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Psychiatric Disorders in Patients Who Lost Family Members to Cancer and Asked for Medical Help: Descriptive Analysis of Outpatient Services for Bereaved Families at Japanese Cancer Center Hospital

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Objective: There have been no previous studies about consultation of the bereaved who have lost a loved one to cancer and ask for medical help. The aim of this study was to investigate their basic characteristics and their psychiatric disorders.

Methods: A retrospective study using clinical and background data obtained over 30 months (from April 2007 to September 2009) was conducted at outpatient services for bereaved families at the Department of Psycho-Oncology at Saitama Medical University International Medical Center, Japan.

Results: During the period of investigation, 51 patients underwent consultation. The patients were frequently female ($P < 0.0001$) and the spouse of the deceased. Regarding the psychiatric diagnoses, major depression was the most common (39%), followed by adjustment disorders (28%).

Conclusions: This study revealed basic characteristics and psychiatric disorders of the bereaved who asked for medical help. Most of the patients were women (86.3%) and 86.3% of them received a psychiatric diagnosis. This information is important for both physicians and psychologists since the bereaved who have lost a loved one to cancer often ask for medical help in clinical settings.

Key words: cancer – bereaved family – consultation – psychiatric diagnosis – retrospective study

INTRODUCTION

Cancer is a disease that is increasing the awareness of mortality among the Japanese. This is due to the fact that one out of three Japanese dies of cancer, which has been the most common cause of death since 1981, and that there has been an increase in the number of fatalities (1). Not only patients but also their family members are affected by cancer. There have been several studies about the psychiatric consultation of cancer patients (2–5) and relatives of cancer patients (6,7) from the view of psycho-oncology. These

studies suggest that cancer patients and their families suffer from physical and psychiatric disorders.

If a patient dies, the ‘family of the patient’ becomes a ‘bereaved family’. The death of a person (spouse or close relative, in particular) is a stressful event in life (8). Bereavement, defined as ‘other conditions that may be a focus of clinical attention’ by the Diagnostic and Statistical Manual of Mental Disorders, 4th edn (DSM-IV-TR), of the American Psychiatric Association (9), from a medical viewpoint, is known to cause a variety of physical and mental disorders as well as increased mortality.

A study reported a 40% increase in mortality, of which 75% was due to heart disease, among males aged 54 years or older within 6 months of a wife's death (10). There has also been a report of increased mortality in females within 3 months of them losing their husbands (11). Other studies have also demonstrated high mortality rates in those who experience the death of a spouse (12,13).

As for physical disorders, there have been reports of heart trouble and high blood pressure, which can increase the risk of many different physical illnesses (14,15).

As for behaviors, around one-third of widows reported drinking alcohol for relief of grief (16), whereas changes in smoking habits and eating habits have also been reported (14).

As for psychiatric and psychological effects, an increased risk of suicide within 1 year of losing a loved one has also been reported (17–19). In a survey of the prevalence of depression after bereavement reported by Clayton et al., 42 and 16% of patients 1 month and 1 year after bereavement met the criteria for depression, respectively. Forty-seven percent of recently bereaved families experienced symptoms meeting the criteria for depression, while this was only 8% at 1 year and 11% overall in a control group, showing that the incidence in bereaved families was very high (20,21). It was also reported that the prevalence of depression in bereaved families was high: 24, 23, 16 and 15% at 2, 7, 13 and 25 months after bereavement, respectively (22). Furthermore, bereavement is one of the most important risk factors for depression among the elderly (23).

As already mentioned, if someone dies, people who were close to the deceased will become vulnerable to a variety of physical and psychological illnesses. Even if they undergo consultations, most patients do not name their distress over the death as a chief complaint to physicians and the relationship between their experience and the illness is often overlooked (24); therefore, appropriate help would not be provided for the bereaved when they need it.

However, the background and clinical status of bereaved families of cancer patients who ask for medical help have not previously been reported. It is necessary to describe the profiles of the bereaved who attend outpatient services for the bereaved.

The purpose of the present study was to investigate the characteristics, reasons for consultation and psychiatric disorders in patients who asked for medical help after the death of a loved one with cancer.

PATIENTS AND METHODS

PSYCHIATRIC INTERVENTIONS AT OUTPATIENT SERVICES FOR THE BEREAVED AT COMPREHENSIVE CANCER CENTER, SAITAMA MEDICAL UNIVERSITY INTERNATIONAL MEDICAL CENTER

Saitama Medical University (SMU) established a Comprehensive Cancer Center attached to the International Medical Center (IMC) and organized a cancer board. This is

the first cancer center affiliated to a university hospital in Japan. The Department of Psycho-Oncology is associated with the cancer board and provides two main services, one for outpatients and one for inpatients. In addition, the Department of Psycho-Oncology provides services for psychologically distressed family members.

As mentioned above, the bereaved are vulnerable to a variety of physical and psychological disorders. Therefore, the International Medical Center, Saitama Medical University (SMUIMC), started an 'outpatient service for bereaved families' at the time of its establishment in April 2007, with the aim of alleviating these distresses in the bereaved. This service is designed to 'help those who have lost a loved one to cancer live a better life', which is in line with the concept of 'postvention' proposed by Schneidman (25), and 'palliative care' as defined by the World Health Organization (WHO). WHO has included the following in the objectives for palliative care: to offer a support system to help the family cope during the patient's illness and in their own bereavement. The provision of palliative care increases as the person nears the end of life and includes support for the family during this entire period. After the patient dies, bereavement counseling for family and friends is also important (26). It provides outpatient services for the bereaved faced with psychological, social, physical and other problems, on the basis of the biopsychosocial model proposed by Engel (27).

The biopsychosocial model evaluates all the factors contributing to both illness and patienthood, rather than giving primacy to biological factors alone. This is the first outpatient service for the bereaved that provides psychological and social care and psychiatric treatment in Japan. This service is currently provided by two psychiatrists and two psychologists for those who have lost their spouse, parent, child or sibling to cancer.

SUBJECTS AND PROCEDURE

We conducted a retrospective survey of people consulting the outpatient services for the bereaved of SMUIMC for 30 months between April 2007 and September 2009. Bereaved individuals were defined as first-degree relatives (spouse, parents and children) and siblings of the deceased who had died of cancer.

In this investigation, we mainly used patient background data, regarding age, gender, relationship to the deceased, cancer site of the deceased, reason for consultation, the period before consultation and psychiatric diagnosis, stored in databases, as well as we referred to medical records as necessary. Psychiatric diagnoses were evaluated according to DSM-IV-TR (9).

Statistical analyses were conducted using the SPSS 17.0 package. The differences among the data were compared by an analysis of means using χ^2 test.

This study was approved by the Institutional Review Board of SMUIMC (08-029).

Table 1. Characteristics of the patients

	Total (n = 51), n (%)
Age (years)	
Mean \pm SD	51.3 \pm 14.7 (median:49)
Range	17–76
Gender	
Male	7 (13.7)**
Female	44 (86.3)**
Relationship to deceased	
Spouse	26 (51.0)
Parent	16 (31.4)
Child	7 (13.7)
Sibling	2 (3.9)
Employment status	
Full time	23 (45.1)
Part time	4 (7.8)
Housewife	21 (41.2)
Retired	1 (2.0)
Student	2 (3.9)
Living arrangement	
Alone	19 (37.2)
Not alone	32 (62.8)
History of any psychiatric disorder	
Present	2 (3.9)
Absent	49 (96.1)
Cancer site of deceased	
Lung	12 (23.5)
Pancreas	7 (13.7)
Stomach	6 (11.8)
Hematopoietic	5 (10.0)
Brain	5 (10.0)
Head and neck	3 (6.9)
Breast	3 (6.9)
Colon	3 (6.9)
Female genitalia	2 (4.0)
Unknown	2 (4.0)
Others	5 (10.0)

**Differences between groups were statistically evaluated with χ^2 test ($P < 0.01$).

RESULTS

CHARACTERISTICS OF THE PATIENTS

During the period of investigation, 949 patients consulted the Department of Psycho-Oncology. Of these patients, 51 (5.4%) had relatives who had died of cancer, which had led them to consult bereaved family services. Their ages ranged

Table 2. Characteristics of consultation

Reason for consultation (multiple choices)	n (%)
Distress	32 (62.7)
To talk to someone	7 (13.7)
Involved in trouble	5 (9.8)
Physical and psychiatric symptoms	3 (5.9)
Difficulty in concentrating	3 (5.9)
Others	4 (8.0)
Period	13.14 \pm 22.43 months

Period: mean time between the loved one's death and the first consultation.

from 17 to 76 years (mean \pm SD: 51.3 \pm 14.7; median: 49). There were 7 males (13.7%) and 44 females (86.3%). There was a significant difference among the consultees between the numbers of males and females ($P < 0.0001$; Table 1).

The most common relationship to the deceased was as a spouse ($n = 26$, 51.0%), followed by parent ($n = 16$, 31.4%), child ($n = 7$, 13.7%) and a sibling ($n = 2$, 3.9%).

Among the background characteristics of the patients, the most common cancer site in the deceased was lung ($n = 12$, 23.5%), followed by pancreas ($n = 7$, 13.7%) and stomach ($n = 6$, 11.8%).

CHARACTERISTICS OF CONSULTATION

The most common reason for consultation was distress from the bereavement, which was recognized in 22 patients (62.7%). Seven patients (13.7%) wanted to talk to someone. Five patients (9.8%) needed help because they had trouble with their relatives, friends and neighbors after the death of a loved one. Three patients (5.9%) showed physical and psychiatric symptoms like insomnia and generalized fatigue. Three patients (5.9%) had difficulty in concentrating on their work (Table 2).

The mean time between the loved one's death and the first consultation (period) ranged from 1 to 108 months ($n = 51$, mean \pm SD: 13.1 \pm 3.2, median: 5.0), with 24.5% of consultations being carried out within 1 month, 44.9% within the following 12 months and 22.4% within the following 24 months.

PSYCHIATRIC DIAGNOSIS

Psychiatric diagnoses of these patients are summarized in Table 3. Over 80% of the bereaved who consulted 'outpatient services for the bereaved' received a psychiatric diagnosis.

Major depression, the most common diagnosis, was observed in 20 patients (39.2%). It was also the most common diagnosis in consultation both within 1 year after the death and over 1 year after the death. There were no significant differences in the ratio of major depression to other psychiatric disorders with regard to the period before the start of consultation (within 1 year after the death and over

Table 3. Psychiatric diagnoses of the patients

Psychiatric diagnosis (multiple choices) ^a	Total (<i>n</i> = 51), <i>n</i> (%)	The period before consultation (months)	
		0–12 (<i>n</i> = 34), <i>n</i> (%)	>12 (<i>n</i> = 17), <i>n</i> (%)
Major depressive disorder	20 (39.2)	15 (44.1)	5 (29.4)
Adjustment disorder	14 (27.5)	9 (26.5)	5 (29.4)
Bereavement reaction	6 (11.8)	5 (14.7)	1 (5.9)
Dissociative disorder	1 (2.0)	1 (2.9)	0 (0)
Generalized anxiety disorder	2 (3.9)	0 (0)	2 (11.8)
Post-traumatic stress disorder	1 (2.0)	1 (2.9)	0 (0)
Others	2 (3.9)	0 (0)	2 (11.8)
No diagnosis	7 (13.7)	4 (11.8)	3 (17.6)

^aPsychiatric diagnosis is defined by DSM-IV (9).

Table 4. Psychiatric intervention

Psychiatric intervention (multiple choices) (<i>n</i> = 51)	<i>n</i> (%)
Psychotropic medication	31 (60.8)
Psychological intervention	43 (84.3)

1 year) ($P = 0.24$). Adjustment disorder was the next most common diagnosis and was observed in 14 patients (27.5%), and bereavement reaction was the third most common and was observed in 6 patients (11.8%).

Other psychiatric diagnoses were generalized anxiety disorder ($n = 2$, 4.0%), post-traumatic stress disorder (PTSD) ($n = 1$, 2.0%), dissociative amnesia ($n = 1$, 2.0%) and schizophrenia ($n = 1$, 2.0%). Seven patients (13.7%) had no diagnosis.

Six patients (11.8%) exhibited the complication of dissociative amnesia during the treatment, with major depression ($n = 2$, 4.0%), adjustment disorder ($n = 2$, 4.0%) or bereavement reaction ($n = 2$, 4.0%). Three patients (5.9%) exhibited the complication of panic disorder during the treatment, with major depression, adjustment disorder and bereavement reaction (data not shown).

PSYCHIATRIC INTERVENTIONS

Thirty-one patients (60.8%) were treated with medication. The following psychotropic drugs were prescribed: benzodiazepines ($n = 8$, 15.7%) or antidepressants ($n = 8$, 15.7%) or, more frequently, the two in combination (benzodiazepines + antidepressants, $n = 14$, 27.5%). One patient (2.0%) was prescribed antidepressants and neuroleptics (Table 4).

Forty-three patients (84.3%) received supportive psychotherapy, cognitive behavioral therapy or unstructured counseling as psychological intervention.

DISCUSSION

This report provides basic information about the bereaved who have lost a loved one to cancer and ask for medical help.

We found that most of the patients who consulted 'outpatient services for bereaved families' at SMUIMC were women. Their characteristics are similar to those of individuals in a study of the background characteristics of relatives of cancer patients (6,7). There are several reasons why women tend to consult bereaved family services. The presence of psychosocial problems or distress is predictive of consultation behavior in women, but not in men (28). Men tend to approach the provision of support negatively even though they perceive themselves as being hurt by the death of a loved one (29,30).

The lung was the most common cancer site and the stomach was the third most common cancer site among the deceased patients; this result is consistent with the most common causes of death among men in Japan (1), reflecting the high proportion of female spouses referred to the outpatient clinic for the bereaved, and it is similar to the findings in a study of the relatives of cancer patients (6,7).

In this study, over 80% of the bereaved who asked for medical help had psychiatric diagnoses. Major depression was the most common psychiatric diagnosis, followed by adjustment disorder. This indicates that most of the bereaved who asked for medical help need psychiatric and/or psychological intervention. Treatment of major depression, especially antidepressant therapy, among the bereaved with bereavement-related depression has been identified as being effective (31). Untreated major depression after bereavement carries the extra burden of prolonging the pain and suffering associated with grief (32). Therefore, more attention should be paid to these diagnoses without dismissing them as 'reasonable given the circumstances' (33). Early detection and appropriate recognition of depression in the bereaved should be encouraged. In addition, adjustment disorders are

often responsive to psychological interventions and positive changes in medical status. The distress that these subjects complained at consultation was not only about their loss, but also from another distress that was an offshoot of the death. This might also be a cause of these psychiatric disorders.

Some patients developed dissociative amnesia in addition to other psychiatric symptoms. Dissociative disorder was not recognized in a previous study of the bereaved who had lost a loved one to cancer. Similar symptoms are included in the criteria for the diagnosis of PTSD, such as an inability to recall an important aspect of the trauma (9). However, six patients did not fulfill the diagnostic criteria for PTSD. They suffered from the symptoms of dissociative amnesia because they could not remember certain things even though they wanted to, which could make them grieve even more. Further studies of dissociative amnesia in the bereaved might be required.

This study has several limitations. First, it was only conducted at one institution, the Comprehensive Cancer Center, and so institution bias may be a problem. Second, this study covered only 51 cases where bereaved family services were used. Further studies are necessary to investigate the findings in more detail. Third, this study was a retrospective study. A prospective study is necessary for more detailed investigation.

In conclusion, we investigated basic characteristics and psychiatric disorders among the bereaved who have lost a loved one to cancer and asked for medical help, using the DSM-IV criteria. The observations that most of the patients who consulted 'outpatient services for the bereaved' were women and over 85% of the patients received a psychiatric diagnosis are important findings. Almost 40% of the diagnoses involved major depression, which is highly responsive to pharmacologic interventions in psychiatric populations. Additionally, about one-third of the diagnoses were adjustment disorders, which are often responsive to psychological interventions and positive changes in medical status. This information is important for both physicians and psychologists since the bereaved who have lost a loved one to cancer often consult and ask for help in clinical settings. In addition, we have to improve our ability to screen for and recognize these factors among the bereaved at an early stage. The present results revealed that appropriate care is necessary for the bereaved who have lost family members to cancer and ask for medical help, and we have to recognize them in clinical settings.

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Conflict of interest statement

None declared.

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Patients' perception of the usefulness of a question prompt sheet for advanced cancer patients when deciding the initial treatment: a randomized, controlled trial

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Abstract

Objective: The objective of this study was to evaluate the patients' perception of the usefulness of a question prompt sheet (QPS) in facilitating the involvement of advanced cancer patients during consultation.

Methods: Advanced cancer patients attending their first consultation after diagnosis were randomly assigned to the intervention group (received QPS and a hospital introduction sheet (HIS)) or the control group (received HIS only). Analysis was conducted on an intention-to-treat basis. The primary outcome measure was patient rating of the usefulness of the material(s) (numerical rating scale of 0–10).

Results: Sixty-three advanced cancer patients (72.4% response rate) were enrolled and analyzed. Nearly three-quarters of patients in both groups read the material(s) before consultation. The rated usefulness of the material(s) for asking questions of physicians was significantly higher in the intervention group than in controls (4.4 ± 3.6 and 2.7 ± 2.8 , respectively; $p = 0.033$). The mean score of the usefulness of the material(s) for understanding the treatment plan tended to be higher in the intervention group than in the controls (4.9 ± 3.6 and 3.3 ± 2.8 ; $p = 0.051$). The mean score of willingness to use the material(s) in the future was significantly higher in the intervention group than in the controls (5.3 ± 3.8 and 2.8 ± 2.8 ; $p = 0.006$). There were no significant differences between the groups in the average total number of questions asked by patients (median, 1.0; interquartile range in both groups, 2.0).

Conclusions: QPS provided before oncology consultation may be useful for advanced cancer patients, on the other hand, it did not directly promote patient confidence to ask questions. Copyright © 2011 John Wiley & Sons, Ltd.

Keywords: cancer; oncology; communication; patient participation; question prompt sheet

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Introduction

In cancer care, good communication is essential for building patient–physician relationship. Patient-centered approaches have been proposed for improving communication between patients and physicians, including the use of a question prompt sheet (QPS) [1–5].

A QPS is a structured list of questions covering the items a patient may want to ask their physicians regarding their illness and treatment. Patients are given the QPS before consultation for them to read and to determine which questions they would like to ask. In cancer setting, randomized controlled

trials have been performed to evaluate the effectiveness of QPS in encouraging cancer patients regardless of the cancer stage to obtain more information about their illness and its treatment. Patients who received QPS asked more questions [6,7] and rated the QPS as significantly more useful for the family [6] as well as more helpful in aiding communication with their physician compared with a control group [8]. However, the patients in the previous randomized studies were commonly at an early disease stage as opposed to the metastatic stage, and their prognosis was typically in the order of years (i.e., 1–5 years), except in one study examining palliative care patients [7,9].

Decision making in patients at the time of initial diagnosis of advanced cancer is quite different than for patients with early stage cancer who are receiving treatments with curative intent or for those with advanced cancer who are already approaching the terminal phase of their illness [10]. Patients who have just been diagnosed with advanced cancer are stunned by the news of having incurable cancer and by the prospect of limited life expectancy [11]. Nevertheless, they are often obliged to make urgent decisions, and this may require an exhaustive search for information about their condition. When deciding on the initial treatment, good communication between an advanced cancer patient and a physician is very important to achieve a better understanding of the medical condition and for the patient to take a more autonomous role in medical care. Therefore, it is important to investigate whether QPS can help advanced cancer patients to ask questions and to collect information when making decisions.

Moreover, Dimoska *et al.* point out that the lack of research examining the use of a QPS by non-English-speaking cancer patients. There are no cancer-specific QPSs that have been translated to other languages [9]. Our previous studies in Japan found that some patients preferred that physicians give them a chance to ask questions, while others did not know what questions to ask and wanted to know the questions most frequently asked by other patients [12,13]. In Japan, it might prove helpful to provide cancer patients with a QPS containing sample questions commonly asked.

In previous QPS studies, the number or duration of questions asked by patients showed a poor correlation with subjective outcomes such as satisfaction [14,15]. Bruera *et al.* described that patient expectations were frequently not met and patients are often not satisfied with information needs [8]. Better communication may not depend on number or duration of questions patients ask. Therefore, in the current study, we investigated the patients' perception of the usefulness of a QPS provided to patients newly diagnosed with advanced cancer in helping them to decide on their initial treatment. Our primary goal was to specifically determine how useful patients found the QPS compared with a hospital introduction sheet (HIS) containing a space in which patients could write their questions freely.

Patients and methods

Setting and participants

The study was performed in the National Cancer Center Hospital East, Japan from February to December 2008. The enrolled subjects were patients with advanced cancer (i.e., locally advanced,

metastatic, recurrent) presenting for their first consultation with an oncologist at thoracic oncology division or gastrointestinal oncology division to discuss the treatment plan. We consecutively recruited patients with advanced nature of the cancer identified from the referral note from their previous physician. Some patients were excluded after recruitment because they were diagnosed as cancer in early stage. The inclusion criteria for the potential patients were as follows: (1) informed of advanced cancer diagnosis, (2) aged 20 years or older, (3) no serious physical or psychological distress recognized by the primary physicians or researchers, (4) no cognitive disorder, (5) able to communicate in Japanese.

Procedure

The potential patients were invited to participate consecutively by their initial physician during the consultation. Thereafter, patients were informed of the purpose and requirements of the study by a researcher. After obtaining written consent, patients were randomly given an envelope, which assigned them to either the intervention group (received QPS and HIS) or the control group (received HIS only). Patients in both the groups were instructed to read the material(s) before their next consultation. Following the next consultation, patients in both groups were asked to complete a questionnaire that assessed the usefulness of the material(s) and their level of satisfaction with the consultation. In addition, the patients were asked about the number and content of the questions for their physician (Figure 1).

The study was approved by the ethics committees of the National Cancer Center, Japan, and registered with UMIN-CTR, number 000001047 (<https://center.umin.ac.jp/cgi-open-bin/ctr/ctr.cgi?function=brows&action=brows&recptno=R000001254&type=summary&language=E>).

Question prompt sheet

We prepared an initial draft of QPS that contained 63 questions based on previous QPS studies [3,8,14,15] and our previous study on the preferences of Japanese cancer patients regarding the disclosure of bad news [12]. Before the study, we performed interviews with 14 cancer patients and five oncologists and made modifications to the QPS, which included removal of 15 similar questions, addition of five extra questions and some minor changes. The final QPS was a 10-page A4 sheet containing 53 questions grouped into 10 topics and a space for new questions (see Appendix A for the questions of the final QPS).

Hospital introduction sheet

The HIS was designed to provide information on the various services and the faculty of the National

Usefulness of a question prompt sheet when deciding treatment

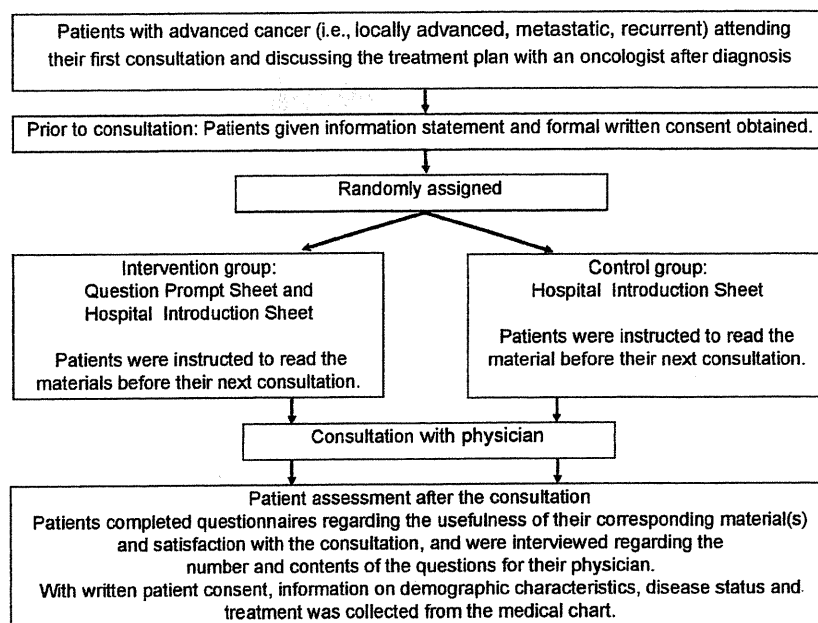


Figure 1. Study procedure

Cancer Center Hospital East, Japan. In addition, the HIS provided information on treatment and contained a space for any questions or messages the patients may have wanted to write.

Measures

Usefulness of the material(s)

Based on a previous study [8], we asked three questions regarding the usefulness of the material(s). Patients were asked to rate the following (assessed by a numerical rating scale of 0 to 10 where 10 represents completely agree and 0 represents completely disagree): (1) the material helped me to ask relevant questions of physicians; (2) the material was useful in understanding the treatment plan; and (3) I will use the material before any consultation in the future.

Satisfaction with the consultation

Patient satisfaction with the consultation was assessed using five items adapted from a previous study [8]. Patients were asked to rate the following (assessed by a numerical rating scale of 0 to 10): (1) the physician answered all the questions; (2) I was able to ask all the questions I wanted to ask; (3) I was able to understand the condition of my disease; (4) I was able to comprehend the treatment plan; and (5) I am satisfied with the consultation.

Number and contents of the questions

The number and contents of the questions were measured by interview immediately after the consultation. We did not use audiotape to record the consultation as in previous studies because audiotaping of consultations is an extremely rare practice in Japan. We feared that audiotaping may

not be acceptable to patients and physicians and may adversely affect recruitment to the study. We asked the patients the following questions and determined the estimated number of patient questions: Did you ask the physician some questions? If so, what kind of questions did you ask? For example, if patient answered that he asked the physician about the side effect and the cost of treatment, we estimated the number of patient questions at 2.

Patient characteristics

With written patient consent, information on demographic characteristics, disease status and treatment was collected from the medical chart.

Sample size calculations

The primary outcome measure was the patient rating of the usefulness of the material(s). Based on a previous study [8], we calculated sample size using the following parameters: 80% power, 0.05 level of significance, 5.70 average score of usefulness increasing to 7.90, with 3.08 as standard deviation. The sample required to detect this difference was 32 per arm. Therefore, the required total sample size was 64 patients.

Statistical analysis

Statistical analysis was conducted on an intention-to-treat basis. The primary outcome measure was patient rating of the usefulness of the material(s). The secondary outcome measures included satisfaction with the consultation, number of total questions and frequency of questions. Differences

in each outcome measure between the intervention group and the control group were measured using independent sample *t*-tests. Proportions in the two groups were compared using Fisher's exact test or Chi-square test. Statistical analysis was conducted using SPSS for Windows version 15 (SPSS Inc., Chicago, IL, USA), with two-tailed statistical tests.

Results

Participant flow, assignment and follow-up

Eighty-seven eligible patients were identified and invited to participate in the study, and 63 consented (72.4%, Figure 2). Non-consent of patients was primarily due to their being too stressed mentally or being severely ill physically. Of the 63 patients [intervention group ($n = 32$); control ($n = 31$)], two (one in each group) had no consultation, one (control group) changed hospitals, and one (intervention

group) withdrew because of mental stress. Thus, a total of 59 patients were analyzed. Strict intention-to-treat analysis was conducted on all randomly assigned 63 patients using all available data from the patients. Dropout, partial absence of data, and failure to use the sheets were included in the analysis as score or number '0'. Patient demographics and clinical characteristics are shown in Table 1. Differences in these variables between groups were not significant.

Approximately 75% of the patients in both groups read their respective material(s) prior to consultation. Forty-four percent of the patients in the intervention group and 23% of the patients in the control group decided on their questions in advance ($p = 0.075$).

Usefulness of the material(s)

The mean usefulness rate (a numerical rating scale of 0 to 10) of the material(s) in helping the patients to ask questions was significantly higher in the intervention group than in the control group (4.4 ± 3.6 and 2.7 ± 2.8 , respectively; $p = 0.033$). The mean score of usefulness of the material(s) in helping the patients to understand the treatment plan tended to be higher in the intervention group than in the control group (4.9 ± 3.6 and 3.3 ± 2.8 , respectively; $p = 0.051$). The mean score of willingness to use the material(s) in the future was significantly higher in the intervention group than in the control group (5.3 ± 3.8 and 2.8 ± 2.8 , respectively; $p = 0.006$; Table 2).

For reference, we conducted treatment analysis including only patients who had read the material(s)

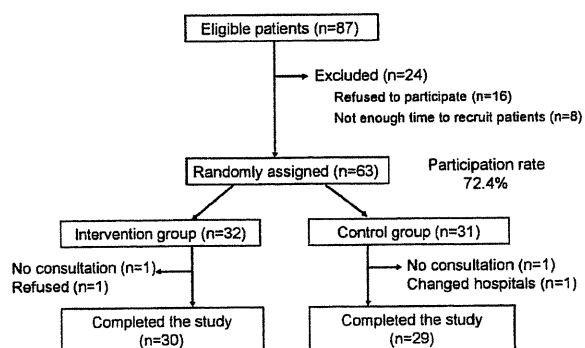


Figure 2. CONSORT diagram

Table 1. Demographics and clinical characteristics of patients ($n = 63$)

		Intervention ($n = 32$), n (%)	Control ($n = 31$), n (%)	Test result
Age, years	Median (range)	63.5 (52–82)	64.0 (28–82)	n.s.
Sex	Male	21 (65.6)	21 (67.7)	n.s.
Type of cancer	Lung	20 (62.5)	19 (61.3)	n.s.
	Gastric	4 (12.5)	3 (9.7)	
	Colorectal	3 (9.4)	4 (12.9)	
Stage	Esophageal	5 (15.6)	5 (16.1)	
	II (Esophageal cancer)	2 (6.3)	0 (0.0)	n.s.
	III	10 (31.3)	11 (35.5)	
	IV	19 (59.4)	18 (58.1)	
Treatment	Relapse	1 (3.1)	2 (6.5)	
	Chemotherapy	23 (71.9)	13 (41.9)	n.s.
	Chemotherapy+radiation	5 (15.6)	12 (38.7)	
	Other	4 (12.5)	6 (19.4)	
Use of the materials ^a	Read the material(s) prior to the consultation	24 (75.0)	23 (74.2)	n.s.
	Decided questions in advance	14 (43.8)	7 (22.6)	n.s.
	Wrote down questions in advance	2 (6.3)	0 (0.0)	n.s.
	Looked at the material(s) during the consultation	1 (3.1)	0 (0.0)	n.s.
	Checked physician's explanation with the material(s)	1 (3.1)	0 (0.0)	n.s.
	Asked questions included in the material(s)	6 (18.8)	1 (3.2)	n.s.

Proportions in the two groups were compared using Fisher's exact test or χ^2 test. Numerical scale was compared using the *t*-test.

^aBased on intention-to-treat analysis, four drop outs (intervention ($n = 2$); control group ($n = 2$)) were included in the analysis as 'nonuser'.

Usefulness of a question prompt sheet when deciding treatment

prior to consultation. The mean usefulness rate of the material(s) in helping the patients to ask questions was significantly higher in the intervention group than in the control group (6.4 ± 2.3 and 3.4 ± 2.7 , respectively; $p < 0.001$; $t = 4.011$). The mean usefulness of the material(s) in helping the patients to understand the treatment plan was significantly higher in the intervention group than in the control group (6.5 ± 2.4 and 4.3 ± 2.5 , respectively; $p = 0.002$; $t = 3.215$). The mean score of willingness to use the material(s) in the future was significantly higher in the intervention group than in the control group (7.0 ± 2.6 and 3.5 ± 2.7 , respectively; $p < 0.001$; $t = 4.594$).

Satisfaction with the consultation

The levels of satisfaction with (1) the ability of the physician to answer the patients' questions, (2) asking questions, (3) understanding the condition of the disease, and (4) comprehending the treatment plan, as well as the overall level of satisfaction with the consultation were high in both groups, although not significantly different (Table 3).

Number and contents of the questions

We determined the estimated number of patient questions from patients' interview. Sixty-three percent of the patients in the intervention group and 71% of the patients in the control group asked question(s) during the consultation (no significant difference). Patients in both groups asked a median of 1.0 question (interquartile range, 2.0) (no significant difference). The majority of questions were related to information about treatment. The analysis

of the number of questions asked in each question category by the two groups showed no significant difference in any category.

Discussion

To our knowledge, this is the first study of evaluation of a QPS for advanced cancer patients deciding on their initial treatment. In addition, this is the first QPS study in Asia. Nearly half of the patients in the intervention group prepared questions prior to consultation (23% of the patients in the control group; no significant difference). We found that, compared with supplying the HIS only, advanced cancer patients who received both the HIS and the QPS rated the materials significantly more favorably with regards to the materials usefulness in helping them to ask questions of the physician and for future consultations. The results show similar findings to the previous study [8].

Unexpectedly, the use of the QPS did not seem to promote question-asking behavior. The total number of questions asked by the patients in the intervention group (median: 1.0) in the current study was, surprisingly, smaller than that in the intervention group in previous studies of patients seeing an oncologist for the first time (mean/median: 8.5–14.0) [6,8,15], although nearly half of the patients in the intervention group had decided on their questions in advance. Although we could not reliably compare the number of questions asked in the present study with that in previous studies (we did not audiotape the consultation as in previous studies), it appears that the patients in the current study asked fewer questions than those in the previous studies.

Table 2. Mean scores of usefulness of the material(s) ($n = 63$)

	Intervention ($n = 32$) Mean (SD)	Control ($n = 31$) Mean (SD)	p -Value
Usefulness of the material(s) in helping to ask questions	4.4 (3.6)	2.7 (2.8)	0.033
Usefulness of the material(s) in helping to understand the treatment plan	4.9 (3.6)	3.3 (2.8)	0.051
Willingness to use the material(s) in the future	5.3 (3.8)	2.8 (2.8)	0.006

SD, standard deviation. All items were rated on a 0–10 scale (e.g. 0 = completely disagree, 10 = completely agree). Scores in the two groups were compared using the t -test. Based on intention-to-treat analysis, four dropouts (intervention ($n = 2$); control group ($n = 2$)), 10 nonusers of the materials (intervention ($n = 6$); control group ($n = 4$)) and four partially missing (intervention ($n = 2$); control group ($n = 2$)) were included in the analysis as score '0'.

Table 3. Mean scores according to satisfaction with the consultation ($n = 63$)

	Intervention ($n = 32$) Mean (SD)	Control ($n = 31$) Mean (SD)	p -Value
Satisfaction with the ability of the physician to answer the patients' questions	8.1 (3.0)	8.2 (2.8)	0.893
Satisfaction with asking questions	6.8 (2.9)	7.8 (2.5)	0.177
Satisfaction with understanding the condition of the disease	8.0 (2.6)	8.2 (2.7)	0.810
Satisfaction with comprehending the treatment plan	8.1 (2.5)	7.8 (2.8)	0.665
Overall level of satisfaction with the consultation	7.9 (2.6)	7.8 (2.8)	0.847

SD, standard deviation. All items were rated on a 0–10 scale (e.g. 0 = completely disagree, 10 = completely agree). Scores in the two groups were compared using the t -test. Based on intention-to-treat analysis, four dropouts (intervention ($n = 2$); control group ($n = 2$)) were included in the analysis as score '0'.

We assume that one of the reasons behind the fewer questions in the current study was that the unique patient–physician relationship in Asian culture. The views in Asian countries on individuality and personal rights are distinctively different from those in North America and Western countries [16,17]. Watanabe *et al.* reported that Japanese cancer patients who felt that they were compelled to make a decision even though they had no sufficient information or understanding of their medical condition and treatment options were dissatisfied with the decision-making process [18]. Nomura *et al.* described the dominant category of patient–physician relationship in Japan as follows: ‘the relationship between a Japanese physician and a patient is clearly asymmetrical, since the patient seeks help and care from a medical expert whose diagnostic evaluations have to be accepted by the patient without discussion’ [19].

In Taiwan, the common practice of nondisclosure of prognosis and detailed disease-related information by healthcare professionals continues, although there is a need to disclose information on the medical condition of Taiwanese cancer patients [20]. Patient–physician relationships in Asian countries have traditionally been based on a paternalistic and hierarchical culture that discourages patients from questioning doctors. For this reason, cancer patients in Asian countries might need more intervention to make them feel comfortable to ask questions of their physicians. In the current study, we did not ask the physicians to refer to or endorse the QPS, however, considering the interactive nature of communication, a combination of QPS and active endorsement of QPS by physicians and/or communication skills training for physicians might be needed to promote question-asking behavior. Indeed, results from some previous studies suggest that physician endorsement of a QPS seems to enhance its effectiveness [3,7].

Overall ratings for the usefulness of the written materials were rather low. One possible reason is that a strict intention-to-treat analysis was conducted. The other possible reason is that we assigned a value of 0 for ratings of the usefulness of the written materials when they were not read by the participants. The rating of the QPS for those who read the materials were higher (range: 6.4–7.0).

In the current study, QPS was perceived by the patients as useful for helping them to ask relevant questions of their physician and for future use without an increase in the number of questions during the consultation. There are several possible explanations for this. First, Bruera *et al.* described that communication may be better when patients are able to ask their most meaningful questions rather than just more questions [8]. In the current study, patients in the intervention group might be able to consider the information they need to know in advance from QPS and thereby ask questions that better address their main concerns rather than

simply asking more questions. Second, QPS might be helpful in collecting and organizing information. Rainbird *et al.* reported that advanced cancer patients have high levels of unmet needs, particularly in the areas of psychological and medical communication/information [21,22]. Teno *et al.* reported that more than one-third of advanced cancer patients wanted more information about their test results at the time of diagnosis [23]. These previous studies indicate that advanced cancer patients experience difficulty in obtaining sufficient information during consultation. QPS may prove useful for advanced cancer patients in collecting and organizing information related to their medical condition. Finally, during the interview, some patients emphasized their expectations for the future use of QPS, since they had decided not to ask any questions in the first consultation because they believed that they must first listen to the physician’s explanation.

The level of satisfaction with the consultation was very high and there was no significant difference between the intervention group and the control group. Brown *et al.* reported that cancer patients rated their levels of satisfaction with the consultation extremely highly, even though their expectations were not met at the stated level desired [24]. Previous QPS studies also reported that the level of satisfaction showed a poor correlation with the number or duration of questions asked [14,15]. It might be difficult to evaluate the effect of QPS based on patients’ satisfaction levels with the consultation. Of note, although not a significant difference, the intervention group rated their satisfaction with asking questions (mean score of 6.8) less favourably than those in the control group (mean score of 7.8). Perhaps, the QPS raised patients’ expectations for being able to ask questions, and if the QPS was not endorsed or referred to by the physician then this caused the patient to be less satisfied with this aspect of the consultation.

Our study has several limitations. First, we could not get the required sample size because of dropout and research period restriction. Insufficient statistical power might lead underestimation. Second, we performed the study in only one cancer center and focused mainly on the first consultation. Thus, we cannot apply the present results to other settings and situations. The impact of the use of QPS over time and in other settings needs to be further examined in the future. Third, we did not audiotape the consultations and therefore were unable to analyze the consultations in detail. In some cases (intervention group ($n = 14$); control group ($n = 8$)), we timed the consultation length. For reference, the average consultation length showed no significant difference between the groups (31.1 ± 14.0 and 26.0 ± 12.2 , respectively; $p = 0.398$; $t = 0.864$). In addition, we interviewed patients and determined the estimated number of

Usefulness of a question prompt sheet when deciding treatment

patient questions and the contents of questions, however, there is no evidence that patients' recall is accurate.

In conclusion, for those advanced cancer patients who read the QPS it seemed to be a moderately useful tool. Compared with controls, patients rated the QPS more favourably in terms of enabling them to ask relevant questions and for future use. The QPS seemed to help patients to prepare questions and it may help patients to articulate and organize their information needs. However, the QPS did not seem to directly promote patient confidence to ask questions. In Asian countries, active endorsement of QPS by physicians and/or communication skills training for physicians might be effective for promoting question-asking behavior. In the future, research

would be needed to examine the impact of the use of QPS over time and in other settings.

Acknowledgements

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Appendix A

Question Prompt Sheet is given in Table A1.

Table A1. Question prompt sheet

Diagnosis	1 What is the diagnosis?
	2 What is the stage of my cancer?
Condition of a disease	3 What is wrong with me?
	4 Where is my cancer located?
	5 Which test showed that?
Symptom	6 What symptoms will the cancer cause?
	7 What kind of treatments for the symptoms do you have?
Test	8 Do I need any more tests before my treatment?
	9 If so, does it hurt?
	10 What do the tests show?
Treatment	11 What treatment options are available for me?
	12 What are my options aside from anticancer drugs?
	13 What is the best case scenario? What is the worst case scenario? What is the most likely case scenario? How about survival length and quality of life?
	14 What complications, short/long side effects and sequelae does each treatment have?
	15 What is your recommendation regarding the best treatment for me?
	16 Which treatment do other patients with the same condition as mine choose?
	17 What is involved in administering the treatment, for example, contents, timing, frequency, duration, schedule, location, costs of treatments?
	18 What is the purpose of the treatment?
	19 What physical limitations will I have during the treatment?
	20 What are the common side effects of the treatment?
	21 Does the treatment cause pain?
	22 What can be done about the side effects?
	23 When will I know whether the treatment is working?
	24 How will I know whether the treatment is working?
	25 What are my next options if the treatment fails?
	26 What costs will I incur throughout my treatment?
	27 What is the percentage of success of this treatment for the other patients?
	28 Can I get my treatment at my local doctor's office?
	29 If I am taking alternative medicine, can I still continue?
	30 Can I take folk medicine or complementary and alternative medicine during treatment?
Life	13 Will the treatment affect my ability to work or perform other activities?
	32 Is there anything I have to do before and during my treatment?
	33 Is there anything I should not do during my treatment, for example, diet, exercise, housekeeping, sexual life, childbirth?
	34 Is it OK for me to do... during the treatment?
	35 Is it OK for me to eat/ drink... during the treatment?
	36 Is it OK for me to go...during the treatment?
	37 Is there anything that I should prepare before my treatment?
	38 What symptoms should I be alert for?
	39 What should I do when some symptoms occur?
Family	40 Will my family be affected by my cancer/ treatment?
	41 Will my family members have higher risk of getting cancer?
	42 Who can my family members talk to if they they have concern and worry?

Table A1. (Continued)

Psychological issues	43 Can I talk about my concern and worry?
	44 How can I cope with sleeplessness caused by anxiety and depressed feeling?
	45 Can you give me any advice on how to cope with the disease?
	46 Is there someone I can talk to about my feeling?
Prognosis	47 How long am I likely to live? The reason why I want to know is...
	48 Is there any chance for cure?
	49 What can I expect in the future?
Other issues	50 What causes cancer?
	51 How much time do I have to think about this? Do you need my decision today?
	52 There are some changes about... (in my life, physical aspect, mental aspect) after the previous consultation.
	53 The things that I hope to take precedence or continue doing in my life are...

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Brief report

Suicidal ideation among patients with gender identity disorder

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ABSTRACT

In this study, we tried to clarify the prevalence of suicidal ideation and self-mutilation including suicide attempts among patients with gender identity disorder (GID) and the relationship of those behaviors to demographic characteristics. A total of 500 consecutive Japanese GID patients without any other psychiatric comorbidity were evaluated at the outpatient GID Clinic of Okayama University Hospital. The lifetime rate of suicidal ideation was 72.0% of the total sample. There were no significant differences in the prevalence of suicidal ideation among groups divided by sex, age, age at onset or education. The lifetime prevalence of self-mutilation including suicide attempts was 31.8% of the total sample. Low level of education was significantly related to self-mutilation among both male-to-female and female-to-male GID patients. Younger age at onset was a significant factor affecting self-mutilation only among MTF GID patients. A lack of strategies to cope with severe distress among persons with lower education might induce a high frequency of self-mutilation including suicidal attempt. GID patients with a low level education might be at high risk of self-mutilation and should be watched with special attention to self-mutilation.

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1. Introduction

Gender identity disorder (GID) is characterized by a strong and persistent identification with the opposite sex and discomfort with one's own sex (American Psychiatric Association, 1994). Compared with many other psychiatric disorders, GID is rare, with an estimated worldwide lifetime prevalence of 0.001%–0.002% (Roberto, 1983) or 0.0019%–0.0024% (Landen et al., 1996a). The incidence of GID patients who requested sex reassignment therapy was reported to be 0.14/100,000/year in Sweden (Landen et al., 1996b). Thus, it has been difficult to establish demographic characteristics, and reports of large samples from countries outside of North America and Western Europe are extremely limited (Okabe et al., 2008; Matsumoto et al., 2009).

For most GID patients, a strong and persistent identification with the opposite sex and discomfort with one's own sex is a life challenge that often creates distress and carries potential stigmatization (Matsumoto et al., 2009; Hoshiai et al., 2010). Over half the GID patients experienced some form of harassment or violence within their lifetimes (Lombardi et al., 2001). Significantly more GID patients

reported suicide ideation and attempts than heterosexual males and females (Mathy, 2003; Clements-Nolle et al., 2006). Higher prevalence of suicidal ideation and suicide-related behaviors among GID patients might be due to societal oppression, stigmatization/discrimination and psychological mechanisms. However, there have been only a few studies on the prevalence of and risk factors for suicidal ideation and suicide-related behaviors among GID patients (Mathy, 2003; Clements-Nolle et al., 2006). The aim of the present study was to clarify the prevalence of and risk factors for suicidal ideation and self-mutilation including suicide attempt among GID patients in Japan.

2. Methods

2.1. GID clinic

The GID Clinic at Okayama University Hospital, the second oldest GID clinic in Japan, was established in Okayama in 1997. During the study period, the GID Clinic at Okayama University Hospital was the only special GID clinic in western Japan. It consists of four departments: psychiatry, urology, gynecology, and plastic and reconstructive surgery. The services at the GID Clinic include diagnosis, counseling, genetic testing, hormonal therapy, plastic surgery, and coordination of social services resources.

2.2. Ethics

This study was approved by the Internal Ethical Committee of Okayama University Graduate School of Medicine, Dentistry, and Pharmaceutical Sciences. After a complete description of the study to the subjects, written informed consent was obtained before their inclusion in the study.

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2.3. Subjects

A total of 603 consecutive Japanese patients consulted the outpatient GID Clinic of Okayama University Hospital between April 1, 1997, and October 31, 2005. All patients were comprehensively evaluated independently by at least two senior psychiatrists with a special interest in this area, and 579 of 603 patients fulfilled the criteria for GID according to the *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition (DSM-IV) (American Psychiatric Association, 1994).

Of 579 GID patients, current psychiatric comorbidity was assessed independently by two senior psychiatrists according to several clinical interviews and clinical records. Current psychiatric comorbidity (Axis I) was diagnosed in 79 patients, and 500 patients were without psychiatric comorbidity. The relationship of psychiatric comorbidity to suicidal ideation and self-mutilation among GID patients was reported previously (Hoshiai et al., 2010). To avoid the influence of current psychiatric comorbidity, only patients without psychiatric comorbidity were included in this study. All 500 patients were chromosomally and endocrinologically screened. Most patients were evaluated by psychological examinations including the stress coping inventory, the sentence completion test and the Baum test. The detailed results of the stress coping inventory were reported previously (Matsumoto et al., 2009). Statistical analyses on the results of other psychological tests have not been performed.

Of 500 patients, 311 (62.2%) were the female-to-male (FTM) type, and 189 (37.8%) were the male-to-female (MTF) type. The mean age at first examination was 26.4±5.8 years for the FTM type, and 32.3±10.6 years for the MTF type ($P<0.001$; independent sample *t*-test, *t* value =−8.078, degrees of freedom 498).

2.4. Suicidal ideation and self-mutilation

The lifetime presence or absence of serious suicidal ideation and self-mutilation was investigated by asking the following questions; "Have you ever seriously thought about committing suicide?" and "Have you ever mutilated yourself (including suicide attempt)?".

2.5. Statistics (data analysis)

Statistical analysis was conducted using SPSS 18.0 J (SPSS Inc., Chicago, IL, USA). The difference of the proportion of MTF and FTM GID patients among groups was evaluated using the χ^2 test. Comparison of suicidal ideation or self-mutilation for group differences was performed by the χ^2 test. The significance level was set at $P<0.05$.

To identify which variables were significantly correlated with suicidal ideation or self-mutilation, we used multiple logistic regression. The multiple logistic regression analysis was performed using suicidal ideation or self-mutilation as a dependent variable. Independent variables were sex, age at first examination, age at onset (age when first thought about having the wrong sex), level of education, stage of therapy, steady partner and job. The final multiple logistic regression model was obtained after stepwise backward elimination of the independent variables using the likelihood-ratio test with $P<0.10$. The strength of the relationship between independent variables and suicidal ideation or self-mutilation was expressed by means of an odds ratio (OR) with 95% confidence interval (CI) and *P*-value. Logistic regression analyses were conducted for MTF and FTM separately.

3. Results

3.1. Prevalence of suicidal ideation and self-mutilation (Table 1)

Demographic characteristics of the patients are shown at Table 1. The level of education was higher among MTF GID patients than among FTM GID patients. The presence of a steady partner was more frequent among FTM GID patients. Almost all variables differed between the MTF and FTM GID patients with the exception of suicidal ideation, self-mutilation and job.

Self-mutilation including suicide attempt was more frequent among GID patients with lifetime suicidal ideation; 43.3% among GID patients with lifetime suicidal ideation compared to 2.1% among GID patients without suicidal ideation. Almost all GID patients with a history of self-mutilation (97.9%) had experienced suicidal ideation.

3.2. Demographic characteristics of patients with suicidal ideation or self-mutilation

The prevalence rate of suicidal ideation was high in all age groups (Table 2). There were no significant differences in the prevalence rate of suicidal ideation among groups divided by age, age at onset, stage of therapy, level of education, steady partner or job (Table 2). Multiple logistic regression analysis revealed that younger age and higher stage

Table 1
Demographic characteristics of patients with gender identity disorder.

Variables	MTF	FTM	χ^2	<i>P</i>
<i>n</i>	189	311		
Age (years): <i>n</i> (%)				
-24	50 (26)	133 (42)		
25-29	30 (16)	98 (32)		
30-34	40 (21)	47 (15)		
35-	69 (37)	33 (11)		
mean age	32.3±10.6	26.4±5.8		<0.001
Age at onset: <i>n</i> (%)				
Before elementary school	54 (29)	219 (70)	119.508	<0.001
Lower grades of elementary school	27 (14)	47 (15)		
Higher grades of elementary school	29 (15)	24 (8)		
Junior high school	40 (21)	16 (5)		
Senior high school and thereafter	39 (21)	5 (2)		
Stage of therapy at first examination: <i>n</i> (%)				
No therapy	83 (44)	185 (60)	11.789	0.003
Hormonal therapy without genital surgery	73 (39)	91 (29)		
With genital surgery	33 (17)	35 (11)		
Level of education: <i>n</i> (%)				
University or higher	71 (38)	66 (21)	15.977	<0.001
High school	97 (51)	206 (66)		
Junior high school	21 (11)	39 (13)		
Steady partner: <i>n</i> (%)				
Present	68 (36)	198 (64)	36.194	<0.001
Absent	121 (64)	113 (36)		
Job: <i>n</i> (%)				
Employed	126 (67)	228 (73)	2.511	0.113
Unemployed	63 (33)	83 (27)		
Suicidal ideation: <i>n</i> (%)				
Positive	141 (75)	219 (70)	1.021	0.312
Negative	48 (25)	92 (30)		
Self-mutilation: <i>n</i> (%)				
Positive	60 (32)	99 (32)	0.000	0.984
Negative	129 (68)	212 (68)		

MTF, male-to-female type; FTM, female-to-male type.

Age at onset, Age at first thought about having the wrong sex.

of therapy at first examination were significantly affecting suicidal ideation among MTF GID patients (Table 3). On the other hand, there were no significant factors affecting suicidal ideation among FTM GID patients (Table 3).

Not a few GID patients among all age groups experienced self-mutilation including suicide attempt (25.5%–35.6%) (Table 4). There were no significant differences in the prevalence rate of self-mutilation among groups divided by age, age at onset, stage of therapy, steady partner or job (Table 4). The rate of self-mutilation was higher among GID patients with lower levels of education (50.0% among GID patients who completed junior high school, 34.3% among GID patients who completed high school, and 18.2% among GID patients who completed university or higher (Table 4). Multiple logistic regression analysis revealed that low level of education was significantly affecting self-mutilation among both MTF and FTM GID patients (Table 5). Younger age at onset was significant factors affecting self-mutilation only among MTF GID patients (Table 5).

4. Discussion

4.1. Suicidal ideation

For more than 10 years, the number of suicides in Japan has been over 30,000 in a population of 120,000,000. In addition, the suicide rate among Japanese has been shown to be higher than in other developed countries (Yoshimasu et al., 2006). Recently, Ono et al. reported that the lifetime prevalence estimates of suicidal ideation was 10.9% in Japan (Ono et al., 2008). On the other hand, Matsumoto et al. reported that the lifetime history of suicidal ideation of 1726 junior and senior high school students was 40.4% (Matsumoto et al., 2008).

Table 2
Comparison of GID patients with and without suicidal ideation.

Variables	Suicidal ideation		χ^2	P
	+	-		
n	360	140		
Age (years): n (%)				
-24	134 (37)	49 (35)	2.602	0.457
25-29	94 (26)	34 (24)		
30-34	65 (18)	22 (16)		
35-	67 (19)	35 (25)		
Age at onset: n (%)				
Before elementary school	196 (55)	77 (56)	1.386	0.847
Lower grades of elementary school	57 (16)	17 (12)		
Higher grades of elementary school	37 (10)	16 (11)		
Junior high school	40 (11)	16 (11)		
Senior high school and thereafter	30 (8)	14 (10)		
Stage of therapy at first examination: n (%)				
No therapy	189 (52)	79 (56)	0.627	0.731
Hormonal therapy without genital surgery	121 (34)	43 (31)		
With genital surgery	50 (14)	18 (13)		
Level of education: n (%)				
University or higher	92 (26)	45 (32)	2.722	0.256
High school	226 (62)	77 (55)		
Junior high school	42 (12)	18 (13)		
Steady partner: n (%)				
Present	192 (53)	74 (53)	0.009	0.924
Absent	168 (47)	66 (47)		
Job: n (%)				
Employed	247 (69)	107 (76)	2.980	0.084
Unemployed	113 (31)	33 (24)		

Among 73 GID patients, the lifetime prevalence of suicidal ideation was reported to be 37.0% (Mathy, 2003). Suicidal ideators among GID patients were more likely than non-ideators to report difficulties with alcohol and drugs (Mathy, 2003). In another study, half of the 163 MTF GID patients with sex reassignment surgery (SRS) had contemplated suicide in their lives before SRS (Ibimbó et al., 2009). We here clarify the high incidence rate of suicidal ideation among both MTF and FTM GID patients (MTF, 74.6%; FTM, 70.4%). The frequency is very high among all age groups or all patients grouped by age at onset or level of education. In the present study, GID patients with current psychiatric comorbidity were excluded. Therefore, the high frequency of suicidal ideation among GID patients cannot be explained by psychiatric comorbidity. However, we did not evaluate sub-threshold psychiatric symptoms. Over half the GID patients (239/402, 59.5%) experienced some form of harassment or violence within their lifetime (Lombardi et al., 2001). Sub-threshold depression and anxiety

Table 3
Multiple logistic regression analysis of factors affecting suicidal ideation.

	B	Standard error	P	Odds ratio	95% confidence interval of odds ratio	
					Lower	Upper
MTF						
Age	-0.038	0.016	0.020	0.963	0.932	0.994
Stage of therapy	0.579	0.263	0.027	1.785	1.067	2.986
Constant	1.358	0.604	0.025			
FTM						
Constant	0.867	0.124	0			

MTF, male to female type.
-2 log likelihood = 205.925; Model $\chi^2 = 8.270$ ($p = 0.016$).
Prediction equation: $p = 1/[1 + \exp(-1 \times \text{Score})]$.
Score = $-0.038 \times \text{Age} + 0.579 \times \text{Stage of therapy} + 1.358$.
FTM, female to male type.
Stage of therapy at first examination; No therapy = 1, Hormonal therapy = 2, With genital surgery = 3.

Table 4
Comparison of GID patients with and without self-mutilation.

Variables	Self mutilation		χ^2	P
	+	-		
n	159	341		
Age (years): n (%)				
-24	60 (39)	123 (37)	2.604	0.457
25-29	42 (26)	86 (25)		
30-34	31 (19)	56 (16)		
35-	26 (16)	76 (22)		
Age at onset: n (%)				
Before elementary school	90 (56)	183 (54)	6.594	0.159
Lower grades of elementary school	28 (18)	46 (13)		
Higher grades of elementary school	17 (11)	36 (11)		
Junior high school	17 (11)	39 (11)		
Senior high school and thereafter	7 (4)	37 (11)		
Stage of therapy at first examination: n (%)				
No therapy	79 (50)	189 (56)	2.061	0.357
Hormonal therapy without genital surgery	54 (34)	110 (32)		
With genital surgery	26 (16)	42 (12)		
Level of education: n (%)				
University or higher	25 (16)	112 (33)	21.655	<0.001
High school	104 (65)	199 (58)		
Junior high school	30 (19)	30 (9)		
Steady partner: n (%)				
Present	85 (53)	181 (53)	0.006	0.937
Absent	74 (47)	160 (47)		
Job: n (%)				
Employed	111 (70)	243 (71)	0.110	0.740
Unemployed	48 (30)	98 (29)		

might influence the high prevalence rate of suicidal ideation among GID patients.

Younger age and higher stage of therapy at first examination were associated with suicidal ideation among MTF GID patients in the present study. Younger age was reported to be significantly associated with the prevalence of suicidal attempt among GID patients (Clements-Nolle et al., 2006). GID patients at younger age may be vulnerable to gender-based harassment. MTF GID patients with hormonal therapy and/or genital surgery showed a higher prevalence of suicidal ideation in our study. More severe distress with suicidal ideation may induce a strong desire and real actions to receive a higher stage of therapy. However, we cannot clarify why younger age

Table 5
Multiple logistic regression analysis of factors affecting self mutilation.

	B	Standard error	P	Odds ratio	95% confidence interval of odds ratio	
					Lower	Upper
MTF						
Level of Education	-0.966	0.268	0.000	0.381	0.225	0.643
Age at onset	-0.336	0.114	0.003	0.714	0.572	0.893
Constant	2.296	0.710	0.001			
FTM						
Level of Education	-0.677	0.223	0.002	0.508	0.328	0.786
Constant	0.625	0.464	0.179			

MTF, male to female type.
-2 log likelihood = 213.842; Model $\chi^2 = 22.386$ ($p < 0.001$).
Prediction equation: $p = 1/[1 + \exp(-1 \times \text{Score})]$.
Score = $-0.966 \times \text{Level of education} - 0.336 \times \text{Age at onset} + 2.296$.
FTM, female to male type.
-2 log likelihood = 379.407; Model $\chi^2 = 9.718$ ($p = 0.002$).
Prediction equation: $p = 1/[1 + \exp(-1 \times \text{Score})]$.
Score = $-0.677 \times \text{Level of education} + 0.625$.
Level of education; Junior high school = 1, High school = 2, University or higher = 3.
Age at onset; Before elementary school = 1, Lower grades of elementary school = 2.
Higher grades of elementary school = 3, Junior high school = 4, Senior high school and thereafter = 5.

and higher stage of therapy were related to prevalence of suicidal ideation, only among MTF GID patients.

4.2. Self-mutilation

The prevalence of suicidal attempt among 515 GID patients was reported to be 32% (MTF, 32%; FTM, 32%) (Clements-Nolle et al., 2006). Younger age (<25 years), depression, substance abuse treatment, forced sex, gender-based discrimination, and gender-based victimization were independently associated with suicidal attempt (Clements-Nolle et al., 2006). In another study, the lifetime prevalence of suicidal attempt was reported to be 23.3% among 73 GID patients (Mathy, 2003). Attempters were more likely than non-attempters to report psychiatric medications as well as difficulties with alcohol and/or drugs (Mathy, 2003). The prevalence of suicidal ideation and suicidal attempt among GID patients was reported to decrease dramatically after SRS (Imbimbo et al., 2009).

In this study, the prevalence rate of self-mutilation including suicide attempt was high among both MTF and FTM GID patients (31.7% in MTF, and 31.8% in FTM GID patients), and similar to that in the study by Clements-Nolle et al. However, in this study, the presence or absence of forced sex, gender-based discrimination and gender-based victimization was not estimated. GID patients with psychiatric comorbidity were not included. Therefore, most of the risk factors reported in their study could not be assessed.

The prevalence rate of self-mutilation was higher among GID patients with less education. Multiple logistic regression analysis revealed that low level of education was a significant factor affecting self-mutilation. The intimate relationship of low level education to suicidal attempt was reported (Ozdel et al., 2009; Tang et al., 2009). The majority of suicide attempters were characterized by low educational status (Ozdel et al., 2009), and dropout from school was associated with suicidal attempt (Tang et al., 2009). A lack of strategies to cope with severe distress among persons with lower education might induce a high frequency of self-mutilation including suicidal attempt (Ozdel et al., 2009; Tang et al., 2009). In GID patients with a low education level, special attention should be paid to the possibility of self-mutilation.

Besides low level of education, younger age at onset was independently associated with self-mutilation among MTF GID patients. Severe distress in childhood might influence the prevalence of self-mutilation (Tang et al., 2009). However, we cannot clarify why younger age at onset was related to prevalence of suicidal ideation, only among MTF GID patients.

4.3. Limitation of this study

Several limitations of this study have to be considered. Firstly, it is a clinic-based study rather than a field study. Therefore, the sample is large, but not necessarily representative of all GID individuals. As stated above, in this study, 60.3% were FTM GID patients, and 39.7% were the MTF type. This proportion is not common in studies on GID. Secondly, the data were based on retrospective self-reporting of the occurrence and timing of suicide-related outcomes and mental disorders, and thus may be subject to underreporting and biased recall. We could not collect information from third-party informants to validate the respondents' reports. Thirdly, we were unable to clarify the frequency of self-mutilation. Therefore, for example, GID patients

reporting self-mutilation include both those with only one instance of self-mutilation and frequent self cutters. Fourth, psychiatric comorbidity was diagnosed according to DSM-IV, but the structured interview for DSM-IV was not used. Regarding the results of Hepp et al. (2005) who found a comorbidity rate of 39% (12/31) using the structured clinical interview, a comorbidity rate of 14% (79/579) in this study was low. The possibility that clinical diagnosis without a structured interview missed psychiatric comorbidity cannot be denied. Further investigation is needed to clarify in more detail the relationship of suicidal ideation and self-mutilation to various risk factors.

Despite these limitations, this is the first report to clarify the prevalence of and risk factors for suicidal ideation and self-mutilation including suicide attempt among GID patients outside of North America and Western Europe.

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Kana Pick-out Test and brain perfusion imaging in Alzheimer's disease

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ABSTRACT

Background: The Kana Pick-out Test (KPT), which was developed in Japan, is suitable for evaluating frontal lobe function and screening for mild dementia. However, the neural substrates involved remain to be elucidated. The aim of the present study was to identify the regional perfusion patterns in the brain associated with performance scores on the KPT in patients with mild Alzheimer's disease (AD), using brain perfusion assessed by single photon emission computed tomography (SPECT).

Methods: Twenty AD patients with high scores on the KPT and 20 age- and sex-matched AD patients with low scores were selected from 227 consecutive Japanese patients of the Memory Clinic of Okayama University Hospital. All 40 subjects underwent brain SPECT with 99mTc-ethylcysteinate dimer, and the SPECT images were analyzed by Statistical Parametric Mapping.

Results: With the exception of KPT scores, no significant differences were found between high and low scoring groups with respect to Addenbrooke's Cognitive Examination scores, Mini-mental State Examination scores, or the depression score of the Neuropsychiatric Inventory subscale. Compared to patients with high scores on the KPT, AD patients with low scores on the KPT showed significant hypoperfusion in the left subgenual cingulate gyrus (SGC) extending to the right SGC.

Conclusions: Our results suggest that functional activity of the SGC is closely related to scores on the KPT. KPT might be a promising strategy to use in detecting early stages of AD with low SGC function.

Key words: Alzheimer's disease (AD), cerebral blood flow (CBF), Kana Pick-out Test (KPT), single photon emission computed tomography (SPECT), Statistical Parametric Mapping (SPM)

Introduction

The Kana (Japanese syllabogram) Pick-out Test (KPT) was developed to evaluate frontal lobe function easily and quickly at the bedside (Kaneko, 1996). The test is said to be suitable for inspecting higher-order brain function and to be a good method for screening persons with mild or slight dementia (Inoue *et al.*, 2003). Although the clinical usefulness of the KPT in dementia is well documented, the neural substrates involved remain unclear. There are few functional neuroimaging studies investigating brain regions related to the KPT performance of dementia patients (Nakatsuka

et al., 2003; Tachibana *et al.*, 2007). In the present study we investigated the relationship of KPT scores to regional cerebral blood flow (rCBF) in order to assess the neural substrates of KPT performance in patients with mild Alzheimer's disease (AD).

In most neuroimaging studies in which rCBF was evaluated, stereotaxic analysis of regions of interest (ROIs) was used. However, the reproducibility and objectivity of the results are controversial because small ROIs were manually placed on selected slices of single photon emission computed tomography (SPECT) images of the patient. Image analysis using ROIs has been criticized for the serious shortcoming that any information outside of the ROIs is not obtained. To overcome the above disadvantages, in the present study we conducted an evaluation using statistical parametric mapping (SPM) comparison which has the advantage of making no a priori anatomical hypotheses.

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