

# Characteristics and Social Support Needs Predicting Anticipatory Grief in the Spouses of Patients with Cancer at the End of Life

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## Abstract

**Background:** Medical staff provide care to spouses of terminal cancer patients through trial and error by meeting their various support needs and spousal factors regarding their anticipatory grief. Studies on the association between spousal characteristics and anticipatory grief have been inconclusive; additionally, there has been insufficient research on support needs for anticipatory grief of spouses. This study aimed to explore the spousal characteristics and social support needs predicting anticipatory grief in spouses of patients with cancer at the end of life. **Methods:** This was a cross-sectional study. Eligible spouses (n = 102) completed a self-report questionnaire in two hospitals with palliative care units in Japan. The questionnaire included demographic information, a tool assessing social support needs of spouses, and the Anticipatory Grief Scale for Family Caregivers. **Results:** Simple regression analyses indicated that patient age, chemotherapy, no treatment, ECOG PS3, children aged under 20 years, total score of “social support needs regarding the disease and treatment of the patients” and subscale scores (“medical condition and cure,” “daily life and social support,” and “intimacy and employment”), and total score of “social support needs of the spouses” and subscale

scores (“family psychological issues and social support” and “intimacy, employment, and society”) were significant variables (all  $p < 0.05$ ) for the multiple regression analysis. Multiple regression analyses revealed that “chemotherapy” and “social support needs of the spouses” in Model 1, and “family psychological issues and social support” in Model 2 significantly predicted anticipatory grief (all  $p < 0.05$ ). **Conclusions:** Patients having no experience of “chemotherapy” and higher “social support needs of the spouses” in Model 1, and greater spousal needs of “family psychological issues and social support” in Model 2 were significant predictors of severe anticipatory grief. Medical staff should pay attention to these risk factors that predict anticipatory grief among spouses.

## Keywords

Cancer, Spouse, Spousal Characteristics, Social Support Needs, Anticipatory Grief

## 1. Introduction

The loss of a loved one is an extremely tragic experience for a family; specifically, the death of a spouse ranks as the most stressful life event [1]. In the field of psycho-oncology, it is well-known that spouses’ demise is a predictor of being at a higher risk for developing complicated grief [2] [3] [4] and a greater level of depressive symptoms after bereavement [5].

Psychological distress and a comprehensive response before patients’ death experienced by their spouses is referred to as “anticipatory grief.” Lindemann (1944) first coined this term to explain the grief responses he observed in people who were not bereaved [6] [7]. He explained that anticipatory grief might work as a safeguard against the impact of a sudden death notice, using an instance where a soldier had just returned from the battlefield and complained that his wife did not love him anymore and demanded immediate divorce as grief work [6]. Lebow (1976) defined “anticipatory mourning” as “the total set of cognitive, affective, cultural, and social reactions to expected death felt by the patient and family” [8]; moreover, he designated “anticipatory grieving” as “that portion of anticipatory mourning involving the affective responses” [8]. While all emotions in response to the threat of losing a loved one are an aspect of anticipatory grief, the main ones are sorrow, depression, and anxiety [9]. Anticipatory grief has been found to be significantly correlated with depression (history of/current depression) [10] [11] and subjective stress [10]; furthermore, it may be a risk factor for poor early bereavement adjustment [10].

Additionally, anticipatory grief measured at the point of time of a patient’s admission to palliative care was a highly, statistically significant predictor of prolonged grief disorder in the long-term [12]; its symptoms appeared to persist for at least three years after bereavement for almost 20% of caregivers [12]. This situation indicated that an intervention for anticipatory grief might be an effec-

tive prevention against prolonged grief disorder for the bereaved. However, medical staff provide care to spouses by trial and error in clinical settings because there are many spousal support needs and various spousal-related factors of their anticipatory grief.

Studies on the association between spousal characteristics and anticipatory grief have been inconclusive. For example, a study demonstrated that caregivers aged below 60 years of terminally ill cancer patients, had higher levels of complicated grief pre-death than did those aged 60 years and above [11]; however, another study found that being 61 years or above was a predictor of an increased risk of complicated grief among the bereaved [4]. Additionally, each person's grief reaction would be idiosyncratic, determined by a unique combination of psychological, social, and physiological factors [9]. In addition to assessing the variables of individual family members, we must analyze those describing the family constellation, the family system's functioning, and the impact of the dying patient and his terminal illness on the family [9]. There are various spousal-related factors affecting anticipatory grief. Thus, it is important to understand the aspects of the spousal characteristics that predict anticipatory grief for evidence-based, appropriate assessments and interventions.

Perceived social support significantly correlates with complicated grief pre-death [11]. In addition, the assistance of a family member in differentiating his own needs from those of the patient is a treatment goal of remaining psychologically separate from the patient [8]; additionally, the assessment of the family's needs is an important first step in supporting their anticipatory grief [7] [9]. However, there are limited studies on the spouse's social support needs regarding anticipatory grief. Therefore, we considered it is necessary to explore the spousal characteristics and social support needs predicting anticipatory grief among spouses to provide appropriate care formulated for anticipatory grief and prevent complicated and prolonged grief after the patients' loss.

In a preliminary survey [13], we developed an original tool to assess social support needs of Japanese spouses based on the Social Problem Checklist (SPC) for Japanese patients with cancer [14] [15] to provide specific care related to individual spousal needs. In this study, we employed a novel measure to assess social support needs of spouses. Furthermore, we explored the spousal characteristics and social support needs predicting anticipatory grief in spouses of patients with cancer at the end of life.

## 2. Methods

### 2.1. Participants

We administered a self-report questionnaire to 138 spouses of cancer patients between September 6, 2017, and August 7, 2020, at the palliative care and general wards (the department of palliative care) of the Heiwa Hospital and the palliative care ward of the Cancer Institute Hospital of the Japanese Foundation for Cancer Research (JFCR). The former is a community-based hospital since 1946 and the latter is Japan's first specialized hospital for cancer. There were no sig-

nificant differences in anticipatory grief among spouses of patients in the two hospitals.

The inclusion criteria were as follows: spouses of cancer patients, prognosis within 6 months until the patients' death as assessed by their doctor, aged 20 to 79 years, able to cooperate with this study as determined by their doctor, capable of completing a questionnaire in Japanese, Japanese, and provided informed consent. The exclusion criteria were as follows: unable to cooperate with this research as determined by their doctor, incapable of filling out a questionnaire in Japanese, not Japanese, having a severe mental illness, and inability to provide informed consent.

Of 138 eligible participants, 111 returned the questionnaire (initial response rate = 80.4%). Of these, 102 spouses were included in the analyses (final response rate = 73.9%) after excluding those who had over 50% missing data on either of the two psychological scales following the recommendation [16]. Subsequently, the mean values of the subscale items that were available were substituted for the remaining missing items [16].

## 2.2. Procedures

This was a cross-sectional survey. The palliative care doctors (HS/RV/ST/YS/KK/OT) informed the appropriate spouses about this research and inquired if they would be willing to be approached by the first author, who is a researcher, and a clinical psychologist (KA). Subsequently, the first author approached these identified spouses to explain this study's purpose and procedures using verbal and written explanations and obtained their permission to partake using an informed consent form. Furthermore, the first author explained that they could discontinue answering the survey form if they wished.

We designed the survey as "the questionnaire for the spouses' stress and support." Participants were asked to complete a 10- to 30-min anonymous questionnaire at the hospital or their home. They either submitted their answered questionnaires to hospital staff or mailed them to the laboratory of the Liaison Psychiatry and Psycho-oncology Unit of the Tokyo Medical and Dental University.

This study was approved by the Medical Research Ethics Committee of the Tokyo Medical and Dental University (M2017-013), the Heiwa Hospital (20170801), and the Cancer Institute Hospital of the JFCR (0137).

## 2.3. Measured Items

### 2.3.1. Demographic and Medical Information (22 Items)

Demographic data (12 items) included the following: hospital ID; spouse's sex; patient's age; spouse's age; relationship with the patient; spousal occupation; spousal educational background; living separately or jointly with the patient; presence or absence of a housemate/housemates other than the patient; familial situation of a housemate/housemates other than the patient; presence or absence of a child/children; and the number and age of children. These data were collected from the questionnaires and patients' case records.

Additional medical information (10 items) comprising the following: primary site of cancer; multiple primary cancers (two cancer sites); previous cancer; previous treatment; treatment status; recurrence/metastasis; ECOG performance status (ECOG: Eastern Cooperative Oncology Group, see **Table 1**); period between cancer's occurrence and the present time; disclosed prognosis to the spouse; and duration between prognostic disclosure to the spouse and the present time. These data were collected from patients' case records.

### **2.3.2. Tool to Assess Social Support Needs of Spouses of Patients with Cancer (73 Items)**

In our preliminary survey, the tool to examine social support needs of spouses of patients with cancer was a 73-item self-rating scale [13]. This original assessment tool was based on the SPC for Japanese patients with cancer [14] [15].

This measure uses a six-point Likert scale ranging from zero (inapplicable) to one (extremely satisfied), two (solved by myself), three (a little), four (quite a lot), or five (very much); we modified these scores based on our preliminary survey's questionnaire [13] to those corresponding to their word meanings because it was easy for participants to answer in clinical settings. We scored each response category as follows: four (very much), three (quite a lot), two (a little), one (solved by myself, extremely satisfied), or zero (inapplicable).

This scale comprises two domains and five factors: (1) Social support needs regarding the disease and treatment of the patients (54 items): "Medical Condition and Cure" (22 items); "Daily Life and Social Support" (25 items); and "Intimacy and Employment" (7 items). The total score of "social support needs regarding the disease and treatment of the patients" can range from 0 - 216. (2) Social support needs of the spouses (19 items): "Family Psychological Issues and Social Support" (14 items); and "Intimacy, Employment, and Society" (5 items). The total score of "social support needs of the spouses" ranges from 0 - 76. "Social support needs regarding the disease and treatment of the patients" entails spousal social support requirements regarding the patients' illness and treatment. In contrast, "social support needs of the spouses" denotes spouses' social support necessities.

In the present study, Cronbach's alpha coefficients for social support needs regarding the disease and treatment of the patients and social support needs of the spouses were 0.96 (0.89 - 0.96 for the subscales) and 0.88 (0.70 - 0.90 for the subscales), respectively.

### **2.3.3. Anticipatory Grief Scale for Family Caregivers (19 Items)**

We used the 19-item Anticipatory Grief Scale for Family Caregivers (AGSFC) [17] to assess participants' anticipatory grief. We chose this scale because it is useful for Japanese families of terminally ill cancer patients; furthermore, the small number of items is less demanding for participants. Additionally, its reliability (Cronbach's alpha: 0.87 (0.70 - 0.85 for the subscales)) as well as the criterion-related and construct validity were confirmed.

The AGSFC has four factors: spiritual pain in preparing for a loss (6 items),

physical and mental fatigability in daily life (6 items), precedent anxiety regarding bereavement (4 items), and exhaustion (3 items). Subscale items are rated on four-point Likert scales, ranging from zero (not at all) to one (a little), two (quite a lot), or three (very much); the total score ranges from 0 to 57. Higher scores indicate more severe levels of anticipatory grief. Cutoff points were as follows: below 25 (not severe), 25 to 34 (somewhat severe), and 35 and above (severe). In a previous study, these cutoff points were based on the distribution curve of the scores by comparing families of patients with terminal and non-terminal diseases [17]. In the present study, Cronbach's alpha coefficient was 0.90 (0.76 - 0.81 for the subscales).

## 2.4. Statistical Analysis

The demographic and clinical characteristics of participants and the study variables were summarized using descriptive statistics (Table 1 and Table 2, respectively). The characteristics and social support needs predicting anticipatory grief were assessed using simple and multiple regression analyses (Table 3 and Table 4, respectively).

In these analyses, the following variables were represented by dummy-coded variables: hospital ID (the Heiwa Hospital = 1, the Cancer Institute Hospital of the JFCR = 0); spousal sex (male = 1, female = 0); primary site of cancer (e.g., having gastrointestinal cancer = 1, not having gastrointestinal cancer = 0); multiple primary cancers (yes = 1, no = 0); having had a previous cancer/cancers (yes = 1, no = 0); the content of previous cancer (e.g., having gastrointestinal cancer = 1, not having gastrointestinal cancer = 0); previous treatment (e.g., receiving chemotherapy = 1, not receiving chemotherapy<sup>1</sup> = 0); treatment status (e.g., being under treatment = 1, not being under treatment = 0); recurrence/metastasis (yes = 1, no = 0); ECOG performance status (PS) (see Table 1) (e.g., being PS 1 and 2 = 1, not being PS 1 and 2 = 0); period between cancer's occurrence and the present time (e.g., under three years = 1, three years and more = 0); disclosed prognosis to the spouse (e.g., two weeks or less = 1, over two weeks and uninformed = 0); period between prognostic disclosure to the spouse and the present time (e.g., under two weeks = 1, two weeks or more and uninformed = 0); having a child/children (yes = 1, no = 0); the number of children (e.g., having only one child = 1, having two or three children and not having any children = 0); children's age (e.g., aged under 20 s = 1, aged 20 years or more = 0); having a housemate/housemates other than the patient (yes = 1, no = 0); familial situation of a housemate/housemates other than the patient (e.g., living with a child/children = 1, not living with a child/children = 0); spousal occupation (e.g., having a full-time job = 1, not having a full-time job = 0); and spousal education (e.g., junior high school graduate = 1, not a junior high school graduate = 0).

All the data were statistically analyzed using SPSS version 23.0 (IBM, Armonk, NY, USA).

<sup>1</sup>Not receiving chemotherapy: Patients who have not received chemotherapy have received other treatments (surgery, radiation, and other pharmacotherapies) or have not received any treatment (no treatment).

### 3. Results

#### 3.1. Demographic and Medical Information of Participants

We distributed the questionnaires to 138 participants and analyzed 102 that were answered and returned (valid response rate = 73.9%). **Table 1** shows their demographic and clinical characteristics.

There were 58 (56.9%) and 44 (43.1%) spouses in the Heiwa Hospital and the Cancer Institute Hospital of the JFCR, respectively. About one-quarter of them were males ( $n = 26$ , 25.5%). The mean ages of patients and spouses were 68.3 years (range 40 - 83) and 66.3 years (range 40 - 79), respectively. Patients were divided into the following age groups: 40 s and 50 s ( $n = 17$ , 16.7%), 60 s ( $n = 30$ , 29.4%), 70 s ( $n = 48$ , 47.1%), and 80 s ( $n = 7$ , 6.9%). Furthermore, spouses were divided into the following age groups: 40 s and 50 s ( $n = 18$ , 17.6%), 60 s ( $n = 45$ , 44.1%), and 70 s ( $n = 39$ , 38.2%).

Current cancers were divided into primary site of cancer ( $n = 96$ , 94.1%) and multiple primary cancers (two cancer sites) ( $n = 6$ , 5.9%). The former comprised gastrointestinal ( $n = 27$ , 26.5%), hepatobiliary and pancreatic ( $n = 21$ , 20.6%), thoracic ( $n = 17$ , 16.7%), female-specific ( $n = 15$ , 14.7%), head and neck ( $n = 6$ , 5.9%), and other cancers ( $n = 10$ , 9.8%).

Only 17 (16.7%) of spouses whose patients had previous cancers, divided into gastrointestinal ( $n = 12$ , 11.8%) and other cancers ( $n = 9$ , 8.8%).

Previous treatments included surgery ( $n = 59$ , 57.8%), chemotherapy ( $n = 90$ , 88.2%), radiation ( $n = 40$ , 39.2%), and other pharmacotherapies including hormone therapy and immunotherapy ( $n = 16$ , 15.7%). There were some untreated cases ( $n = 3$ , 2.9%). The treatment status of nearly all patients was completed and discontinued ( $n = 100$ , 98.0%), except for those who were under treatment ( $n = 2$ , 2.0%).

Overall, 92.2% of patients ( $n = 94$ ) had recurrence/metastasis and 85.3% ( $n = 87$ ) were PS3 and over on ECOG performance status (PS, see **Table 1**). Moreover, for approximately 60% of patients, the period between cancer's occurrence and the present time was under 3 years ( $n = 62$ , 60.8%).

During this survey, the disclosed prognosis to 83.3% of the spouses divided into 2 weeks or under ( $n = 36$ , 35.3%) and 1 - 3 months ( $n = 49$ , 48.0%); only 11 (10.8%) were uninformed. For over 60% of participants, the period between prognostic disclosure to the spouse and the present time was under 2 weeks ( $n = 63$ , 61.8%).

Furthermore, 88.2% of spouses ( $n = 90$ ) had a child or children, while 56.9% ( $n = 58$ ) had two. Children were divided into the following age groups: below 20 years ( $n = 7$ , 6.9%); 20 s and 30 s ( $n = 56$ , 54.9%); 40 s and 50 s ( $n = 52$ , 51.0%), and no answer ( $n = 1$ , 1.0%). All participants lived together with the patients ( $n = 102$ , 100.0%) and 42.2% ( $n = 43$ ) had a housemate or housemates other than the patient. Additionally, 37.3% ( $n = 38$ ) resided with their child or children; 34.3% ( $n = 35$ ) and 38.2% ( $n = 39$ ) were full- or part-time employees and homemakers, respectively. Half (50.0%) of all participants ( $n = 51$ ) were high school graduates.

**Table 1.** Demographic and clinical characteristics of participants (n = 102).

<b>Variables</b>	<b>Means (SD) or numbers (%)</b>
<b>Hospital</b>	
Heiwa Hospital	58 (56.9%)
Cancer Institute Hospital of JFCR	44 (43.1%)
<b>Male spouse</b>	
	26 (25.5%)
<b>Patient age (y), Mean (SD), [Min - Max]</b>	68.3 (8.6), [40-83]
40 s and 50 s	17 (16.7%)
60 s	30 (29.4%)
70 s	48 (47.1%)
80 s	7 (6.9%)
<b>Spouse age (y), Mean (SD), [Min - Max]</b>	66.3 (7.8), [40-79]
40 s and 50 s	18 (17.6%)
60 s	45 (44.1%)
70 s	39 (38.2%)
<b>Current cancer</b>	
<b>Primary site of cancer<sup>1</sup></b> (without multiple primary cancers)	
Gastrointestinal cancer <sup>2</sup>	27 (26.5%)
Hepatobiliary and pancreatic cancer <sup>3</sup>	21 (20.6%)
Thoracic cancer <sup>4</sup>	17 (16.7%)
Female-specific cancer <sup>5</sup>	15 (14.7%)
Head and neck cancer <sup>6</sup>	6 (5.9%)
Other cancers <sup>7</sup>	10 (9.8%)
<b>Multiple primary cancers</b> (multiple answers)	6 (5.9%)
<b>Previous cancer<sup>1</sup></b> (multiple answers)	
Gastrointestinal cancer <sup>8</sup>	12 (11.8%)
Other cancers <sup>9</sup>	9 (8.8%)
<b>Previous Treatment</b> (multiple answers)	
Surgery	59 (57.8%)
Chemotherapy	90 (88.2%)
Radiation	40 (39.2%)
Other pharmacotherapies <sup>10</sup>	16 (15.7%)
No treatment	3 (2.9%)
<b>Treatment Status</b>	
Under treatment	2 (2.0%)
Treatment completed and stopped	100 (98.0%)



## Continued

<b>Recurrence/metastasis</b>	
Yes	94 (92.2%)
<b>ECOG Performance status<sup>11</sup></b>	
PS 0	0 (0.0%)
PS 1 and 2	15 (14.7%)
PS 3	37 (36.3%)
PS 4	50 (49.0%)
<b>Period between occurrence of cancer and the present time</b>	
Under 3 years	62 (60.8%)
At least 3 but less than 6 years	21 (20.6%)
6 years and over	19 (18.6%)
<b>Disclosed prognosis to the spouse</b>	
2 weeks or under	36 (35.3%)
1 month - 3 months	49 (48.0%)
4 - 6 months	6 (5.9%)
Uninformed	11 (10.8%)
<b>Period between prognostic disclosure to the spouse and the present time</b>	
Under 2 weeks	63 (61.8%)
At least 2 weeks but less than 3 months	21 (20.6%)
3 months and over	7 (6.9%)
Uninformed	11 (10.8%)
<b>Child/Children</b>	
Yes	90 (88.2%)
<b>Number of children</b>	
N = 0	12 (11.8%)
N = 1	17 (16.7%)
N = 2	58 (56.9%)
N = 3	15 (14.7%)
<b>Children's ages (y)</b> (multiple answers)	
Under 20 s	7 (6.9%)
20 s and 30 s	56 (54.9%)
40 s and 50 s	52 (51.0%)
No answer	1 (1.0%)
<b>Living together with a patient</b>	102 (100.0%)
<b>Housemate other than a patient</b> (multiple answers)	43 (42.2%)

## Continued

Child/Children	38 (37.3%)
Grandchild/Grandchildren	7 (6.9%)
Others <sup>12</sup>	9 (8.8%)
<b>Spouse's occupation</b>	
Full time job	19 (18.6%)
Part time job	16 (15.7%)
Homemaker	39 (38.2%)
Retirement <sup>13</sup>	12 (11.8%)
Unemployed	6 (5.9%)
Others <sup>14</sup>	10 (9.8%)
<b>Spouse's education</b>	
Junior high school	5 (4.9%)
High school	51 (50.0%)
Vocational school and junior college	26 (25.5%)
Higher than a college degree	18 (17.6%)
No answer	2 (2.0%)

<sup>1</sup>Cancer categorization based on the website of Division of Cancer Information Service of Center for Cancer Control and Information Services of National Cancer Center Japan [18].

<sup>2</sup>Stomach cancer, esophagus cancer, colon cancer, and duodenal carcinoma.

<sup>3</sup>Liver cancer, bile duct cancer, gallbladder cancer, and pancreas cancer.

<sup>4</sup>Lung cancer.

<sup>5</sup>Breast cancer, uterine cancer, ovarian cancer, and fallopian tube cancer.

<sup>6</sup>Larynx cancer, carcinoma of gingiva, parotid gland cancer, and pharyngeal cancer.

<sup>7</sup>Bladder cancer, kidney cancer, prostate cancer, retroperitoneal sarcoma, peritoneal cancer, and brain cancer.

<sup>8</sup>Stomach cancer, esophagus cancer, colon cancer, or any combination of these.

<sup>9</sup>Prostate cancer, liver cancer, breast cancer, uterine cancer, ovarian cancer, bladder cancer, kidney cancer, thyroid cancer, lung cancer, or any combination of these.

<sup>10</sup>Hormone therapy and immunotherapy.

<sup>11</sup>ECOG: Eastern Cooperative Oncology Group.

ECOG Performance status (PS) scores [19] [20] [21]:

PS 0: Fully active, able to carry on all pre-disease performance without restriction.

PS 1: Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work.

PS 2: Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours.

PS 3: Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours.

PS 4: Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair.

<sup>12</sup>Patient and spouse's parents, patient and spouse's grandparents, patient and spouse's siblings, and child-in-law.

<sup>13</sup>Retirement because of spouse's own request for patient's disease, mandatory age, and retirement from part time job.

<sup>14</sup>Taking a leave of absence from work due to patient's disease and other occupations (e.g., independent business, personal business, and real estate).

### 3.2. Descriptive Statistics for Study Variables

**Table 2** shows the descriptive statistics of the psychosocial scales of the sample. Regarding the AGSFC, 34.31% (n = 35) of spouses' scores indicated high anticipatory grief.

**Table 2.** Descriptive statistics for study variables (n = 102).

Variables	Means (SD) or numbers (%)	Cronbach's alpha
<b>Tool to assess social support needs of spouses of patients with cancer</b>		
<b>Social support needs regarding the disease and treatment of the patients</b>	76.90 (39.61)	0.96
Medical condition and cure	39.99 (21.64)	0.96
Daily life and social support	34.69 (19.23)	0.92
Intimacy and employment	2.22 (4.95)	0.89
<b>Social support needs of the spouses</b>	17.21 (10.67)	0.88
Family psychological issues and social support	16.80 (10.32)	0.90
Intimacy, employment, and society	0.40 (1.32)	0.70
<b>Anticipatory Grief Scale for Family Caregivers (AGSFC)</b>	28.99 (11.36)	0.90
Spiritual pain in preparing for a loss	11.55 (4.36)	0.80
Physical and mental fatigability in daily life	6.83 (4.16)	0.81
Precedent anxiety regarding bereavement	6.68 (3.19)	0.80
Exhaustion	3.92 (2.49)	0.76
AGSFC high ( $\geq 35$ ), n (%)	35 (34.31%)	
AGSFC middle (25 to 34), n (%)	33 (32.35%)	
AGSFC low (<25), n (%)	34 (33.33%)	

### 3.3. Simple and Multiple Regression Analyses for Variables Predicting Anticipatory Grief

**Table 3** and **Table 4** present the results of the simple and multiple regression analyses, respectively. The latter were conducted simultaneously to assess significant variables predicting anticipatory grief.

We employed simple regression analyses to determine the significant independent variables with respect to AGSFC total score as the dependent variable for the

multiple regression analysis. Demographic and clinical characteristics of participants, total score of “social support needs regarding the disease and treatment of the patients,” subscale scores (“medical condition and cure,” “daily life and social support,” and “intimacy and employment”), total score of “social support needs of the spouses,” and subscale scores (“family psychological issues and social support” and “intimacy, employment, and society”) were entered into the simple regression analyses with AGSFC total score as the dependent variable. Among the independent variables, patient age, chemotherapy, no treatment, ECOG PS3 in patients, children aged under 20 years, total score of “social support needs regarding the disease and treatment of the patients” and subscale scores (“medical condition and cure,” “daily life and social support,” and “intimacy and employment”), and total score of “social support needs of the spouses” and subscale scores (“family psychological issues and social support” and “intimacy, employment, and society”) were significant variables with respect to AGSFC total score for the multiple regression analysis (all  $p < 0.05$ ; **Table 3**).

**Table 4** displays the result of the multiple regression models for the independent variables predicting anticipatory grief. We conducted simultaneous multiple regression analyses to examine the significant independent variables predicting spousal AGSFC total score as the dependent variable. Multicollinearity was not a problem as all independent variables in Models 1 and 2 had  $|r| < 0.9$  and VIF  $< 10$  [22].

First, to explore the spousal characteristics and total scores of social support needs predicting anticipatory grief, patient age, chemotherapy, no treatment, ECOG PS3 in patients, children aged below 20 years, total score of “social support needs regarding the disease and treatment of the patients,” and overall score of “social support needs of the spouses” were entered simultaneously into the multiple regression analysis with AGSFC total score as the dependent variable. Among the independent variables, chemotherapy and total score of “social support needs of the spouses” significantly predicted the value of AGSFC total score (both  $p < 0.05$ ). This model accounted for an adjusted value of 37% of the variance in spousal AGSFC total score (Model 1, **Table 4**).

Second, to examine the spousal characteristics and subscale scores of social support needs predicting anticipatory grief, patient age, chemotherapy, no treatment, ECOG PS3 in patients, children aged under 20 years, and subscale scores of “social support needs regarding the disease and treatment of the patients” (“medical condition and cure,” “daily life and social support,” and “intimacy and employment”) and “social support needs of the spouses” (“family psychological issues and social support” and “intimacy, employment, and society”) were entered simultaneously into the multiple regression analysis with AGSFC total score as the dependent variable. Among the independent variables, “family psychological issues and social support” significantly predicted the value of AGSFC total score ( $p < 0.05$ ), in which this model accounted for an adjusted value of 35% of the variance in spousal AGSFC total score (Model 2, **Table 4**).

**Table 3.** Summary of simple regression analyses for variables predicting anticipatory grief (n = 102).

Variables	B (95% CI)		R <sup>2</sup>	p
<b>Patient's age</b>	-0.28	(-0.53, -0.02)	0.04	0.037*
<b>Previous Treatment</b>				
Surgery	1.09	(-3.45, 5.62)	0.00	0.635
Chemotherapy	-9.06	(-15.78, -2.34)	0.07	0.009*
Radiation	-2.57	(-7.14, 1.99)	0.01	0.266
Other pharmacotherapies <sup>a</sup>	1.00	(-5.16, 7.16)	0.00	0.748
No treatment	13.34	(0.33, 26.34)	0.04	0.045*
<b>ECOG Performance status</b>				
PS 1 and 2	-6.04	(-12.25, 0.18)	0.04	0.057
PS 3	5.25	(0.70, 9.79)	0.05	0.024*
PS 4	-1.82	(-6.29, 2.65)	0.01	0.421
<b>Children's ages</b>				
Under 20 s <sup>b</sup>	9.97	(1.28, 18.66)	0.05	0.025*
20 s and 30 s <sup>b</sup>	-1.34	(-5.89, 3.21)	0.00	0.561
40 s and 50 s <sup>b</sup>	-3.76	(-8.23, 0.71)	0.03	0.098
<b>Social support needs regarding the disease and treatment of the patients</b>	0.15	(0.10, 0.20)	0.27	<0.001*
Medical condition and cure	0.20	(0.11, 0.30)	0.15	<0.001*
Daily life and social support	0.32	(0.22, 0.42)	0.30	<0.001*
Intimacy and employment	0.74	(0.31, 1.17)	0.10	0.001*
<b>Social support needs of the spouses</b>	0.61	(0.43, 0.78)	0.32	<0.001*
Family psychological issues and social support	0.61	(0.43, 0.79)	0.31	<0.001*
Intimacy, employment, and society	2.24	(0.59, 3.88)	0.07	0.008*

\* $p < 0.05$ . <sup>a</sup>Hormone therapy and immunotherapy; <sup>b</sup>n = 101.

**Table 4.** Models of multiple regression analyses for variables predicting anticipatory grief (n = 101).

Variables	B (95% CI)		$\beta$	Adjusted R <sup>2</sup>	p
<b>Model 1</b>					
Patient's age	-0.05	(-0.31, 0.22)	-0.03	0.37	0.741
Chemotherapy	-6.91	(-13.49, -0.33)	-0.20		0.040*
No treatment	2.11	(-10.11, 14.32)	0.03		0.733
ECOG PS3	3.12	(-0.70, 6.93)	0.13		0.109

**Continued**

Children's age: under 20 s	4.28	(-4.56, 13.12)	0.10		0.339
Social support needs regarding the disease and treatment of the patients	0.03	(-0.04, 0.10)	0.10		0.441
Social support needs of the spouses	0.46	(0.20, 0.72)	0.43		0.001*
<b>Model 2</b>					
Patient's age	-0.04	(-0.31, 0.24)	-0.03		0.787
Chemotherapy	-6.66	(-13.45, 0.14)	-0.19		0.055
No treatment	3.31	(-9.36, 15.98)	0.05		0.605
ECOG PS3	3.26	(-0.61, 7.13)	0.14		0.098
Children's age: under 20 s	2.66	(-7.91, 13.22)	0.06		0.618
Medical condition and cure	0.02	(-0.10, 0.14)	0.04	0.35	0.762
Daily life and social support	0.00	(-0.21, 0.21)	0.00		0.999
Intimacy and employment	0.26	(-0.22, 0.74)	0.11		0.292
Family psychological issues and social support	0.49	(0.16, 0.81)	0.44		0.004*
Intimacy, employment, and society	0.51	(-1.35, 2.38)	0.06		0.588

\* $p < 0.05$ .**4. Discussion**

This study suggested that patients having no experience of “chemotherapy” and higher “social support needs of the spouses” in Model 1, and greater spouses’ needs for “family psychological issues and social support” in Model 2 significantly predicted severe anticipatory grief among participants. To the best of our knowledge, it is the first demonstration of the association between patients’ experience of chemotherapy and spousal anticipatory grief. Furthermore, spouses’ own social support needs predicted spousal anticipatory grief at the end of life.

First, in Model 1, the data suggested that “chemotherapy,” as patients’ previous treatment, was a significant predictor for participants’ anticipatory grief. Although there was no significant association between the two variables in Model 2, chemotherapy might have potentially predicted spousal anticipatory grief. Significant association between the two variables “chemotherapy” and “anticipatory grief” was observed in Model 1 and the B coefficient (partial regression coefficient) of “chemotherapy” in Model 2 was clinically meaningful ( $B = -6.66$ ). Additionally, its  $p$  value was 0.055, which was close to the significant  $p$  value 0.05 in Model 2. We therefore considered this finding from the following two possible perspectives: “communication with the multidisciplinary team during chemotherapy” and “spousal fulfillment and regret.”

In the first perspective, the spouses of those cancer patients having previous experiences of chemotherapy might have opportunities to consult the multidisciplinary chemotherapy staff regarding the treatment's side-effects and mental strain more than the spouses of those who did not undergo chemotherapy. Recently, the multidisciplinary team approach is advocated in cancer practice, including treatment decision-making [23] [24], adverse event management [24], and psychological intervention [23]. Specifically, this method during chemotherapy has become prevalent in Japan [25] [26]. Moreover, good communication with the multidisciplinary team during chemotherapy might reduce patients' anxiety toward the process. Another study showed that effective communication with doctors and nurses promotes chemotherapy utilization, for example, decision-making to undergo chemotherapy and dispelling negative expectations of the process of chemotherapy in patients with breast cancer [27]. However, poor communication with physicians proved to be a barrier [27]. These communications might affect not only the patients, but also their spouses. Consequently, good communication of the chemotherapy multidisciplinary team with patients and spouses might alleviate the latter's anticipatory grief during the terminal period.

In the second possible perspective, the previous experience of chemotherapy of patients with cancer might promote their spouses' fulfillment and reduce regret. Because they felt confident and had a sense of control regarding caregiving, did their best for patients by making them receive a standard cancer treatment, participated in decision-making regarding whether patients should undergo chemotherapy, and supported the process of chemotherapy including its side-effects and patients' daily life. Caregivers' confidence increased in recognizing and addressing the important side-effects at the mid-point of chemotherapy [28]; furthermore, the caregiving process became a routine or a second nature for them until the completion of chemotherapy [28]. By the mid-point of chemotherapy, for some caregivers, the treatment's routine and the familiarity of the associated symptom patterns reduced their uncertainty [28]. Although caregiving and the demands of patients' treatment remained unremitting, understanding the happenings provided a sense of control [28]. Additionally, strong promoters of chemotherapy use had family support (e.g., spousal participation in decision-making regarding undergoing chemotherapy or insisting the patient do so) and patients' positive attitudes about and perceptions of the effects and benefits of chemotherapy (e.g., the reality of undergoing chemotherapy was better than that expected) [27]. Therefore, spouses might have less regret at the patients' end of life because they could join and support essential decision-making processes when the latter choose to receive chemotherapy; further, they may find it easier to provide care than expected. Another study reported that bereaved caregivers of patients with advanced cancers experience gratitude, fulfillment, and peace from spending time with the latter and knowing that they were doing their best for them [29]. This positive experience of caregivers with patients transitioned from the active cancer treatment to the end of life [29]. It may apply to those spouses whose pa-

tients underwent chemotherapy because they could overcome a critical treatment period together while doing their best for them. This experience might reduce spousal regret as a reaction of anticipatory grief at the patients' terminal period. Barriers to chemotherapy use, however, include excessive information and that anxiety interfering with patients' ability to read materials about cancer, troublesome feelings experienced on obtaining information about chemotherapy from other cancer patients, and negative perception of the process based on family and other patients' illness experiences and historical background [27]. Risk factors associated with refusal of anti-cancer treatments including surgery, chemotherapy, radiation, or any combination of these were old age, low educational status, less weight, and poor performance status in lung cancer [30]. Characteristics associated with being untreated included advanced age, Black race, unmarried status, and insufficient private insurance for head and neck cancer [31]. Median survival for untreated patients across the cohort was 12 months, as compared to 100 months for treated patients in head and neck cancers [31]. Many factors might be related to untreated and refusal of anti-cancer treatments. Although there was no significant association between patients' being "untreated" and spousal anticipatory grief in our multiple regression models, spouses of patients who have not received chemotherapy may be more susceptible to regret than those of patients who have undergone it. This response may be because they were unable to convince patients to undergo this standard cancer treatment; additionally, it may be exacerbated by the fact that they could not participate in the decision-making process regarding the prognosis when patients intentionally refused chemotherapy. Further, this remorse may be associated with the decreased survival period of untreated patients. Moreover, when patients' physical conditions became exceedingly severe, resulting in an inability to receive chemotherapy, their spouses might blame themselves for failing to notice the patients' cancer symptoms sooner, and for financial unpreparedness and not having insurance for patients' treatment. Burnell and Burnell (1989) explained these emotional reactions to bereavement as "guilt" [7]. They mentioned that the survivor might feel remorseful for not taking certain crucial precautionary measures that could have prevented the death [7]. Guilt and self-reproach are normal grief feelings [32]. However, the level of guilt predicted complicated grief and depression later in bereavement [33]; the bereavement-related guilt had a closer association with complicated grief than depression [33]. "Regret," a similar reaction, may also be a unique marker of difficulties in the grieving process [34]. It is likely, therefore, that spouses of patients who have not undergone chemotherapy might feel a higher level of anticipatory grief than those of patients who have received it. Future research should assess the factors of patients' experience/no experience of chemotherapy that predict spousal anticipatory grief. Additionally, future studies should investigate the associations between the frequency and satisfaction of communication with medical staff during chemotherapy, spouses' positive experiences during chemotherapy (e.g., confidence and fulfillment of caregiving), their regret about patients' not having experience of



chemotherapy, and spousal anticipatory grief during the patients' terminal stage. For clinical implications, the viewpoint of patients having no experience of chemotherapy as a risk factor of spousal anticipatory grief is remarkable for medical staff. The medical team should explore the background of patients' not having experience of chemotherapy and pay attention to both positive and negative sides of spouses' experience/no experience regarding past patients chemotherapy when they listen to spousal caregiving description during the treatment period.

The multiple regression analyses represented the following: "social support needs of the spouses" in Model 1 and "family psychological issues and social support" in Model 2 may predict anticipatory grief significantly among spouses of patients with cancer at the terminal period. These results are analogous to those of previous studies suggesting that spousal psychosocial needs might promote greater levels of poor health themselves and that caregivers psychosocial issues tend to increase especially near the patients' terminal period. For example, a study explained that caregivers with significant unmet psychosocial needs were more likely to be those in poor health and to be caring for a patient who had reached the palliative care only stage [35]. In another study, more caregivers were depressed and had a higher level of perceived burden at the start of the terminal period compared to the start of the palliative care period [36]. In our original tool to assess social support needs of spouses of patients with cancer [13], the subscale items of "family psychological issues and social support" from "social support needs of the spouses" included: self-coping and information to deal with spouse's anxiety and depression; relationship and communication with people around the spouse; feeling burdened and isolated; support for spousal psychological issues from medical staff; advice regarding the patient's disease and medical treatment life; taking care of house chores; performing spousal responsibilities in the house; enjoying hobbies, recreations, and social activities; and excessive concerns about the spouse by the patient. Studies reported similar unmet psychosocial needs with our subscale items that were associated with caregivers' psychological distress and burden. For example, greater caregivers' emotional distress was associated with their higher unmet needs in the domains of healthcare service and information, as well as emotional and psychological needs [37]. Higher anxiety in caregivers was related to their higher unmet needs in two domains, that is, emotional and psychological needs and communication and family needs [37]. Caregivers' greater fatigue was linked to their higher information needs and healthcare professional/service needs [38]. Furthermore, caregivers' greater sleep disturbance was associated with their greater overall caregiving, daily living, and psychological/emotional needs [38]. These findings from previous studies support our results. Regarding the AGSFC's items [17], anticipatory grief includes psychological distress and burden among caregivers (spiritual pain in preparing for a loss, physical and mental fatigability in daily life, precedent anxiety regarding bereavement, and exhaustion). Hence, with

their own psychological and social support needs, they tend to have higher anticipatory grief at the end of the patients' life. The death of a spouse is the most stressful life event [1]. Therefore, spouses may have the highest psychological and physical needs among caregivers; moreover, they focus on dealing with patients' needs rather than their own. Regarding social support needs, most studies found that those who do not cope appropriately with bereavement have inadequate or conflicted social support [32]; further, an extended grieving alienates the social network [32]. Consequently, spouses' own higher social support needs might affect their severe anticipatory grief.

These findings are meaningful for clinical settings because they indicate that medical staff should pay greater attention to psychological and social support needs to reduce anticipatory grief of spouses of terminal cancer patients. For example, to support spousal unmet needs regarding family psychological issues and social support, we should assess these needs (e.g., whether or not spouses have a person and a place to share their feelings and experiences). Additionally, spouses should be offered consultations with clinical psychologists and psychiatrists, opportunities to access to doctors and nurses who listen to their emotions and experiences and offer guidance and support, information on brief relaxation techniques (e.g., breathing method, autogenic therapy, and mindfulness), and recommendations for respite hospitalization and spouses' own rest time. Spouses should be referred to the Cancer Counseling and Support Center and to peer support groups for the family, and offered advice on social welfare services (e.g., domestic helpers) by medical social workers. These approaches might be helpful for spouses' anticipatory grief as well. However, caregivers have higher unmet needs than patients [35] [39]. Further, family caregivers' needs pertaining to their relatives' cancer prevail for many years after the latter's death, and continued to breed the bereaved family members' suffering [40]. Therefore, the unmet needs' assessment among spouses of patients with cancer before their demise is especially important to prevent the former's continuous, complicated, and prolonged grief after the patients' death. In our previous study [13], using an online survey, we described the social support needs of 559 spouses of patients, mostly in their early cancer stage (e.g., 41.7% were undergoing treatment, 24.3% had recurrence/metastasis, and 57.6% were in ECOG PS0). Our results emphasize the social support needs of spouses of patients at their terminal stage in clinical settings to explore the effect on anticipatory grief using an original tool. We need, however, to modify this measure to make it easier and accessible for spouses. Our findings suggest that medical staff should pay attention to spouses who have a greater number of or more severe risk factors (patients having no experience of chemotherapy, social support needs of the spouses, and spousal needs for family psychological issues and social support). Their needs should be assessed carefully and adequate care should be provided for each need to alleviate anticipatory grief when medical staff meet spouses. It is hoped that these preventive viewpoints and approaches regarding anticipatory grief might help to

reduce complicated and prolonged grief of spouses after the patients' demise.

This study has several limitations. First, palliative care doctors recruited participants for whom they provided care in palliative care settings. It creates the possibility of sampling bias. Samples of participants whose patients are under cancer treatment in general wards and take palliative care in home care are needed in future research. Second, there may be additional sampling bias regarding the levels of anticipatory grief within our sample. Although 34.31% ( $n = 35$ ) of participants scored high on anticipatory grief, spouses having extremely severe anticipatory grief might not have participated in this study. Furthermore, samples including the spouses of younger patients who were in their 20 s and 30 s, younger spouses who were in their 20 s and 30 s, and more male spouses are needed in future research. Nevertheless, this study found no significant differences between males and females on anticipatory grief. Third, there may be confounding factors in the association between "chemotherapy" and "anticipatory grief" as independent and dependent variables, respectively. Therefore, confounding factors in the independent variables would be needed to explore the relationship between the two. Regarding confounding factors, for example, the frequency and satisfaction level of communication with medical staff during chemotherapy, trust or distrust of the medical treatment, the level of cognitive function of patients and spouses to understand chemotherapy, the existence of disease complications and comorbidity, the stage of cancer at diagnosis, the level of family cohesiveness, conjugal attachment, marital quality, family finances, utilization of cancer insurance, and the frequency and satisfaction of access to peer support for patients and spouses during chemotherapy should be considered to examine the link between "chemotherapy" and "anticipatory grief" in future research. Fourth, we were unable to assess the background of patients' experience/no experience of chemotherapy that predicted spousal anticipatory grief in this research. Future studies should evaluate these aspects and the association between the risk factors (e.g., the frequency and satisfaction of communication with medical staff during chemotherapy, spouses' positive experiences during chemotherapy, and their regret about patients' not having experience of chemotherapy) and anticipatory grief at the terminal stage among spouses of patients with cancer. Fifth, the two models did not account for the adjusted values (adjusted  $R^2$ ) of the variances' high percentage because there might be possibility of other more effective factors to affect anticipatory grief. Additional factors (independent variables), such as spouses' psychological distress and traits (e.g., anxiety and depression), quality of life, past psychiatric history, previous cancer experience, and satisfaction level and positive experience regarding medical staff's support in the prior and present hospitals may be related to anticipatory grief, and these factors are needed to enhance the adjusted values (adjusted  $R^2$ ) of the models in future research. Furthermore, the tool used to assess social support needs of spouses includes negative sentences (e.g., insufficient information regarding how to take care of the patient from now on) and is lengthy (73 items)

[13]; hence, it should be revised for ease of administration. Finally, this scale is unstandardized [13]; however, its content validity was confirmed in multidisciplinary meetings [13]. Therefore, the results of this study should be interpreted with caution. Despite these limitations, this study is significant as it examined the characteristics and social support needs predicting anticipatory grief in the spouses of patients with cancer at the end of life in Japan. In future research, more representative clinical data should be collected for further validation of the outcomes of this study. Qualitative data using semi-structured interviews to obtain spouses' opinions of this tool would be useful to develop it. Additionally, it would help in describing the details of spousal social support needs predicting anticipatory grief to shed light on the findings of this study.

## 5. Conclusion

We found that patients having no experience of “chemotherapy” and higher “social support needs of the spouses” in Model 1, and greater spouses' needs for “family psychological issues and social support” in Model 2 were significant predictors of severe anticipatory grief among participants. These results suggested that medical staff should pay more attention to spouses who show these risk factors, assess their needs regarding psychological issues and social support carefully, and provide adequate care for each of the social support needs to alleviate anticipatory grief. Additionally, the perspective of patients having no experience of chemotherapy as a risk factor of spousal anticipatory grief was remarkable. Medical staff should explore the background of patients' not having experience of chemotherapy and concentrate on both positive and negative sides of spouses' experience/no experience regarding previous patient chemotherapy when listening to their caregiving descriptions during the treatment period. The next step would be to develop a tool to assess social support needs of spouses of patients with cancer for ease of administration in clinical settings and to describe the details of spousal social support needs predict anticipatory grief in further research. Although this study had several limitations, our findings have important implications. To the best of our knowledge, this is the first study to reveal that patients having no experience of “chemotherapy” and spouses' own social support needs predict spousal anticipatory grief. These preventive perspectives and approaches for anticipatory grief might help spouses as well as medical staff in clinical settings. They will potentially facilitate the prevention of complicated and prolonged grief after the patients' death.

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### Conflicts of Interest

The authors have no conflicts of interest to declare.

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