individuals tend to respond constructively despite their exposure to stressful circumstances and/or internal distress.[14,15] Thus, patients who showed high scores for resilience might be apt to face their problem constructively. Such characteristics of health outcomes related to patients’ responses to an informational booklet may give rise to subsequent effects on their health outcomes.

In this longitudinal study of cancer patients who read the informational booklet, we investigated the health outcomes of QOL, fatigue, anxiety, cognitive plight, and resilience at two survey points (1 week and 6 months) and longitudinally evaluated the relationship between the responses to the booklet and the patients’ health outcomes.

Methods

Patients and procedures

The participants included patients who had been newly diagnosed with GI cancer and had undergone surgery. The inclusion criteria were age ≥20 years, and the exclusion criteria were “history of psychiatric disorder” or “judged to be disqualified due to affective condition by a primary nurse.” For 4 months starting in October 2009, hospital nurses recruited patients before discharge from the hospital after surgery. After obtaining their informed consent, questionnaires and an information material (a booklet) that described cancer patients’ problems and adaptation tasks were distributed to 120 patients. The same questionnaire survey was administered twice. The first questionnaire was completed within 1 week of discharge (1 week) and returned through the mail. Patients could choose to respond to the first survey only. The data obtained only at the first survey have been analyzed and published.[1] Among those patients who answered the first questionnaire, only those who reported in the inquiry sheet the intention to complete the second questionnaire and to return it within 6 months of surgery were sent the second questionnaire. At this stage, the first and second questionnaires were paired by identification numbers.

A flowchart of the response rates at the two survey points’ recruitment is shown in Figure 1. Of the 48 questionnaires distributed for the second survey, 41 were returned. Questionnaires returned after the due date or containing one or more nonresponsive items in any instruments were excluded from the analysis, leaving only 32 evaluable questionnaires. The patients were asked to return the questionnaire within 1 week of receiving it. The valid response rates of the 120 questionnaires distributed at the first survey were 66.7% for the first survey and 26.7% for the second survey.

Human rights

This study was carefully conducted to protect the participants’ rights in terms of both privacy and confidentiality. All the participants provided informed consent both orally and in writing to participate in the study, and they voluntarily participated in the two surveys. 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 the research ethics committees of the hospitals in which the survey was conducted.

Responses to information

The booklet was created to help cancer patients understand their illness and recovery process by describing in detail different scenarios faced by patients with GI cancer in Japan; the scenarios are categorized according to 14 adaptation tasks that include “Sharing feelings about cancer,” “Dealing with feelings of loss,” “Managing fatigue,” and “Letting family know how to be supportive.”[1] The booklet is written at a ninth-grade reading level and in
Study measures

The health outcomes were assessed by means of five instruments measuring QOL, fatigue, anxiety, cognitive plight, and resilience, and the participants’ demographic and clinical information was gathered using a self-administered data form.

The current study measured QOL by using the Japanese version of the World Health Organization (WHO) QOL-26.[16] The WHO QOL-26 is a subjective indicator that identifies “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.”[17] It is also a comprehensive measure that consists of four domains: physical, psychological, social, and environmental, with an additional two questions assessing overall QOL. It comprises of 26 items assessed using a five-point scale; a higher mean score indicates higher levels of perceived QOL. The internal consistency reliability (Cronbach’s alpha) of the mean of the total score was 0.97 in the community and population samples.[14] The reliability and validity of the Japanese version of the WHO QOL-26 were verified in a study of Japanese cancer patients.[18]

Fatigue is one of the most prevalent symptoms among ambulatory cancer patients.[19] Fatigue was measured by means of the cancer fatigue scale (CFS), which is composed of three subscales: physical, affective, and cognitive.[20] The CFS, which was developed in Japan, contains 15 items assessed using a five-point scale. A higher score indicates more severe fatigue. The reliability and validity of the CFS were verified in a study of Japanese cancer patients, and the internal consistency reliability was 0.88 in 307 cancer patient samples.[21]

Anxiety is a significant indicator of the emotional conditions of cancer patients. It was measured by means of the state anxiety subscale of the Japanese version of Spielberger’s State-Trait Anxiety Inventory-Form Y Scale (STAI-JYZ),[22] which meets widespread acceptance as an instrument measuring anxiety. The state anxiety scale consists of 20 items rated on a five-point scale and evaluates current feelings of apprehension, tension, nervousness, and worry. A higher score indicates increased anxiety. Illustration of the high reliability (Cronbach’s Alpha, 0.91) and the content and construct validity of the Japanese version is provided in a specification of the STAI-JYZ.[22]

A cancer diagnosis imposes existential plight on patients; meanwhile having cancer can be an ambiguous, extraordinary, unpredictable, or uncontrollable experience. According to a study by Weisman and Worden, the existential plight in cancer continues for 2–3 months into the illness.[23] Meanwhile, according to the attribution theory,[24] people are motivated to explain, interpret, and understand their causal environments in such plight and in such an uncertain situation as cancer. However, defense mechanisms against existential plight may sometimes obstruct their consideration. In such a situation, cancer patients may experience various kinds of cognitive plight.

To measure such cognitive plight, three items were developed for our preceding study: “(somehow) I ask why this is happening to me;” “(meanwhile) I am aware that I have been trying to avoid thinking about my feelings;” and “(thus) I notice that my emotions and thoughts are disordered.”[1] Each item was rated on a five-point scale. A higher mean (average score of three items) indicates increased cognitive plight. The internal consistency of reliability was 0.84 in 67 cancer patients.[3]

Resilience was measured with Part One of the Sukemune-Hiew Resilience Test (S-H resilience), which evaluates the perception of being able to perform adaptation tasks effectively despite exposure to stressful circumstances and/or internal distress.[25] The S-H resilience test was developed for Japanese, is composed of three factors (social support, self-efficacy, and sociability), and contains 27 items rated on a five-point scale. A higher score indicates increased resilience. In 2,581 community samples, the internal consistency reliability for the subscales was from 0.77 to 0.85, and the concurrent validity was verified on the basis of the moderate correlation with QOL, anxiety, and depression.[25]

Statistical analysis

At both survey time points, descriptive statistics for the five variables (health outcomes) were determined. The differences in terms of the demographic or clinical characteristics for each study variable were assessed using a two-tailed t-test after significant homogeneity of variance was verified. Correlations between the paired variables at the two survey points were assessed using calculating the Pearson product-moment correlations, and the differences in the paired variables between the two survey points were tested using a paired t-test. Moreover, for each survey point,
multiple regression analysis using the forced entry method was performed taking QOL as a dependent variable.

Responses to the booklet at the 1-week survey were used in the analysis. Although the presence or absence of change in the responses was asked as an extra question at the 6-month survey, 41% of the responses (13 respondents) were nonanswers. The associations between the three kinds of responses to the booklet and the demographic or clinical characteristics were examined using Chi-square analysis. For each survey point, descriptive statistics for the study variables in terms of the responses to the booklet were determined, and the differences among the responses for each study variable were assessed using ANOVA. And for each health outcome (QOL, fatigue, anxiety, cognitive plight, and resilience) that was repeatedly measured, the interaction between the health outcome and the responses to the booklet, the main effects of the health outcome on the response to the booklet and the main effects of the responses to the booklet on the health outcome were tested using two-way ANOVA.

Statistical analyses were performed using SPSS, version 18 (IBM, New York, USA). $P < 0.05$ were considered statistically significant.

## Results

### Characteristics of the study population and study variables

The demographic and clinical characteristics of the 32 patients at the 1-week survey are shown in Table 1. Their mean age was 60.9 years (standard deviation, 10.3), and 68.8% of them were men. The number of gastric cancer patients was higher than that of colorectal cancer patients (62.5% vs. 37.5%).

### Characteristics of the study variables at the two survey time points

The descriptive statistics and reliability of the study variables at the two survey time points are shown in Table 2. The coefficient alpha of each study variable showed high scores from 0.75–0.94. At the 1-week survey, patients without a spouse had significantly lower QOL and higher fatigue than did patients with a spouse ($t = 2.09, P = 0.045$ and $t = −2.08, P = 0.046$, respectively). At the 6-month survey, patients with no comorbidity had significantly higher QOL and lower cognitive plight than did patients with some comorbidities ($t = −2.65, P = 0.013$ and $t = 2.72, P = 0.011$, respectively).

The highest correlation between the 1-week and 6-month surveys was shown for resilience ($r = 0.75, P < 0.001$), and the second-highest correlation was shown for QOL ($r = 0.72, P < 0.001$). The other variables were moderately correlated with each other ($r = 0.52–0.59, P < 0.001$). Compared with the mean QOL and anxiety scores at the 1-week survey, those scores at the 6-month survey were significantly improved ($t = −3.91, P < 0.001$ and $t = 2.19, P = 0.037$, respectively). However, for the other variables, no significant difference was found in the comparisons between the two-time points.

At each time point, each variable excluding resilience correlated highly or moderately with each other, whereas resilience correlated only with QOL at the 1-week

| Variable | Mean | SD | α |
|----------|------|----|---|
| Age, mean (SD) | 60.9 (10.3) | 0.90 |
| Gender, n (%) | | | |
| Male | 22 (68.8) | 0.94 |
| Female | 10 (31.3) | |
| Cancer site, n (%) | | | |
| Colorectal | 12 (37.5) | 0.94 |
| Gastric | 20 (62.5) | |
| Comorbidity, n (%) | | | |
| Present | 14 (43.8) | 0.94 |
| Absent | 18 (56.3) | |
| Employment status, missing data: 1 (3.1%), n (%) | | | |
| Employed | 18 (56.3) | 0.94 |
| Not employed | 13 (40.6) | |
| Marital status, missing data: 1 (3.1%), n (%) | | | |
| Married | 26 (81.3) | 0.94 |
| Single | 5 (15.6) | |

SD: Standard deviation
and 6-month surveys, with correlation coefficients of 0.48 \((P = 0.006)\) and 0.39 \((P = 0.028)\). The findings from the multiple regression analyses in which QOL was taken as a dependent variable are shown in Table 3. Although the demographic and disease variables in addition to fatigue, anxiety, cognitive plight, and resilience were supposed to go into the regression formula as independent variables by using forward entry, in practice, a few demographic and disease-related variables were carefully selected because of the small sample size of this study. Marital status that was related with fatigue and QOL at the 1-week survey and comorbidity that was related with cognitive plight and QOL at the 6-month survey went into the formula. At the 1-week survey, the three variables of fatigue, cognitive plight, and resilience affected QOL and the model explained 71.3% of the variance for that equation. At the 6-month survey, the three variables of anxiety, fatigue, and comorbidity affected QOL and the model explained 79.8% of the variance.

**Changes in the variables in light of the response to the booklet**

Eleven patients (34.4%) agreed with the statement “The scenarios reflect my situation;” 17 patients (53.1%) agreed with the statement “I vaguely understood the content;” and four patients (12.5%) agreed with the statement “I will deal with my tasks as described in the scenarios.” These responses to the booklet were not associated with the demographic or clinical characteristics. The association with sex could not be tested because all the patients who agreed with the statement “I will deal with my tasks as described in the scenarios” were female.

At each survey point, no significant difference in the responses was found among the mean values of each variable. Table 4 shows the mean values of each variable calculated in light of the responses to the booklet at the 1-week and 6-month surveys. In both groups, the QOL at the 6-month survey was improved in comparison with the 1-week survey. In the patients who agreed with the statement “The scenarios reflect my situation,” no noticeable change in the mean values of the variables was found between the two survey time points. In the two-way ANOVA that analyzed each repeated measure health outcome (QOL, fatigue, anxiety, cognitive plight, and resilience) and responses to the booklet with three levels, only the main effect of repeated measure QOL was significant \((F[1, 29] = 16.62, P < 0.001)\). The interaction between the repeated measure QOL and the responses to the booklet was not significant \((F[2, 29] = 1.3, \text{n.s.})\). In the *post hoc* test using the Bonferroni method, significant differences in QOL between the two points were found in patients who agreed with the statement “I vaguely understood the content” or “I will deal with my tasks as described in the scenarios” \((P = 0.004, P = 0.007, \text{respectively})\). In addition, the main effect of the responses to the booklet was not significant and a main effect of repeated measure anxiety was not adopted because the homogeneity of the variance-covariance matrix was not verified.

**Discussion**

As a whole, the QOL and anxiety of patients who had read the booklet were significantly improved at 6 months over those at 1 week. However, when taking account of the fact that this sample did not involve patients who did...
not read the booklet, because they were characterized by high fatigue and cognitive plight and low QOL in our previous study, a conservative evaluation of their improvements is warranted. Meanwhile, in the findings from two-way ANOVA, the QOL of patients who agreed with the statement “I vaguely understood the content” or “I will deal with my tasks as described in the scenarios” was significantly improved at 6 months, but the QOL of patients who agreed with the statement “The scenarios reflect my situation” was not improved. When compared with the average score (3.30) of QOL, which was the basic finding from the sample consisting of 197 patients with poly-type and poly-stage cancers in the instruction manual for the WHO-QOL26, the average scores of QOL of patients who agreed with the statement “The scenarios reflect my situation” were lower both at 1 week and at 6 months (3.08 and 3.23, respectively) than the average score at the basic survey.

At both surveys, patients who agreed with the statement “The scenarios reflect my situation” showed not only low QOL but also high anxiety. A study that investigated the possibility of predicting anxiety and depression 6 months after the cancer diagnosis (including GI cancer) found that anxiety and depression close to the diagnosis explained 39% of the variance in anxiety and depression 6 months later. High anxiety in the early stage of cancer survivorship seems to cause high anxiety that persists afterwards. In the current study, the multiple regression analysis at 6 months indicated that the QOL was negatively explained by anxiety, fatigue, and comorbidity and that the effect of anxiety was the strongest of the three factors. Those findings suggest that low QOL at 6 months in patients who agreed with the statement “The scenarios reflect my situation” was linked with their high anxiety.

On the other hand, the improvement at 6 months in QOL of patients who agreed with the statement “I will deal with my tasks as described in the scenarios” or “I vaguely understood the content” may be related to their adaptation style. Considering the meaning expressed in the statement “I will deal with my tasks as described in the scenarios,” it is foreseeable that patients who agreed with this statement are apt to self-manage their tasks as described in the scenarios. In contrast, it is difficult to conceive that patients who agreed with the statement “I vaguely understood the content” self-manage their tasks by seeking the illness-related information. They were apt to figure out the scenarios with vague understanding, and their resilience was not high; however, their QOL at 6 months had improved. The patients’ vague understanding of the scenarios may reflect their adaptation style.

Considering that >40% of patients did not answer the question about whether their response to the booklet had changed, many patients seemed to not fully remember the contents of the booklet after the 6-month interval. Moreover, the independent variables for QOL, with the exception of fatigue, differed between the 1-week survey and the 6-month survey, thus also indicating that their information needs may have changed between the two survey points. It is necessary that information corresponding with patients’ needs is provided at opportune moments. At the 1-week survey, the three variables of fatigue, cognitive plight, and resilience affected the patients’ QOL. Many cancer patients need fatigue countermeasures to use informational materials. And interventions in light of resilience and cognitive plight may be carried out through activating recognition of illness-related problems and tasks, especially in the early stage of cancer survivorship. Recognizing cancer-related problems imposes stressful tasks and thus may have discouraged the patients who agreed with the statement “I vaguely understood the content,” but it may have served as an opportunity for the motivation to adapt in patients who agreed with the statement “The scenarios reflect my situation.” A study of psychologically distressed colorectal cancer patients verified that an intervention that promotes patients’ disclosure or expression of thoughts and feelings about stressful events improved the patients’ psychological functioning. If patients who agreed with the statement “The scenarios reflect my situation” had been provided an opportunity to express their psychological distress, their anxiety and QOL might have been improved some more.

Limitations and Implications
The small sample size and the fact that the findings were based on data from only a small portion of all the patients who had undergone surgery for GI cancer make it difficult to generalize the results of this study to other populations. The small sample size also made it difficult to carry out some parametric methods since significant homoscedasticity between the variables was not verified. In a longitudinal research design, selection bias is apt to arise out of the losses to follow-up. Moreover, in this study, the patients had to complete five instruments with many question items, and hence the burden of answering the questioner possibly compounded their fatigue and reduced the return percentage.

The patients’ responses to the illness-related information were assessed using four choices of close-ended questions. The choices identified only limited aspects of images that patients took in through the booklet, so the interpretation of choices could vary from patient to patient. We cannot deny the possibility that more appropriate ideas could be adopted as indicators of those responses. Moreover, if the patients...
had been provided with the illness-related information through other sources, settings, or approaches, the results might have been different. The design of this longitudinal study is that of an analytical observation study without a control. Thus, it was not within the scope of the study to investigate the effects of the provision of illness-related information through the booklet.

As our next step, we will use the findings of this study to develop supportive care for cancer patients/survivors using illness-related information. Another study will be planned with an experimental design and hence that we can verify the effects of the provision of illness-related information on the health outcomes of cancer patients.

Conclusion

The QOL of postoperative patients with GI cancer 1 week after discharge was predicted by three variables, resilience, cognitive plight, and fatigue, and 6 months after surgery, by three variables, anxiety, fatigue, and comorbidity. As a whole, QOL and anxiety were significantly improved at 6 months over those at 1 week. QOL was significantly improved in patients who agreed with the statement “I vaguely understood the content” or “I will deal with my tasks as described in the scenarios” but not in patients who agreed with the statement “The scenarios reflect my situation.” The anxiety in patients who agreed with the statement “The scenarios reflect my situation” was high at both survey points. These findings suggest that the low QOL at 6 months in those patients was linked with their high anxiety. Information corresponding with GI cancer patients’ health condition must be provided at opportune moments. Although the small sample size and the data from a small portion of the patients who had undergone surgery for GI cancer make it difficult to generalize the results, this study suggests that the association between the responses to the booklet and their health outcomes partially indicates the directional property about how to support their information usage.

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Conflicts of interest

There are no conflicts of interest.

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