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The Psychosocial Influences of Waiting Periods on Patients Undergoing Endoscopic Submucosal Dissection

ABSTRACT

This study aimed to clarify psychosocial influences of waiting periods on patients undergoing endoscopic submucosal dissection for cancer at an advanced medical care facility in Japan. Subjects were consenting patients hospitalized from 2009 to 2010. Qualitative and quantitative data were gathered about patients' characteristics, disease and stage, and waiting period. Qualitative content analysis was used to analyze free statements and interview data. Subjects included 154 patients with an average wait period of 46.28 days for admission. Qualitative analysis revealed the following wait period perceptions. For calmness, results indicated (1) no anxiety, (2) relief based on doctors' positive judgment, (3) whatever happens/no choice, and (4) trust in doctor. For uneasiness, perceptions included (1) the sooner, the better/eagerly waiting, (2) anxiety and concern, and (3) emotional instability. Four waiting period coping types were identified: (1) making phone inquiries, (2) busy and forgot about the medical procedure, (3) relief from anxiety, and (4) unable to function well in daily life. Patients need to be educated about cancer progression and provided an estimated wait time. They also require more information about how to manage daily life such as monitoring factors from the nursing domain including physical condition, digestive symptoms, diet, and exercise.

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Endoscopic submucosal dissection (ESD) has become a standard treatment of early-stage cancers of the digestive organs. In Japan, ESD has been covered by health insurance since April 2006 (Toyonaga, Nishino, Man-I, East, & Azuma, 2012), and use of this procedure has quickly spread throughout the country (Jung et al., 2008; Ono et al., 2008; Onozato et al., 2008; Probst, Golger, Arnholdt, & Messmann, 2009). According to the Japanese Association of Clinical Cancer Centers, patients with stage 1 gastroenterological cancer have a 75%–90% 5-year survival rate (Foundation for Promotion of Cancer Research, 2013). However, the prognosis for each digestive organ differs, ranging from 40% to 70% for stage 2 and 3 cancers (Foundation for Promotion of Cancer Research, 2013).

Early detection and treatment at stage 1 are most important for patients with gastrointestinal cancer, and EDS criteria have expanded to include the entire gastrointestinal tract. Endoscopic submucosal dissection is less invasive than laparotomy and has enabled

en bloc resection. Therefore, there are high expectations for EDS. However, in Japan, only advanced treatment hospitals can perform ESD. Consequently, patients must wait for examinations and ESD for a period of time after cancer diagnosis.

Background

Understandably, the psychological condition of patients with cancer is frequently depressed following diagnosis. Previous studies indicate that diagnosed outpatients become depressed and anxious about negative scenarios such as exacerbation and metastasis (Sato, Mastumiya, Soga, & Tanaka, 2003; Senzaki, 2001). Consequently, patients tended to spend the waiting period anxious and predicting worse-case scenarios (Sato et al., 2003). In a study of emotion and coping behaviors among patients who underwent gastrectomy, male and patients with early cancer who were more proactive tended to cope by gathering information (Senzaki, 2001). Coping is related to stress management.

Substantial research in a variety of medical fields has been conducted in regard to patients' states of mind during the waiting period for cancer diagnosis (Brocken, Prins, Dekhuijzen, & van der Heijden, 2012), hip surgery (Laudicella, Siciliani, & Cookson, 2012), transplants (Li et al., 2008), and eye therapies (Quintana et al., 2011). Reports indicate that there are differences in how patients function during waiting periods that can arise from distress and socioeconomic factors (Brocken et al., 2012; Laudicella et al., 2012). Longer wait times can reduce patients' hopes for organ transplants, with men experiencing more illness-related pain and suffering than women (Li et al., 2008). Thus, patients likely struggle to maintain self-efficacy.

Although patients eligible for ESD have been diagnosed with cancer, they are typically symptom free, their disease is usually at an early stage, and they have a good prognosis if they receive expeditious treatment. However, these patients' mental states and behaviors during the waiting period have yet to be clarified. That said, it is likely that the waiting period from cancer diagnosis to treatment can be a psychological and social burden. This study aimed to examine patients' psychological and social burden during the waiting period in order to understand the psychosocial risks that can occur during this time.

Methods

Subjects

Subjects included patients admitted to an advanced treatment hospital in Kansai for esophageal, gastric, or colon ESD. Participants who could not independently express a desire to participate were excluded.

Data were gathered from April 2009 to May 2010, and written consent was obtained.

Data Collection

After providing consent, subjects completed a self-administered questionnaire that included items related to demographic information on factors such as age, gender, and endoscopic polyp resection or EDS history. Information regarding participants' emotion, anxiety, and treatment expectations was gathered using open-ended questions.

The General Self-Efficacy Scale (GSES) was administered prior to ESD (Sakano, 1989). The GSES is a 16-item questionnaire designed to evaluate beliefs and coping with hardship. All GSES questions are closed-ended, and participants respond with either "yes" or "no." The score is calculated by summing the responses to all 16 items. Scores range from 0 to 16 and higher scores indicate stronger self-efficacy. Scores are divided from 1 to 5 on the basis of low to high scores ranging from "very low" to "very high."

Pathological data and length of time from initial reservation to hospital admission were gathered from medical and nursing records. Semistructured interviews were conducted 4 days following ESD. Questions inquired about subjects' thoughts about the waiting period from the time they made the hospital reservation to hospitalization. The interview included the following items: "How did you spend your time during the waiting period?", and "What did you think about during the waiting period?"

Data Analysis

Frequencies were used to analyze all demographic data from the questionnaire including patient background, EDS waiting period, and tumor location. The five degrees of GSES scores were classified into three groups: low, medium, and high. Subsequently, the relationship between patient background and GSES scores was investigated for statistical significance using the χ^2 test (Bonferroni correction). We used the Kruskal-Wallis test ($p > .05$) to analyze the relationship between the five GSES degrees and continuous variables, age, and waiting period. All statistical analyses were performed using SPSS version 14.0 (SPSS Inc., Chicago, IL).

Content analysis was used to analyze qualitative data and involved data summarization and classification (Krippendorff, 1980). Free responses pertaining to anxiety and treatment expectations collected in the self-administered questionnaire took the form of either a word or short sentences. Words and sentences were then named and classified according to their meaning. Interviewers analyzed interview data and each phrase was coded into themes. Codes with similar meanings were named and categorized.

Ethical Considerations

This study followed the ethical principles stated in the Declaration of Helsinki (1964). Study approval was obtained from the Medical Ethics Committee of the Kobe University School of Medicine.

Results

A total of 154 patients (117 men; 37 women) completed the questionnaire and semistructured interviews. Participants' average age was 68.65 years (range, 30–89 years). Regarding primary diagnoses, 44 subjects had esophageal tumor(s), 60 had gastric tumor(s), 45 had colon tumor(s), and five had other tumors (appendix and duodenum tumors), respectively. The most frequent cancer type was 0-IIc ($n = 48$), followed by laterally spreading tumor, granular type (LST-G) ($n = 23$), 0-IIa ($n = 19$), 0-IIb ($n = 17$), and laterally spreading tumor, non-granular type (LST-NG) ($n = 12$) (Table 1). The average waiting period from hospital reservation to ESD admission was 46.28 days (longest period, 171 days; shortest, 3 days; SD = 19.79) (Table 1).

Patient Expectations and Anxieties

A total of 86 subjects provided free responses about ESD expectations. Responses regarding ESD expectations were first coded and categorized. The most common code was “complete cure” ($n = 32$), followed by “recovery including becoming healthy” ($n = 24$), “low risk for procedure-related complications” ($n = 15$), and “complete resection,” ($n = 10$). Less frequent answers included “no recurrence or metastasis,” and “live longer.”

Coding and categorization of the anxiety-related responses ($n = 88$) showed that the most common answer was “no anxiety” ($n = 31$), followed by anxiety about “complications” ($n = 16$), “no metastasis and cancer recurrence” ($n = 11$), “whether or not the cancer was completely resected” ($n = 10$), and about “postoperative recovery” ($n = 5$). Less frequent responses were “omakase: leave it to the doctor,” and “mechanical trouble”.

Waiting Period Perceptions

Data on the subjects' thoughts during the waiting period were gathered via semistructured interviews, analyzed qualitatively and inductively, and divided into waiting period perceptions. The first category was labeled calmness and four subcategories were identified: (1) no anxiety, (2) relief based on doctors' positive judgment, (3) whatever happens/no choice, and (4) trust in doctor. The second category was uneasiness with three subcategories identified: (1) the sooner, the better/eagerly waiting; (2) anxiety and concern; and (3) emotional instability.

TABLE 1. Patients' Information

Patients ($n = 154$)	n (%)	%
Gender		
Male	117	75.98
Female	37	24.4
Tumor location		
Esophagus	44	28.6
Stomach	60	39.0
Colon	45	29.2
Other	5	3.2
Pathological type		
0-IIa	19	12.3
0-IIb	17	11.0
0-IIc	48	31.2
0-IIa+IIc	9	5.8
0-IIb+IIc	1	0.6
0-IIc+IIa	3	1.9
I	3	1.9
I SP	1	0.6
ATP	1	0.6
LST-G	23	14.9
LST-NG	12	7.8
No comment	16	10.4
General self-efficacy score		
Very low	14	9.1
Low	39	25.3
Neutral	46	29.9
High	43	27.9
Very high	3	1.9
Not answered	9	5.8

Note. 0 = superficial carcinoma; 0-IIa = elevated type; 0-IIb = flat type; 0-IIc = depressed type; ATP = atypical epithelium; I = protruded type; I SP = semipedunculated type; LST-G = laterally spreading tumor, granular type; LST-NG = laterally spreading tumor, non-granular type.

For perceptions during the waiting period in the [calmness] category, “no anxiety” codes were based on the following reasons: “no anxiety based on experience,” “no anxiety because of information obtained about the disease and its treatment,” “no anxiety because of early disease stage,” and “no anxiety based characteristics such as optimism and staying positive.”

The next subcategory was “relief based on doctors’ positive judgment,” which included the following reasons: “because the doctor indicated the patient would be all right,” “because of receiving education about the specific cancer stage,” and “because the doctor did not express a need for immediate hospitalization.” These categorizations demonstrate that patients who had a worry-free waiting period had a physician-related basis for their lack of anxiety. Next, the subcategory of “whatever happens/no choice” consisted of following codes: “whatever happens because I am very old,” “no choice because I am resigned to my cancer progress during the waiting period,” “I have no choice but to wait,” and “whatever will be, will be.” In addition, the subcategory for “trust in doctor” included “trust in the doctor because I believe that he/she will remove the tumor.” The last two subcategories revealed how patients mentally prepared during waiting periods.

In terms of the [uneasiness] during waiting category, the first subcategory was “the sooner, the better/eagerly waiting,” and included “the sooner, the better,” “I want to undergo ESD as quickly as possible,” “I want to complete surgery as safely as possible,” and “I was eagerly waiting for ESD.” For the “anxiety and concern” category, patients expressed “anxiety about cancer exacerbation,” “anxiety about tumor enlargement,” “anxiety about metastasis,” “anxiety about cancer progression,” “concern about treatment procedure,” “concern about the whether or not the cancer can be treated,” and “look forward to treatment,” and “impatiently waiting for treatment.” Furthermore, the “emotional instability” subcategory consisted of “waiting impatiently,” “feeling depressed,” “irritated by the waiting period,” and “I felt stressed” (Table 2).

Waiting Period Coping Behaviors

Data on subjects’ daily lives during the waiting period were gathered via semistructured interviews, analyzed qualitatively and inductively, and divided into waiting period coping behaviors. Four coping types were identified: (1) making phone inquiries, (2) busy and forgot about the medical procedure, (3) relief from anxiety, and (4) unable to function well in daily life.

The first waiting period coping type was “making phone inquiries,” which included “making calls (to the hospital) to ensure I would be admitted because I felt anxious after a month had passed.” Another coping type was “busy and forgot about the medical procedure,” which included “I had been busy, then I had been forgotten.” In terms of the “anxiety relief” coping type, another response was “I went to a hot spring to forget, and took a trip because I wanted relief from my anxiety.” The final coping type was “unable to function well in daily life,”

which included “I could not concentrate on my daily tasks because I had been nervous.” These coping types demonstrated how daily life and work pressures remained during the waiting period, and that worries and anxieties during this time prevented patients from relaxing in daily life (Table 3).

Self-Efficacy Test (GSES Scores)

A total of 154 subjects completed the GSES. Test scores revealed that 14 subjects were “very low,” 39 were “neutral,” 43 were “high,” 3 were “very high,” and 9 provided “no answer,” respectively. The Kruskal-Wallis test revealed no significant differences between the five GSES score groups, age, and waiting period length. After dividing the five groups into three categories (low, medium, and high), the χ^2 test also indicated no significant between-group differences in GSES scores, gender, and tumor location.

Discussion

This study showed that patients undergoing ESD hope that the procedure will lead to a complete cure or complete resection. In addition, it demonstrated that patients’ concerns primarily involved adverse events associated with the procedure and their tumors. Furthermore, the study clarified patients’ perceptions and coping behaviors during waiting periods averaging 1.5 months. Patients spoke of worries and anxieties involving disease progression (e.g., exacerbation, tumor growth, and metastasis) as well as concerns about the therapeutic method they experienced during the waiting period.

The average ESD treatment waiting period was 46 days. The 46-day waiting period impacts some patients’ psychosocial behaviors and quality of life (QOL). In this study, there were no significant differences between GSES score degrees and the waiting period. We also identified patients’ waiting period coping behaviors and that patients had two opposite perceptions (calmness and uneasiness). Patients were particularly anxious about “complications,” “tumor growth and worsening,” and “recurrence or metastasis.” For patients with early-stage cancer, the waiting period was perceived as quite long. According to a systematic review by Brocken et al. (2012), waiting for results or treatment after cancer diagnosis causes patients’ anxiety. Similarly, patients’ self-estimated chances of receiving an organ was associated with wait time length and happiness (Li et al., 2008). A study of total hip displacement also found a significant QOL difference depending on short versus long waiting periods. Therefore, waiting periods for treatment and diagnosis can cause patient stress and anxiety. Consequently, patients’ behaviors are motivated by their attempts to cope with feelings and emotions.

TABLE 2. Patients’ Perceptions

Categories	Subcategories	Codes
Calmness	“No anxiety”	No anxiety based on experiences No anxiety because of information obtained about the disease and its treatment No anxiety because of early disease stage Non anxiety-based characteristics such as optimism and staying positive
	“Relief based on doctors’ positive judgment”	Because the doctor indicated the patient would be all right Because of receiving education about the specific cancer stage Because the doctor did not express a need for immediate hospitalization
	“Whatever will be; no choice” “Trust in doctor”	Whatever happens because I am very old No choice because I am resigned to my cancer progress during the waiting period I have no choice but to wait Whatever will be, will be Trust in the doctor because I believe that he/she will remove the tumor
Uneasiness	“The sooner, the better; eagerly waiting”	The sooner, the better I wanted to undergo ESD as quickly as possible. I want to complete surgery as safely as possible. I was eagerly waiting for ESD.
	“Anxiety, concern”	Anxiety about cancer exacerbation Anxiety about tumor enlargement Anxiety of metastasis Anxiety about cancer progression Concern about treatment procedure Concern about whether or not the cancer can be treated Look forward to treatment Impatiently waiting for treatment
	“Emotional instability”	Waiting impatiently Feeling depressed Irritated by the waiting period I felt stressful

Note. ESD = endoscopic submucosal dissection.

As mentioned, a waiting period of longer than 1 month influences patients with cancer since it increases stress and anxiety, leading to decreased QOL.

Perceptions and understanding about a 1-month waiting period differ significantly between patients and physicians. Because patients fear that cancer progression will negate the possibility of a cure, they perceive 1 month as a very long waiting time. Patients then experience increased stress and decreased QOL as they wait for ESD. In contrast, physicians have access to evidence about cancer’s actual progression. Current studies estimate that cancer cells take 1 year to transform from stage 1 to stage 2 during the early stage of gastric and colon cancers. Medical institutions specializing in cancer treatment also disclose waiting periods to the public (~3–5 weeks). Furthermore, receiving treatment after diagnosis can take 8 weeks or longer if the

process includes a transitional period for decision-making about appropriate treatments. This is a typical time frame for physicians but is not necessarily understood by patients, even if they know their cancer is early-stage.

Burmeister et al. (2010) found that the median waiting period to start radiation therapy for patients with lung cancer was 33 days; however, this was a longer period than recommended by the Royal Australia and New Zealand College of Radiologists. Another study about elective surgery found that the patients’ waiting period was 248 days and influenced by socioeconomic factors, educational status, and living area (Laudicella et al., 2012). Although there are criteria for ESD treatment, an appropriate waiting period for ESD is needed. This information should be included in patients’ informed consent for the procedure because it relieves anxiety.

TABLE 3. Patients' Coping Behavior

Coping Type	Behavior	Reason
"Making phone inquiries"	Making calls (to the hospital) to ensure I would be admitted	Because I felt anxious after a month had passed
"Busy and forgot about the medical procedure"	I had been busy I had worked harder	I had forgotten
"Anxiety relief"	I went to a hot spring I took a trip Family took me to the pool	Because I want to forget Because I want to relieve anxiety
"Unable to function well in daily life"	I could not concentrate on my daily tasks I could not settle down to work I left things unfinished	Because I had been nervous Because I had an uneasy feeling

We can derive clinical implications from the current study's results. Health care providers must provide patients with precise information to increase understanding and prevent stress and anxiety during outpatient care. Since patients particularly fear cancer progression, health care providers should preferably inform them of waiting period length and educate them about cancer progression. In addition, patients would likely find relief in a follow-up appointment during the waiting period if it is longer than 1 month. Furthermore, patients require not only disease-related information but also knowledge about physical condition management and appropriate actions pertaining to their daily lives during the waiting period. These clinical actions would relieve patients' anxiety and increase QOL.

Limitations

Patients' characteristics may have influenced results since the study was conducted only at one institution. Thus, other studies should examine the characteristics and thoughts of patients undergoing ESD at other facilities.

In addition, we could not analyze the relationship between perceptions and coping behaviors with qualitative data or self-efficacy with quantitative data. Therefore, we expect future studies to examine the influence of psychosocial factors on patients' feelings and actions during the waiting period. Furthermore, we recommend future research on patients' QOL while waiting for treatment.

Conclusion

Waiting periods between ESD hospital reservations and admittances averaged 46 days. During this time, subjects became anxious about disease progression and utilized coping behaviors. Waiting periods are perceived differently by diagnosed patients and

physicians, who have existing knowledge about cancer progression. Study results suggest the types of information patients require while waiting for ESD, the most important pertaining to likely cancer progression. In a clinical context, health care providers must educate patients about cancer progression, provide an estimated wait time, and develop effective follow-up methods during the waiting period. Patients also require more information about how to continue with daily life, especially in areas relevant to the nursing domain such as how to monitor physical condition, digestive symptoms, diet, and exercise. In short, to relieve psychosocial concerns and maintain QOL, patients require effective support. ☼

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