**Fatigue in advanced cancer patients: congruence between patients and their informal caregivers about patients’ fatigue severity during cancer treatment with palliative intent and predictors of agreement**

***Running head: Dyadic agreement on cancer patients’ fatigue***

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**Abstract**

**Context:** Informal caregivers (ICs) are increasingly involved in the monitoring of symptoms during advanced cancer patients’ treatment with palliative intent. A common, but subjective symptom during this extended treatment phase is fatigue.

**Objective:** This exploratory longitudinal study aimed to determine agreement between patients and ICs about patients’ fatigue severity. In addition, predictors of agreement over time were studied.

**Methods:** A sample of 107 advanced cancer patients (life expectancy ≥ six months) and their ICs completed the subscale fatigue severity of the Checklist Individual Strength based on the patient’s status at baseline and six months later. This 8-item subscale has a validated cut-off to determine the presence of clinically relevant levels of fatigue. ICs’ own fatigue severity, strain, self-esteem, and relationship satisfaction were examined as predictors of agreement.

**Results:** 107 dyads completed measures at baseline, 69 dyads six months later. At baseline, ICs’ significantly overestimated patients’ fatigue severity (*p* <.001) with a moderate amount of bias (Cohen’s *d* = 0.48). In 81 of the 107 dyads (76%) there was congruence about the presence or absence of severe fatigue. On a group level, congruence did not significantly change over time. On a dyad level, there was a tendency to either remain congruent or reach congruence. Next to baseline congruence, ICs’ fatigue severity and strain predicted ICs’ in fatigue ratings (R2=0.23).

**Conclusions:** The majority of ICs accurately predict presence or absence of clinically relevant levels of patients’ fatigue. ICs’ own fatigue severity and strain should be taken into account, as they influence agreement.

**Keywords:** Cancer, Oncology, Fatigue, Informal Caregiver, Proxy-rating

**Introduction**

A diagnosis of cancer, particularly when the disease is incurable, impacts not only the patient but also the informal caregiver (IC) [1]. ICs are faced with new responsibilities in medical, emotional, and practical domains [2]. The main aims of care for patients with incurable cancer are to prolong patients’ lives, while maintaining acceptable quality of life (QoL) by providing pain and symptom relief [3]. Due to advances in medical treatment, patients with certain types of incurable cancer receiving treatment with palliative intent may now live for an extended period [4, 5]. This extended phase of cancer treatment with palliative intent is associated with the occurrence of several physical and psychological symptoms. One of the most frequently reported symptoms is fatigue [6]. Fatigue is often cited as being among the most distressing symptoms [7-9] and has a negative impact on QoL, performance status, and daily activities [7, 10, 11]. Both patients and ICs have to deal with this distressing and disabling symptom [12].

Cancer-related fatigue (CRF) is defined by the NCCN as “a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning” [13], which cannot be objectively measured. Patients directly perceive their fatigue, whereas ICs can only know about the patients’ fatigue indirectly, that is, from what the patient communicates verbally or non-verbally. It is important to understand ICs’ perceptions for several reasons. First, perceptions drive IC responses to patients’ fatigue, which in turn can have an impact on patients. For example, failing to perceive that the patient feels severely fatigued would prevent ICs from giving attention to this symptom, thereby potentially resulting in a perceived lack of social support by the patient. In turn, it is known that a perceived lack of social support can be a perpetuating factor of fatigue [14]. Second, ICs are increasingly involved in the care for advanced cancer patients. For example, monitoring and management of symptoms during palliative treatment may rely on information from ICs. It is therefore important to know whether an IC can give a meaningful additional rating of the severity of patients’ fatigue.

Studies focusing on patient and proxy-ratings typically assess physical and psychosocial symptoms by asking both patients and proxies to complete questionnaires based on the patients’ status. Findings of a review by Tang & McCorkle (2002) confirmed that ICs’ ratings of terminal cancer patients’ QoL agreed moderately well and when discrepancies existed, ICs held a more negative view of patients’ QoL than did patients [15]. However, agreement in fatigue ratings has not been studied extensively in incurable cancer patients receiving treatment with palliative intent. A cross-sectional study focusing on agreement in symptom ratings by 52 advanced lung cancer patients and their ICs found that fatigue ratings were moderately correlated [16]. Yet, ICs rated patients’ fatigue significantly higher than did patients themselves. ICs’ perceived lack of social support, self-reported health, and caregiver self-esteem influenced agreement in various dimensions of symptoms. However, none of these three factors appeared to have an impact for agreement on fatigue. Another cross-sectional study, assessing agreement between 66 advanced cancer patients and their ICs found that agreement for lack of energy was poor to fair [17]. In addition, levels of disparity were correlated with IC characteristics (e.g. emotional state, caregiver burden) on several individual symptoms and on all symptom subscales of the Memorial Symptom Assessment Scale. However, these studies had a cross-sectional design and thus it is not possible to determine the pattern of agreement in fatigue ratings over time, nor temporal relationships between patients’ and ICs’ ratings of fatigue and other variables. Furthermore, no attempt was made to determine agreement on clinically relevant levels of fatigue, even though decisions about symptom management will often be based on the evaluation of whether fatigue is severe enough to be clinically relevant.

The present exploratory longitudinal study had three aims. First, we aimed to examine at the dyadic and group level whether ICs’ ratings of patients’ fatigue are congruent with patients’ ratings both when fatigue severity is measured continuously, and when the presence or absence of clinically relevant levels of fatigue is determined using a questionnaire with a validated cut-off for severe fatigue. Based on previous studies reporting poor agreement for more subjective symptoms [15, 18], we expected lack of agreement for ICs’ ratings of patients’ fatigue severity on a continuous level. However, we did not have hypotheses about the magnitude of this expected disagreement or about the agreement of ICs’ and patients’ ratings for clinically relevant levels of fatigue. Second, we studied the patterns of agreement over time to investigate whether agreement between ICs’ and patients’ perceptions changed over time. We had no specific hypothesis for this research question. Finally, predictors for the degree of agreement between ICs’ and patients’ fatigue severity ratings over time were explored. Based on the findings of previous studies [16, 17], we explored several characteristics associated with the IC (i.e. ICs’ fatigue severity, caregiver strain, and/or caregiver self-esteem) that could explain a significant amount of variance in ICs’ perceptions. For ICs’ with a partner relation to the patient, relationship satisfaction was added as a potential predictor since it has been suggested that this relates to closeness [19], i.e. sharing thoughts or feelings [20], and thus might influence the congruence between ICs’ and patients’ perceptions.

**Methods**

Study population

The current study was part of a larger study examining fatigue in advanced cancer [21, 22]. Patients were recruited between December 2008 and June 2010 from two Dutch hospitals, the Radboud university medical center (Nijmegen) and the Jeroen Bosch Hospital (Den Bosch). Patients with advanced (i.e. incurable or metastatic) cancer who visited the department of medical oncology for cancer treatment with palliative intent with a life expectancy of at least six months were invited to participate in the study together with their IC. Potential patient participants were identified by the treating physician and telephoned by a researcher to explain study procedures. In addition, patients received written information. Eligible patients that gave consent were asked to identify their principal IC. ICs could either be the patients’ partner or have another relation to the patient (e.g. parent, daughter/son, or friend). Identified ICs were telephoned by a researcher to verify willingness to participate and also received written information. All patients and ICs gave oral informed consent. Paper versions of the questionnaires were sent to patients and ICs by mail in separate packages, which could be returned in a self-addressed, stamped envelope. ICs were explicitly instructed to complete the questionnaires apart from their patient-partners. Medical ethical committees of both hospitals approved the study.

Fatigue measurement

Fatigue severity in patients and ICs was assessed with the subscale fatigue severity of the *Checklist Individual Strength* (CIS-fatigue)[23]*.* Besides reporting their own fatigue, ICs also responded to a version of the CIS-fatigue adapted to elicit their perspective on the patients’ fatigue. ICs were instructed to focus on how their partner (or parent, daughter/son, or friend) had felt during the last two weeks. In addition, first-person item statements were changed into the third-person perspective (e.g. ‘My partner feels fatigued’). The CIS-fatigue consists of 8 items, scored on a 7-point Likert scale. Total scores range from 8 (no fatigue) to 56 (severe fatigue). The cut-off for severe fatigue is set at 35, i.e. two standard deviations (SD) above the mean of a healthy control group [23]. This cut-off has been used previously for assessing severe fatigue in cancer patients during or after curative cancer treatment [24-27] as well as in patients receiving cancer treatment with palliative intent [28]. The CIS-fatigue was administered at baseline (T0) and six months later (T1).

Patient and informal caregiver characteristics

At baseline, characteristics of the patients including demographic data (i.e. age and gender) and medical data (i.e. tumour type and treatment modality) were retrieved from medical records. In addition, ICs answered demographic questions (i.e. age, gender, and relation to the patient) at T0 and questionnaires about caregiver strain and caregiver self-esteem at T0 and T1. The *Caregiver Strain Index (CSI)* contains 13 yes/no statements about perceived caregiver strain [29]. Total scores range from 0 to 13 and a score of 7 or more indicates high caregiver burden. Positive experience of care giving was measured with the subscale self-esteem of the *Caregiver Reaction Assessment-Dutch (CRA-D)* [30]*.* The CRA-D self-esteem consists of 7 items scored on a 5-point Likert scale of 1-5. Total scores range from 7 to 35 and a higher score represents more caregiver self-esteem [31]. ICs with a partner relationship to the patient also completed a questionnaire about their relationship satisfaction. The subscale marital satisfaction of the *Maudsley Marital Questionnaire (MMQ)* [32] consists of 10 items scored on a 9-point Likert scale of 0-8. Total scores range from 0 (very satisfied) to 80 (very dissatisfied).

Statistical analysis

Only data from dyads where both members had completed the CIS-fatigue were included in the analyses. Due to the natural course of the illness, significant attrition was expected. No missing data were replaced. Analyses for T1 data only included dyads that completed the CIS-fatigue at both T0 and T1.

**ICs’ ratings of patients’ fatigue at baseline.** First, an intraclass correlation coefficient (ICC) [33] was calculated to examine congruence between patient and IC proxy ratings on the CIS-fatigue [34]. The strength of congruence as reflected by the ICC was labelled as follows: ≤ 0.40 poor to fair agreement; 0.41-0.60 moderate agreement; 0.61-0.80 good agreement; 0.81-1.00 excellent agreement [35]. Second, for each dyad, a continuous congruence score (CCS) was calculated by subtracting the patients’ CIS-fatigue score from the ICs’ CIS-fatigue proxy score, so that a positive CCS denoted the ICs’ proxy assessment of patients’ fatigue severity as being higher than that of the patient [36]. Given the possible range of 8 to 56 for scores on the CIS-fatigue, possible CCSs ranged between -48 and 48. In accordance with previous studies examining dyadic congruence, a minimal threshold for a clinically relevant CCS was set at >10% of the possible range [37, 38]. Therefore, CCSs exceeding 4.8 or -4.8 were considered clinically relevant. At the group level, additional paired samples t-tests were used to determine the mean CCS at baseline, being indicative of bias in ICs’ proxy score relative to those of the patient. The statistical magnitude of any observed bias was examined by calculating the effect size (Cohen’s *d*) using mean CCS and SD [39]. An effect size of at least 0.2 was considered small, 0.5 was considered moderate, and 0.8 was considered large [39, 40].

To examine absolute congruence, CIS-fatigue scores of patients and ICs’ CIS-fatigue proxy scores were dichotomized as denoting the presence (≥35) or absence (<35) of severe fatigue. Dyadic congruence about the presence or absence of severe fatigue was determined and coded (0=congruence, 1=incongruence). At the group level, proportion agreement was calculated to evaluate the amount and direction of congruence between patients and ICs. Incongruent dyads were further classified as to whether the IC under- or over-estimated the presence of severe fatigue relative to the patient.

**ICs’ ratings of patients’ fatigue over time.** First, a paired samples *t*-test was used to test whether the means for CCS at T0 and T1 differed over time. Second, two separate Bland-Altman plots were drawn for agreement at T0 and T1 to visually inspect patterns of agreement over time [41, 42]. In this graphical method, the differences between patient and IC ratings (CCS) are plotted against the gold standard, i.e. patients’ fatigue ratings [43]. The 95% limits of agreement were defined as the mean CCS ± 1.96 times the SD of the differences. Horizontal lines were drawn for the mean CCS and the upper and lower limits of agreement. We inspected width of the 95% limits of agreement, trends in agreement, and consistency of variability across the graph for T0 and T1. In addition, we calculated the proportion of dyads with a CCS exceeding the threshold for clinical relevance.

To examine absolute congruence over time, we calculated the numbers and percentages of dyads that were classified as congruent or incongruent about the presence or absence of severe fatigue at T0 and T1.

**Predictors of continuous congruence.** Bivariate correlations between baseline predictors and CCS at T0 and T1 were determined. Following the methods described by Snow et al. (2005), a multivariate hierarchical regression analysis was conducted to determine which IC characteristics at T0 significantly predicted CCSs at T1 [36]. Predictors were entered into the regression model in three blocks: (1) CCS at T0, (2) T0 predictors that significantly correlate with CCS at T1, (3) the remaining predictors. All data analyses were performed using Statistical Package for Social Science (SPSS; version 20) for Windows. The significance level was set at 0.05.

**Results**

Patients’ and ICs’ characteristics

Of the 142 eligible dyads for the larger study, 131 agreed to participate and 107 completed the CIS-fatigue at T0, enabling inclusion in this study (75% response). Due to expected attrition, 69 of the 107 dyads filled out the CIS-fatigue at both time points (64% response). The most common reason for loss of dyads was because the patient died during the study (n=21), followed by patients that did not want to participate any further mostly because of disease deterioration (n=14) or for unknown reasons (n=4). The demographic and medical characteristics of the total group of 107 patients and ICs are presented in Table 1.

ICs’ ratings of patients’ fatigue at baseline

At baseline, the intraclass correlation indicated excellent agreement between patient and IC proxy ratings (ICC = 0.81). Patients mean CIS-fatigue scores and ICs’ mean CIS-fatigue proxy scores were 31.9 and 36.6, respectively. ICs’ CIS-fatigue proxy scores differed significantly from patients’ CIS-fatigue scores. ICs tended to overestimate the level of fatigue (mean difference 4.74, SD9.97, *t:*4.917, *p* <.001). The effect size suggested that the amount of systematic bias was moderate (Cohen’s *d* = 0.48). At the group level, the mean CCS for fatigue severity did not exceed the clinically relevant threshold (i.e. 4.8 or -4.8). The CCS for each dyad exceeded the clinically relevant threshold in 68 of the 107 dyads (64%).

When the cut-off for severe fatigue (i.e. ≥ 35) was applied, 81 of the 107 dyads (76%) were congruent about the presence (n=43) or absence (n=38) of severe fatigue in patients. Of the remaining 26 incongruent dyads, 22 ICs (85%) overestimated the presence of severe fatigue, while only 4 ICs (15%) underestimated the presence of severe fatigue.

ICs’ ratings of patients’ fatigue over time

The following results are related to the 69 dyads that completed the CIS-fatigue (patient and proxy-rating) at both T0 and T1. Dyads lost to follow-up (n=38) were not significantly different with respect to mean CCS at T0 compared to dyads that completed both assessments (n=69). In addition, ICs’ own fatigue severity, self-esteem, relationship satisfaction, and strain did not differ significantly at baseline (all *p*’s > 0.05).

The mean CCS for fatigue severity was lower at T1 (2.97, SD10.28) compared to T0 (4.62, SD10.54), though not significantly so (*p* > 0.05). Figures 1A and 1B depict Bland-Altman plots of the difference between patient and IC ratings of patients’ fatigue. For both time points, a wide range for the limits of agreement was found. No trends were observed and variability across the graph was consistent at both time points. The CCS for each dyad exceeded the clinically relevant threshold in 45 (65%) and in 48 (70%) of the 69 dyads at T0 and T1, respectively.

We calculated the numbers and percentages of dyads that were classified as congruent or incongruent about the presence or absence of severe fatigue at T0 and T1. Forty-two of the 51 dyads (82%) that were classified as congruent at T0 were also congruent at T1. However, 13 of the 18 dyads (72%) that were incongruent at T0 were in agreement about the presence or absence of severe fatigue at T1.

Predictors of continuous congruence

Table 2 shows descriptives for patients’ fatigue and ICs’ own fatigue severity, strain, self-esteem, and relationship satisfaction at T0 and T1. All variables remained largely stable over time (*p*’s > 0.1). Table 3 displays predictor-outcome correlations for T0 and T1. The CCS at T0, ICs’ own fatigue severity and strain correlated significantly with the CCS at T1 (*p*’s < 0.05).

Subsequently, three-block hierarchical regression was used. In block 1, the CCS at T0 was entered as a control variable. Block 2 predictors included those variables that significantly correlated with CCS at T1 (ICs’ own fatigue severity and strain). Remaining predictors in block 3 (self-esteem and relationship satisfaction) were entered based on previous research [16, 19]. The CCS at T0 predicted 13% of the variance in CCSs at T1. ICs’ own fatigue severity and strain accounted for an additional 10% of the variance in CCSs at T1. Block 3 variables did not account for significant additional variance. Thus, 22% of the variability in CCSs at six months was explained by the CCS at baseline, ICs’ own fatigue severity and strain (Table 4).

**Discussion**

The present exploratory longitudinal study was performed to determine congruence between patients and ICs about patients’ fatigue severity both on a continuous and clinically relevant level during cancer treatment with palliative intent in patients with a life expectancy of at least six months. In addition, we examined a number of possible predictors of agreement between ICs’ and patients’ ratings of patients’ fatigue. The results show that ICs rate patients’ mean fatigue severity significantly higher than patients themselves. This echoes with findings in other studies where, across diseases and symptoms, ICs tend to over report on more subjective patient symptoms and underestimate quality of life [44]. However, the overestimation effect in our study was only of moderate size and patient and IC ratings of patients’ fatigue on a continuous scale were highly correlated. When fatigue ratings were dichotomised around a cut-off of clinically significant fatigue, there was a greater degree of agreement. In the small proportion of incongruent dyads, overestimation was more likely to occur. No trend for a change in ratings of fatigue on a continuous scale over time was observed. When fatigue ratings were dichotomised, an overall tendency to either remain congruent or reach congruence over time existed.

We found that in addition to baseline congruence, several characteristics of the ICs also predicted congruence at six months. The fact that ICs’ own fatigue severity and strain were associated with less congruence could be due to a reporting bias, which in itself could be related to negative affect on the part of the IC. That is, more strained ICs report higher levels of fatigue for themselves and for their patient partners, because both measures are confounded or inflated by negative affect. Mulligan *et al.* (2014) showed that negative affect is not only associated with reporting your own symptoms, which is already a well established finding, but also with reports of symptoms in others [45]. Contrary to our expectations, we did not find a relationship between caregiver self-esteem and relationship satisfaction and congruence. However, overall mean scores reflected a reasonable amount of caregiver self-esteem and high relationship satisfaction, which may have prevented us from finding significant results due to a restriction of range effect.

In the present study, it is hard to know what an IC is actually rating when they rate the patients’ fatigue. We do not know how ICs estimate how tired the patient feels. It would be interesting to explore whether they are for example relying on behavioural or verbal correlates of fatigue to make the judgement. McPherson and Addington-Hall (2004) analyzed family members’ narratives and found that family members draw on different sources when evaluating advanced cancer patients’ pain, anxiety, and depression, such as contextual cues, expectations, behavioural referents, knowledge in general and knowledge of the patient [46]. Whether this also applies to estimating fatigue remains to be determined. Davis *et al.* (2007) used a think-aloud approach to study discordance in parent-proxy and child self-reported quality of life [47]. Application of this qualitative approach while ICs complete the fatigue questionnaire might be helpful in further unravelling this.

Measurement issues do not only play a role in the IC-proxy rating. Fatigue is a subjective symptom and we worked on the assumption that the patient’s experience is primary and that the patient’s expressed ratings are the most valid measures. Therefore, patients’ fatigue ratings were taken as the gold standard to which the IC-proxy rating was compared. Yet, patients’ ratings themselves might be affected by various factors. For example, a response shift may cause patients to continuously rate fatigue at the same level as previously, even though the IC can observe more fatigue-related behaviour (e.g. resting more). Alternatively, a qualitative study reported that advanced cancer patients admitted intentionally minimizing symptoms to prevent ICs from becoming distressed [48]. Thus, for consultations where important treatment decisions are to be made, a second rating of patients’ fatigue by an IC may provide physicians with a more complete reflection of patients’ fatigue and facilitate discussing how well patients are holding up with treatment.

The study has several limitations including the high attrition rate, which resulted in a rather small sample size for the longitudinal analyses. The main reason for attrition was because the patient died during the study. Although this might have led to a selected group of relatively fit patients at T1, we did not find significant differences between dyads that completed the study and dropouts with respect to baseline CCS or IC characteristics. Next, the patient-IC relationship was quite homogeneous, with almost 90% having a partner relationship. This limits the possibility of generalizing our findings to ICs with a different relation to the patient. A further limitation is that we adapted the CIS for proxy use without validation of the adapted version. In addition, although we tried to secure non-contamination of questionnaires between patients and ICs, it is possible that ICs discussed questions or answers with patients. Moreover, we focused on IC characteristics as potential predictors for agreement but other factors, such as cognitive functioning, patients’ performance status, or presence of other symptoms, were not measured in this study and may also impact agreement. Also, cancer staging information was not recorded, though based on eligibility criteria only patients with a stage 3 or 4 cancer diagnosis were eligible. Information about performance status or time since diagnosis was not collected and would have been particularly useful in the context of our findings on the course of agreement over time. Finally, we analysed our data without multiple test adjustment following recommendations for exploratory studies by Bender & Lange (2001), thus significant results should be viewed as exploratory results [49]. Despite these limitations, to our knowledge this was the first exploratory study investigating ICs’ perceptions of patients’ fatigue with a longitudinal design, allowing to study the pattern of agreement over time and to explore temporal relationships between IC characteristics and agreement. Moreover, the current study used a cut-off point to determine clinically meaningful agreement about the presence or absence of severe fatigue, adding to studies that merely examined agreement on a continuous level.

In conclusion, ICs can accurately predict presence or absence of clinically relevant levels of severe fatigue in advanced cancer patients receiving treatment with palliative intent. However, on a continuous level ICs tend to overestimate patients’ fatigue. For ICs, this may trigger the feeling that they need to do more for the patient, which could lead to increased IC strain. We suggest that it would be useful to include measures of ICs’ ratings of patients’ fatigue when delivering extended care for advanced cancer patients. Agreement did not change significantly over time. It is however important to take into account ICs’ affective state when asking for judgments about patients’ fatigue in both research and clinical settings, as the response is likely to be affected if the IC is fatigued or feeling strained. The latter finding also seems to point to the need to attend to ICs’ own fatigue and burden in the context of caring for a patient with advanced, incurable cancer.

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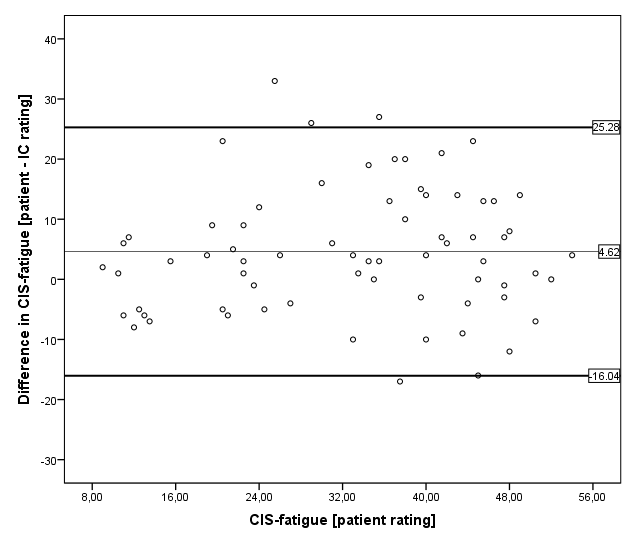
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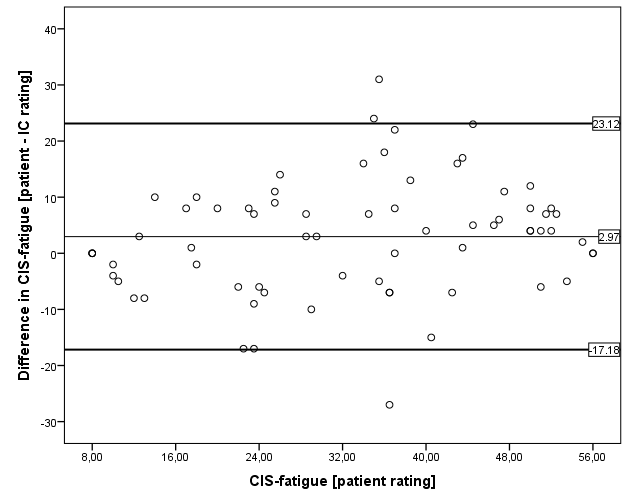
**Table 1 Baseline characteristics (n=107)**

|  |  |  |
| --- | --- | --- |
|  | **Patients (%)** | **Informal Caregivers (%)** |
| Mean age in years  (Min-Max) | 59  (30-79) | 60  (27-80) |
| *Gender:*  Male  Female | 43 (40.2)  64 (59.8) | 55 (51.4)  52 (48.6) |
| *Relation to patient:*  Partner  Other |  | 96 (89.7)  11 (10.3) |
| *Tumor type:*  Gastrointestinal  Breast  Urogenital  Bone and soft tissue  Gynecologic  Other | 31 (29.0)  28 (26.2)  13 (12.1)  11 (10.3)  10 (9.3)  14 (13.1) |  |
| *Treatment modality:*  Chemotherapy  Targeted therapy  Hormonal therapy  Chemo + Targeted therapy  Other | 55 (51.4)  19 (17.8)  13 (12.1)  15 (14.0)  5 (4.7) |  |

**Figure 1A Bland-Altman plot for agreement at T0 (n=69)**



**Figure 1B Bland-Altman plot for agreement at T1 (n=69)**



**Table 2 Descriptives of patient and caregivers variables for dyads who completed both T0 and T1 (n=69)**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Descriptives T0** | | | **Descriptives T1** | | |
| **Patient and caregiver variables** | **Mean** | **SD** | **N** | **Mean** | **SD** | **N** |
| Patient fatigue | 30.68 | 13.32 | 69 | 31.71 | 14.50 | 69 |
| Caregiver fatigue proxy scores | 35.30 | 14.08 | 69 | 34.68 | 16.16 | 69 |
| Caregiver fatigue | 22.70 | 13.39 | 69 | 22.59 | 13.27 | 68 |
| Caregiver strain a | 2.87 | 1.86 | 68 | 2.87 | 2.06 | 67 |
| Caregiver self-esteem a | 26.38 | 3.78 | 66 | 25.78 | 4.25 | 68 |
| Caregiver relationship satisfaction b | 9.42 | 9.36 | 60 | 10.37 | 10.41 | 60 |

a Due to missing data total N is < 69. b Only calculated for ICs with a partner relation to the patient.

**Table 3 Predictor-CCS correlations for dyads who completed both T0 and T1 (n=69)**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Predictor-CCS T0 correlations** | | **Predictor-CCS T1 correlations** | |
| **Baseline predictor variables** | ***R*** | ***P* value** | ***R*** | ***P* value** |
| CCS T0 | 1 | n.a. | .373 | .002\* |
| Caregiver fatigue | .335 | .005\* | .418 | <.001\* |
| Caregiver strain a | .272 | .025\* | .342 | .004\* |
| Caregiver self-esteem a | -.319 | .009\* | -.234 | .058 |
| Caregiver relationship satisfaction b | .075 | .571 | .239 | .066 |

\* Statistically significant values (*p* < .05).

CCS = Continuous congruence score. a Due to missing data total N is < 69. b Only calculated for ICs with a partner relation to the patient.

**Table 4 Regression model to predict CCS T1**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Unstand. Coefficients** | | **Model Summary** | | | |
|  | **Beta** | **S.E.** | **d.f.** | **R2** | **R2 change** | **F change** |
| **Block 1**  CCS T0 | .357 | .125 | 1, 56 | .127 | .127 | 8.137\* |
| **Block 2**  CCS T0  Caregiver fatigue  Caregiver strain | .247  .138  1.135 | .128  .109  .766 | 1, 54 | .224 | .098 | 3.395\* |
| **Block 3**  CCS T0  Caregiver fatigue  Caregiver strain  Caregiver self-esteem  Caregiver relationship satisfaction | .231  .108  .986  -.193  .161 | .132  .112  .788  .440  .149 | 1, 52 | .250 | .026 | .884 |

\* Statistically significant values (*p* < .05).

CCS = Continuous congruence score.