

CLINICAL INVESTIGATION

Association Between Frailty and Patients' Experience of Cancer Treatment and Care

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ABSTRACT

Background: The relationship between frailty and patient experiences of cancer care and treatment remains underexplored. This study evaluated this association using validated tools to assess frailty and various aspects of patient experience.

Methods: We conducted a prospective observational study of 584 patients with cancer who underwent comprehensive geriatric assessment (CGA) at a geriatric oncology service prior to treatment decision-making (August 2020–July 2022). Frailty was classified using a CGA-based frailty index as fit (<0.2), pre-frail (0.2–0.35), or frail (>0.35). Patient experience was assessed using the Control Preference Scale (CPS), Patient Assessment of Care for Chronic Conditions (PACIC) subscales (delivery system design/decision support and problem-solving/contextual counseling), and Decision Regret Scale (DRS). Logistic regression examined associations between frailty and outcomes, adjusting for relevant covariates.

Results: The median age was 80 years (range, 51–97). Twenty percent of the patients were fit, 38% were pre-frail, and 42% were frail. Frailty was not associated with discordance between preferred and actual CPS roles ($p=0.14$). However, frail patients were less likely than fit patients to report high-quality care based on PACIC scores at 3 and 6 months ($p<0.05$). Moderate to strong regret (DRS score > 25) was expressed by 115 patients (28%) at 3 months and 109 patients (31%) at 6 months. Adjusted odds ratios for moderate to strong regret in frail versus fit patients were 2.61 (95% CI, 1.40–4.91; $p=0.003$) at 3 months and 2.41 (95% CI, 1.30–4.50; $p=0.005$) at 6 months.

Conclusion: Frailty was associated with lower perceived quality of care and higher decision regret following cancer treatment but not with differences in decision-making roles. Further research is warranted to understand the mechanisms underlying these associations to improve care experiences for older adults with cancer.

1 | Introduction

The cancer care journey presents unique challenges for all patients, but particularly for older adults with cancer, as both aging- and cancer-related frailty are more prevalent in this population compared to younger patients. Frailty is described as a

clinical state of increased vulnerability to stressors due to declines in reserve and function across multiple physiological systems [1]. In older adults with cancer, frailty has been associated with a higher risk of adverse health outcomes, including post-operative complications, systemic therapy toxicity, and cancer recurrence or progression [2–4]. Additionally, frailty is linked

Summary

- Key points
 - Frailty status was not associated with patients' preferred or actual roles in oncologic treatment decision-making.
 - Increasing levels of frailty at baseline were associated with lower perceived quality of care during cancer treatment.
 - Patients with frailty were more likely to experience decision regret about their cancer treatment.
- Why does this paper matter?
 - This study highlights the importance of recognizing frailty as a factor influencing cancer care experiences in older adults with cancer. Findings support the need to tailor care to better meet the needs of patients with frailty.

to poorer survival and health-related quality of life (HRQOL) [5–9]. However, beyond HRQOL, there is limited knowledge about how frailty may influence patients' experiences of cancer care and treatment.

One of the first challenges patients face in their cancer journey is making decisions about their care and treatment. This process involves weighing the risks and benefits of multiple options under conditions of uncertainty. To ensure that care aligns with patients' goals and preferences, shared decision-making (SDM) between patients and healthcare providers is advocated. Individualizing the SDM process requires an understanding of the diverse preferences for involvement in decision-making among cancer patients, which can range from active to passive roles [10]. Previous studies have identified a mismatch between patients' preferred decision-making roles and their actual perceived roles [11, 12]. This mismatch occurs when patients perceive themselves as having a more passive or more active role in decision-making than they would prefer. Moreover, when treating oncologists were asked about their perceptions of the patient's preferred role in decision-making, their perceptions often did not align with the patients' actual preferences [13].

Another significant challenge for patients and their caregivers is navigating the often-complex healthcare system to receive cancer care and treatment. This may be particularly difficult for older adults with cancer who often have multiple health issues requiring care from various healthcare professionals. Unmet health care needs or challenging experiences during cancer care, especially when combined with poor treatment outcomes, may lead to decision regret, defined as "remorse or distress over a treatment decision" [14, 15]. In the geriatric oncology literature, decision regret has also been described as the "overall gestalt of whether cancer treatment was worth it" [16].

In this study, we prospectively evaluated the roles of patients in treatment decision-making, their perceived quality of care, and decision regret among older adults with cancer who underwent a comprehensive geriatric assessment (CGA) prior to making a treatment decision. We also assessed whether these patients' experiences varied according to their level of frailty.

2 | Methods

2.1 | Study Design and Participants

This was a prospective observational study conducted at the NHO Kyushu Cancer Center (NKCC) in Japan. Consecutive patients with cancer who had undergone a CGA at the geriatric oncology service (GOS) prior to cancer treatment decisions between August 2020 and July 2022 were included in this study. We followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement to ensure the clear reporting of this study [17]. The study was approved by the NKCC institutional review board (2020–25), and informed consent was obtained from all participants.

2.2 | Setting

The NKCC is a 410-bed Japanese cancer hospital. A board-certified physician in geriatrics and medical oncology (T.F.N.) performed the CGA for the GOS. The CGA included four major elements: (1) physical health, (2) functional status, (3) psychological health, and (4) socioenvironmental parameters [18]. In addition to our guideline-concordant CGA process, we incorporated an assessment of the patient preferences using a simplified health Outcome Prioritization Tool and the first statement in the Attitude Scale (quantity vs. quality of life) [19, 20]. The CGA consultation was conducted with the patient and, whenever possible, with their caregiver(s). Referral for CGA consultation was made at the discretion of the treating physician. The referring physician was provided with a summary of the CGA findings, along with recommendations for cancer treatment and targeted interventions to address the identified vulnerabilities. After the CGA, the treatment decision was made through discussions between the treating physician, the patient, and their caregiver(s). Further details about the CGA consultation have been previously reported [20].

2.3 | Exposure: FI-CGA-10

We used the validated 10-item frailty index based on a CGA (FI-CGA-10) to measure fitness and frailty levels [21]. The FI-CGA-10 consists of 10 domains: cognition, mood, communication, mobility, balance, nutrition, basic and instrumental activities of daily living, social support, and comorbidity. Impairments in each domain are scored as 0 (no problem), 0.5 (a minor problem), and 1.0 (a major problem). The measures and scoring definitions for these 10 domains have been previously described [21]. Consistent with the traditional three frailty categories, FI-CGA-10 scores are categorized as fit (0 to <0.2), pre-frail (0.2–0.35), and frail (>0.35). The FI-CGA-10 score for each patient was calculated based on the pretreatment CGA conducted at the GOS.

2.4 | Outcomes: CPS, PACIC, and DRS

We administered the CPS, PACIC, and DRS as self-report questionnaires; patients completed them independently or with caregiver assistance when needed.

We used the Control Preference Scale (CPS) to assess the degree of involvement patients prefer and actually experience in

medical decision-making [22]. The CPS asks patients to select one of five statements that best reflect their preferred and actual roles: active, active shared, collaborative, passive shared, and passive (Table S1) [23, 24]. Preferred and actual roles were assessed at the time of CGA and approximately 3 months after the CGA, respectively. The five roles were collapsed into three categories (active, collaborative, or passive) as in previous studies, and patients were categorized as having either concordance or discordance between their preferred and actual roles [10].

We assessed the quality of care from the patient's perspective using the Patient Assessment of Care for Chronic Conditions (PACIC) [25]. Two PACIC subscales most relevant to our setting were selected: delivery system design/decision support (3 items) and problem-solving/contextual counseling (4 items) (Table S2) [20, 26]. The PACIC asks patients how often they experienced each care process on a Likert scale from 1 (almost never) to 5 (almost always). Subscale scores were calculated by averaging the individual item scores. Higher scores indicate higher quality of care, with scores of 4–5 considered high quality [27]. As in the previous study, we evaluated the proportion of patients reporting high-quality care (score ≥ 4) as an outcome. The PACIC subscales were measured at the time of the CGA and approximately 3 and 6 months after post-CGA.

We used the Decision Regret Scale (DRS) to assess levels of regret about cancer treatment decisions [14]. The DRS comprises five items, each rated on a scale from 1 (strongly agree) to 5 (strongly disagree), with items 2 and 4 reverse-coded (Table S3). The mean of the five items was converted to a scale of 0–100 by subtracting 1 and multiplying by 25. Higher scores indicate greater decision regret (0 indicates no regret; 1–25, mild regret; and > 25 , moderate to strong regret). Consistent with previous studies, we evaluated the proportion of patients reporting moderate to strong regret (DRS score > 25) as an outcome [15, 28, 29]. The DRS was assessed at approximately 3 and 6 months after the CGA.

2.5 | Statistical Methods

Descriptive analyses were performed to summarize sample characteristics and outcomes using means for continuous variables and frequencies or proportions for categorical variables. A Sankey diagram was used to visualize concordance or discordance between the patients' preferred and actual roles [30]. Logistic regression was used to describe the association between the frailty status (fit, pre-frail, or frail) and the outcomes, adjusting for covariates (age, sex, cancer type, and stage). A two-sided p value < 0.05 was considered statistically significant for all analyses. Analyses were performed using Stata 17 software (StataCorp LLC, College Station, TX, USA).

3 | Results

3.1 | Patient Characteristics

A total of 607 patients underwent a CGA at the GOS during the study period. Six patients were found to have a non-cancer diagnosis and were excluded from the final cohort. Seventeen

TABLE 1 | Patient and clinical characteristics.

| Characteristic | No. of patients (n = 584) | % patients |
|------------------------------|------------------------------|------------|
| Age, years | | |
| ≤69 | 15 | 2.6 |
| 70–74 | 76 | 13 |
| 75–79 | 200 | 34 |
| 80–84 | 184 | 32 |
| 85–89 | 85 | 15 |
| ≥90 | 24 | 4.1 |
| Sex | | |
| Male | 351 | 60 |
| Female | 233 | 40 |
| Cancer type | | |
| Gastrointestinal tract | 291 | 50 |
| Hepatobiliary and pancreatic | 118 | 20 |
| Head and neck | 55 | 9.4 |
| Hematologic malignancy | 38 | 6.5 |
| Genitourinary | 21 | 3.6 |
| Lung | 19 | 3.3 |
| Gynecologic | 18 | 3.1 |
| Other | 24 | 4.1 |
| Cancer Stage ^a | | |
| In situ | 9 | 1.5 |
| Localized | 151 | 26 |
| Regional | 166 | 28 |
| Distant | 258 | 44 |

^aCancer stage was assessed using the 2018 version of Summary Stage [31].

patients had the CGA conducted twice at different time points; only their initial CGA results were included. The final cohort consisted of 584 patients (Table 1). The median age of the patients was 80 years (range, 51–97 years), and 60% were male. The most common type of cancer was gastrointestinal tract (50%).

The mean \pm standard deviation (SD) of the FI-CGA-10 score was 0.36 ± 0.19 . Based on the three-level classification, 20% of patients ($n = 116$) were categorized as fit, 38% ($n = 220$) as pre-frail, and 42% ($n = 248$) as frail. During the six-month period following the CGA consultation, 480 patients received at least one of the following cancer treatments: surgery ($n = 244$), radiotherapy ($n = 85$), non-surgical local therapy ($n = 22$), and/or systemic therapy ($n = 268$). Additionally, 104 patients opted for best supportive care without undergoing any of these treatments. The number of patients reporting outcome data at baseline and at subsequent time points is shown in Figure S1.

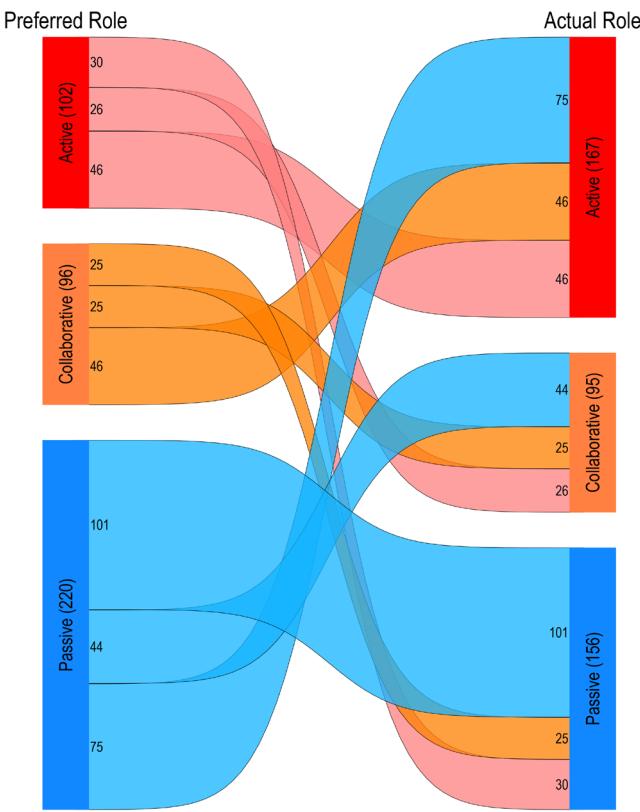


FIGURE 1 | Sankey diagram of preferred role versus actual role in treatment decision-making. Preferred and actual roles in treatment decision-making were assessed using the Control Preference Scale (CPS).

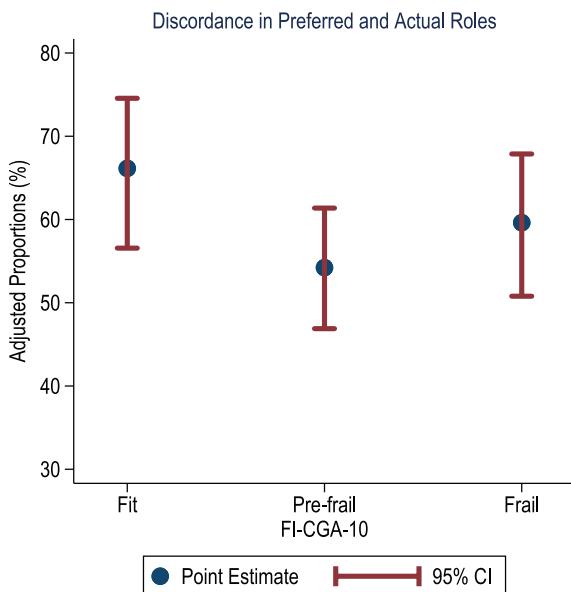


FIGURE 2 | Adjusted association between discordance in preferred and actual roles and frailty category. Preferred and actual roles in treatment decision-making were assessed using the control preference scale (CPS). Abbreviations: CI, confidence interval; FI-CGA-10, 10-item frailty index based on a comprehensive geriatric assessment.

3.2 | Outcome Data and Main Results

The roles that patients preferred and actually experienced in treatment decision-making are summarized in Table S4. Among

the 418 patients who reported their actual role, 246 (59%) experienced discordance between their preferred and actual roles (Table S5). Specifically, 165 patients (39%) assumed a more active role than they preferred, whereas 81 patients (19%) had a more passive role than preferred (Figure 1). There was no significant association between frailty status and discordance in preferred versus experienced roles (Figure 2, $p=0.14$).

Overall, the mean PACIC subscale scores (range 1–5) were 3.7 ($SD=1.0$) at 3 months and 3.7 ($SD=1.0$) at 6 months for delivery system design/decision support, and 3.6 ($SD=1.1$) at 3 months and 3.7 ($SD=1.0$) at 6 months for problem-solving/contextual counseling. High-quality care (score ≥ 4) was experienced by 50% of patients at 3 months and 51% at 6 months for delivery system design/decision support, and by 46% of patients at 3 months and 49% at 6 months for problem-solving/contextual counseling (Table S6). Frail patients were less likely to perceive high-quality care related to delivery system design/decision support at both 3 months (adjusted odds ratio (OR), 0.38; 95% CI, 0.22–0.67; $p=0.001$) and 6 months (adjusted OR, 0.45; 95% CI, 0.25–0.82; $p=0.01$) compared with fit patients (Figure 3). Similarly, the adjusted OR for perceived high-quality care related to problem-solving/contextual counseling in frail patients compared with fit patients was 0.47 (95% CI, 0.27–0.81; $p=0.007$) at 3 months and 0.47 (95% CI, 0.26–0.86; $p=0.01$) at 6 months (Figure 3).

Overall, the mean DRS score was 20.5 ($SD=16.3$) at 3 months and 21.2 ($SD=14.9$) at 6 months. Mild regret (Score 1–25) was reported by 213 patients (51%) at 3 months and 192 patients (54%) at 6 months. Moderate to strong regret (score > 25) was expressed by 115 patients (28%) at 3 months and 109 patients (31%) at 6 months (Table S7). The adjusted OR for moderate to strong regret in frail patients compared with fit patients was 2.61 (95% CI, 1.40–4.91; $p=0.003$) at 3 months and 2.41 (95% CI, 1.30–4.50; $p=0.005$) at 6 months (Figure 4).

4 | Discussion

To our knowledge, this is the first prospective study to evaluate patient experience of cancer care and treatment by frailty level. Various aspects of patient experience were assessed using the CPS, PACIC, and DRS. Frailty was quantified using the FI-CGA-10, a multi-component tool designed to assess the multifactorial complexity of the frailty syndrome. All of these instruments have been previously validated [14, 21, 22, 25].

Numerous studies have examined factors associated with CPS roles and the discordance between preferred and experienced decision-making roles [10–12]. Most of these studies used a cross-sectional design, assessing both preferred and actual CPS roles at a single point after the treatment decision had already been made [11, 12]. In contrast, we assessed patients' preferred roles during the CGA consultation, before the treatment decision was made, and evaluated the actual roles experienced after the decision. This design minimized potential bias, ensuring that patients' preferred roles were not influenced by their actual decision-making experience. We found discordance between preferred and experienced roles in approximately 60% of patients, which is comparable to the 40%–60% frequency of discordance reported in previous studies of cancer patients [10, 32, 33].

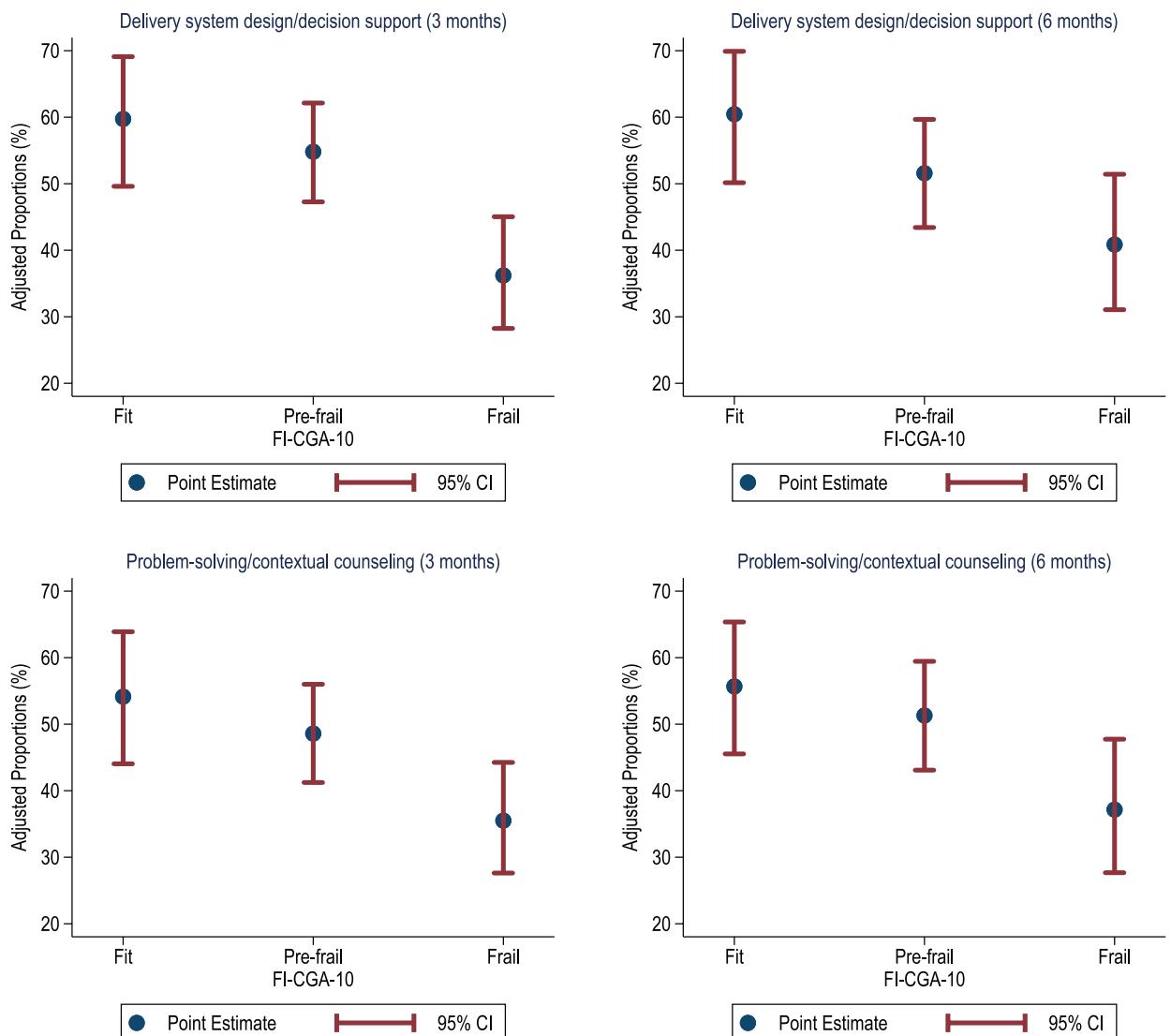


FIGURE 3 | Adjusted association between perceived high-quality care and frailty category. High-quality care is defined as a patient assessment of care for chronic conditions (PACIC) subscale score ≥ 4 . Abbreviations: CI, confidence interval; FI-CGA-10, 10-item frailty index based on a comprehensive geriatric assessment.

When discordance occurred, prior research indicated that patients were more likely to have experienced a less active role in decision-making than they preferred [10, 11, 32, 33]. However, in our study, more patients experienced a more active role than they initially preferred. We do not believe that this finding is solely attributable to cultural differences. Recent studies have demonstrated that, contrary to the traditional image of a passive attitude, Japanese patients are interested in shared or active decision-making, similar to Western patients [34–36]. In line with Western studies, when discordance occurred, a greater proportion of Japanese patients experienced a more passive role in decision-making than they preferred [35, 36]. In our study, discussing preferences for health outcomes and decision-making involvement during the CGA consultation, often in the presence of caregivers, may have influenced patients' behavior [20]. This process might have increased patients' awareness of the choices available and the importance of their preferences in treatment decision-making. This hypothesis requires further evaluation through controlled studies. The novelty of our study lies in examining the relationship between frailty and CPS roles, an area

that has not been explored previously. Regardless of frailty status, we observed a wide range of both preferred and actual CPS roles, and frailty did not predict discordance between these roles. Our findings support the notion that there are no consistent or reliable factors associated with CPS roles and discordance.

The PACIC has been extensively used to assess the chronic care model [27, 37, 38] and has also been applied in oncology settings to evaluate patients' perceptions of quality of care [26, 39, 40]. However, no studies to date have examined the relationship between frailty status and perceived quality of care in patients with cancer. Our findings indicate that higher baseline frailty levels are associated with lower perceived quality of care during cancer treatment. Brédart et al. demonstrated that higher care needs correlate with lower perceived quality of care in patients with breast cancer undergoing chemotherapy, radiation, or surgery [41]. Similarly, higher frailty levels have been linked to greater care needs among patients with cancer who have undergone surgery or systemic therapy [42, 43]. These findings suggest that patients with higher frailty levels may have more

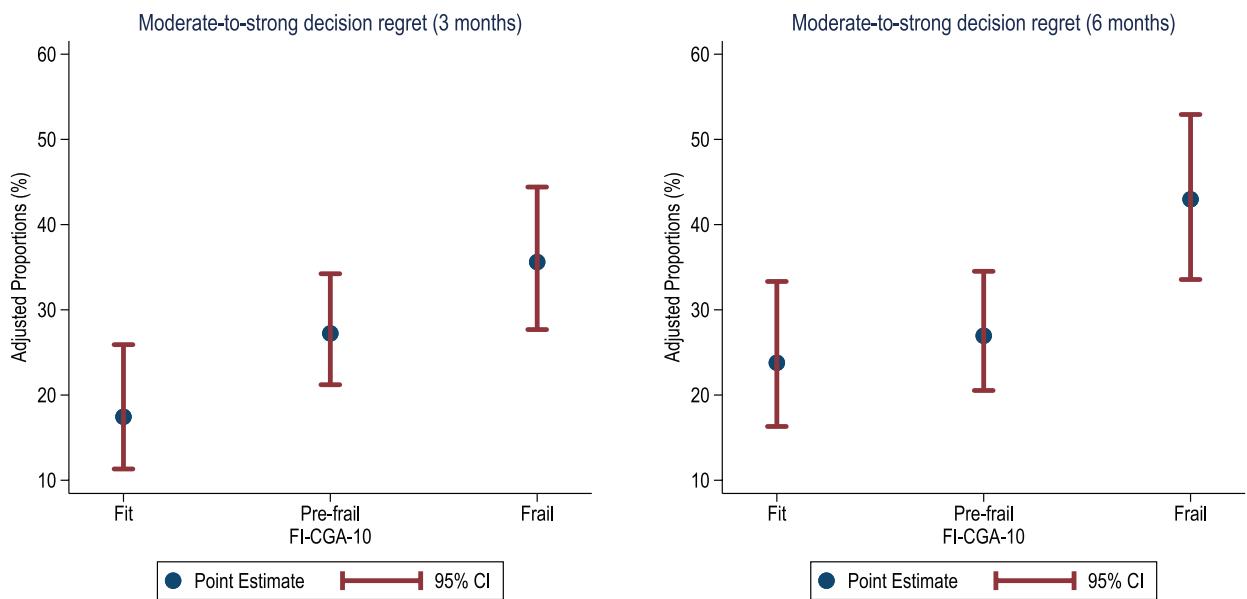


FIGURE 4 | Adjusted association between moderate-to-strong decision regret and frailty category. Moderate to strong regret is defined as a decision regret scale (DRS) score > 25 . Abbreviations: CI, confidence interval; FI-CGA-10, 10-item frailty index based on a comprehensive geriatric assessment.

unmet health care needs. Studies have shown that poorer general health is linked to lower perceived quality of care in both cancer and non-cancer populations [44–46]. Kane et al. reported that patients with poorer health status following surgery perceived lower quality of care [47]. Additionally, Nguyen et al. found that patients with lower HRQOL at baseline reported lower perceived quality of care during cancer treatment [48]. This may partially explain our findings, as frail patients are known to be at a higher risk for health status decline after cancer treatment [49, 50]. Further research is necessary to uncover the mechanisms by which frailty influences perceived quality of care, with the goal of improving the cancer care experience for this vulnerable population.

The DRS is a validated and widely used scale for measuring experienced decision regret in health care settings [29]. To our knowledge, only one published study has examined the association between frailty and DRS in patients with cancer [15]. This prospective cohort study included 274 patients aged ≥ 50 years with cancer who underwent major head and neck surgery at a single center. At 6 months post-surgery, 27% of patients had a DRS score > 25 , indicating moderate to strong regret [15]. A significant unadjusted association (OR = 1.38) was observed between the Fried frailty score and moderate to strong regret. Agung et al. used a single-item question from the DRS, scored on a 3-point ordinal scale (no, unsure, and yes), in 669 patients aged ≥ 65 years who underwent elective major surgery, such as orthopedic (49%), abdominal (21%), and vascular (14%) procedures [51]. One year after surgery, approximately 10% of patients responded “unsure or yes” to the question regarding decision regret. These responses were more common among patients with a Clinical Frailty Scale (CFS) of 4 (OR = 1.61) and 5 or higher (OR = 2.06), compared to those with a CFS of 3 or less, after adjusting for potential confounders. CFS of 4 and 5 or higher may approximate the pre-frail and frail categories based on the FI-CGA-10 [21]. We

observed that frail patients were more likely than fit patients to experience moderate to strong decision regret. Although differences exist in the study populations, designs, and measures, our results support the hypothesis that patients with baseline frailty are at an elevated risk of experiencing decision regret related to their cancer treatment.

This study has several limitations. First, the cohort consists of a heterogeneous population of older adults with various types of cancer who received different treatments after undergoing CGA at the GOS. Our findings may not generalize to more specific and homogeneous populations. However, the study's relatively large sample size represents the general experiences of older adults with cancer for whom the treating oncologist deemed a pre-treatment CGA beneficial to their care. Second, we did not use a qualitative research method, which we believe could provide deeper insights into potential mechanisms underlying the observed association between frailty and patient experiences in cancer care. Third, we used only two of the five PACIC subscales that we felt were most relevant to this study. As a result, an overall summary score, typically an average of all five subscales, could not be calculated. This selection of subscales allowed us to administer the DRS and CPS without modification, whereas considering the response burden on participants.

We observed a range of preferred and actual roles in treatment decision-making, independent of frailty status. As neither patient characteristics nor frailty status reliably predict this preference, it is essential to engage patients in decision-making according to their desired role by explicitly eliciting their preferences. We also found that patients with higher levels of frailty reported lower perceived quality of care and greater decision regret following cancer treatment. Further research is needed to clarify the mechanisms underlying these associations and to identify strategies to enhance the care experience for these patients. Based on our findings and the current evidence, we believe there is a

need to better support patients with frailty in the SDM process by presenting likely scenarios based on their frailty levels and available treatment options, whereas carefully considering their values and preferences. Importantly, implementation of CGA must be adapted to local resources; the recent ASCO Global Guideline recommends a resource-stratified approach that begins with brief geriatric screening and proceeds to more detailed assessment and management for those who screen positive [52]. Increased allocation of resources to patients identified as frail is warranted to provide more personalized interventions that meet their specific needs and improve outcomes. Finally, we suggest that future implementation efforts actively engage patients, caregivers, and clinicians in priority-setting, intervention development, and outcome selection to maximize the relevance, feasibility, and uptake of care models.

Author Contributions

Conception and design: Tomohiro F. Nishijima. Acquisition of data: Tomohiro F. Nishijima. Statistical analysis: Tomohiro F. Nishijima, Mototsugu Shimokawa. Interpretation of data: All authors. Writing original draft: Tomohiro F. Nishijima. Revision and final approval of the manuscript: All authors.

Disclosure

There was no sponsor's role in the design, methods, subject recruitment, data collection, analysis, and preparation of the paper.

Conflicts of Interest

The authors declare no conflicts of interest.

Linked Article

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Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Data S1:** [jgs70157-sup-0001-Supinfo.pdf](https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.70157-sup-0001-Supinfo.pdf).