

# Practices for Reporting Scale Structure and Summarizing Scores in Studies Using FAMCARE Scale to Assess Caregiver Satisfaction with Cancer Care: A Scoping Review

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**Background:** Satisfaction with care is a concept quantified through diverse measurement tools. However, studies have indicated that measuring satisfaction is challenging due to the construct's multidimensional expression. Thus, obtaining valid results requires careful consideration of the construct's nature and measurement methods.

**Purpose:** The primary aim of this study was to examine how studies involving cancer caregivers have addressed the dimensionality of the construct when using satisfaction with care as an outcome, and whether this is reflected in the score reporting practices. We chose to investigate this by conducting a scoping review of the measurement tool Family Satisfaction with End-of-Life Care Scale (FAMCARE Scale), where scores can be reported as the mean of overall score, subscale scores and single-item scores.

**Methods:** This scoping review consisted of systematic searches using Medline, CINAHL, Embase, PsycInfo, Cochrane Library, and Epistemonikos. Two researchers used the Rayyan Qatar Computing Research Institute system to perform a blinded screening process. We extracted information on study design, purpose, evaluating of structural validity, variations in the type of scores reported, and justification for choosing the type(s) of scores that were analyzed.

**Results:** Twenty-three studies were included in the review, and their designs and reporting practices of score type varied substantially. Five studies reported analyses to test the scale's structural validity. Ten studies provided a justification for their choice of reporting method. The most common reporting practice found was using mean of overall scores, present in 20 of the included studies. Twelve studies reported mean of subscale scores, and ten reported single-item mean scores.

**Conclusion:** We found substantial variability in score reporting practices, highlighting the need for a more in-depth understanding and reflection on the multidimensional nature of caregiver satisfaction.

**Keywords:** cancer caregiver, family caregiver, family satisfaction, neoplasm, palliative care

## Introduction

Dissatisfaction with the cancer care received by patients and their families can be a source of stress for family caregivers.<sup>1–3</sup> Hence, assessments of family caregivers' satisfaction with the care received is vital because it values the users' opinions and can provide helpful information about the services rendered.<sup>4</sup> For this reason, satisfaction with care is a widely used outcome measure to investigate and improve the quality of care in healthcare research.<sup>5,6</sup> The assessment of satisfaction may be defined as an evaluation of distinct dimensions of the care received by the patient or their family.<sup>2</sup> The satisfaction of family caregivers with the end-of-life care provided to patients with cancer is associated with several dimensions,

including accessibility, coordination, competence, symptom management, communication, education, emotional support, personalization of care, and decision-making support.<sup>5</sup>

Despite good intentions to measure satisfaction with care, studies have shown that the constructs and theory underlying satisfaction measurements are not simple. Thus, the utility and information derived from satisfaction measurements in health care have been repeatedly challenged for several reasons.<sup>4</sup> First, satisfaction is a construct that has been found to lack conceptual clarity and meaning,<sup>7</sup> such that a clear definition has not yet been defined.<sup>8</sup> Second, studies have indicated that measuring satisfaction is challenging due to the construct's multidimensional expression,<sup>7,8</sup> which occurs when it refers to different but related dimensions that are regarded as one theoretical concept.<sup>9</sup>

Although there is a consensus that satisfaction with care is multifaceted, many studies use surveys with items that measure overall satisfaction or treat the measures as unidimensional,<sup>7</sup> which means that the items or questions of a scale that all tap into the same underlying construct. In this approach, all items contribute equally,<sup>10</sup> and a sum score can represent an unobservable construct, such as satisfaction. This is acceptable as long the scale's development, analysis, interpretation, and results are based on a conceptual framework that explains how items relate to the construct and the measurement theory underlying the score generation.<sup>11</sup> Unidimensional measures are based on reflective (effect) indicators, which are expected to be correlated.<sup>12,13</sup> Variations in the observed item scores are considered an effect of the variations in the underlying latent construct. However, in a multidimensional measure based on formative (causal) indicators, the opposite is true,<sup>14</sup> whereby each item individually affects and forms the construct.<sup>12,13</sup> In the latter model, the latent construct captures the total variance among items that only represent a dimension of a concept.<sup>12</sup>

It is important for researchers to present the conceptual framework underlying the construct they measure. Furthermore, it is essential to clarify whether the scale of a multi-item instrument is a unidimensional or multidimensional scale, as these scales should be treated differently to avoid a misspecification of the scale's structure.<sup>12,13,15</sup> If this characteristic is not considered before the scale's use, the question of whether the instrument measures what it is intended to measure (construct validity) will not be resolved. In the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) checklist for assessing the methodological quality of studies, the COSMIN panel described construct validity as the degree to which an instrument truly measures the construct (s) it purports to measure.<sup>16</sup> Structural validity is an aspect of construct validity, which concerns the internal relationships between the items.<sup>17</sup> The use of appropriate statistical techniques is recommended, for example, confirmatory factor analysis (CFA) or structural equation modelling (SEM) to examine the relationship between items and dimensions of the construct.<sup>11,17</sup>

In light of the ongoing debate about the usefulness of satisfaction with care as an outcome measure, given that studies often indicate a tendency toward ceiling effects,<sup>18</sup> we wanted to explore how structural validity and the scales' dimensionality has been addressed in prior studies and whether this is reflected in the reporting practices of score results, if at all. Although several instruments are available to measure cancer caregiver satisfaction,<sup>19</sup> we have chosen to study the described challenges through the Family Satisfaction with End-of-Life Care (FAMCARE Scale).<sup>2</sup>

## The FAMCARE Scale

FAMCARE Scale was selected as it is a widely used measure in cancer research.<sup>19,20</sup> It is a 20-item self-report questionnaire with a Likert scale ranging from 1 to 5 (*Very Satisfied, Satisfied, Undecided, Dissatisfied, and Very Dissatisfied*). Responses from a Likert scale can be evaluated either as mean scores, depending on the type of item summarization, or as percentages, where the FAMCARE Scale ranges from 20 to 100, with higher scores indicating greater caregiver satisfaction with care provided.<sup>2</sup>

The FAMCARE Scale was developed and validated by Linda Kristjanson<sup>2</sup> and measures the degree to which family caregivers are satisfied with the healthcare that has been provided to the patient and themselves.<sup>2,21</sup> The scale was developed through a three-step process based on qualitative interviews with 20 caregivers of patients with advanced cancer. Caregivers identified important aspects of care from health professionals, resulting in 74 items for patient care and 77 for family care. The 20 items rated as most important became the 20 items on their scale. A cluster analysis of the 20 items suggested that the conceptual structure of the FAMCARE Scale may be unidimensional, encompassing four distinct sub scales: (1) *Information giving* (5 items), (2) *Physical patient care* (7 items), (3) *Psychosocial care* (4 items), and (4) *Availability of care* (4 items).<sup>2</sup> The FAMCARE Scale has later been validated and used in various cancer settings

and locations.<sup>3,22,23</sup> Both shortened (FAMCARE-5,-6,-10-19)<sup>3,24,25</sup> and revised versions (FAMCARE-2)<sup>26</sup> of the original 20-item FAMCARE Scale have been developed and tested in other studies.<sup>27</sup> In a validation study of the psychometric properties of the Norwegian version of the FAMCARE Scale, Ringdal et al<sup>3</sup> found that a strong one-dimensional scale may be formed out of 19 of the 20 items, when item 14; *time required to make a diagnosis* was removed. Subsequently, the FAMCARE Scale's unidimensionality has been confirmed by some<sup>3,23,25</sup> but not others.<sup>22,28</sup> Both Kristjanson<sup>2</sup> and Ringdal et al<sup>3</sup> encouraged further investigation into the reduction of items and the scale merits.

Based on our research questions, we have chosen to explore studies that include scales with 20 and 19 items. For the sake of simplicity, we refer to the scale as the FAMCARE Scale regardless of whether 19 or 20 items are used. However, when found clarifying we refer to FAMCARE-20 or FAMCARE-19. To the best of our knowledge, we have not encountered any prior research that addresses our specific approach.

## Aim

The primary aim of this study was to examine how studies involving cancer caregivers have addressed the dimensionality of the construct when using satisfaction with care as an outcome, and whether this is reflected in the practices of summarizing and reporting score. We chose to focus solely on the FAMCARE Scale to explore the topic in depth and to facilitate comparison between studies. To explore this topic more thoroughly, we established five sub-goals. We aimed to gain further insights into: (1) the studies' designs and characteristics, (2) their evaluation of the scale's structural validity, (3) their justification for the types of scores reported, (4) variations in the type of scores reported, and (5) the results of the overall mean score and single-item mean scores in each study to identify any score differences between them that may highlight the scale's clinical utility.

## Materials and Methods

### Study Design

This scoping review is conducted in accordance with the Joanna Briggs Institute (JBI) methodology for scoping reviews.<sup>29</sup> The results are reported using the preferred Reporting Items for Systematic Reviews and meta-analyses (PRISMA) guidelines,<sup>30</sup> and the PRISMA Extension for Scoping Reviews (PRISMA-ScR).<sup>31</sup>

### Eligibility Criteria

Studies that have investigated the satisfaction of family caregivers  $\geq 18$  years old, who cared for patients with cancer who were also  $\geq 18$  years old, were eligible for inclusion in our study if their satisfaction with care was measured using the 19-or 20-item FAMCARE Scale. The studies included all phases of the cancer trajectory and family caregivers of patients with cancer in hospitals, communities, and hospices. Articles published in English or Scandinavian languages were included. There was no limitation on the year of publication, and all types of studies were considered relevant as long as the results of the caregivers' satisfaction were reported as single-item, sub-scale, or sum scores.

## Information Sources

### Identification of Studies

A research librarian was consulted during the development of the search strategies. Systematic searches were conducted using Medline, CINAHL, Embase, PsycInfo, Cochrane Library, and Epistemonikos. The following search terms were used: "satisfaction with care", "caregiver",\* "carer",\* "family", "family satisfaction", "FAMCARE", "neoplasm", "palliative", "palliative care", and "cancer", (\*) signifies truncation. The systematic searches were conducted on June 19, 2019, with the last up-dated search in January 2024.

### Contacting Authors

To compare the overall and single-item means in the studies and determine whether important clinical details were missed when only overall mean scores were reported (aim 5), we contacted the authors of studies that did not report this information. We asked if they would be willing to share the data, in order to obtain as much available data as possible for this purpose.

## Data Selection

The Rayyan Qatar Computing Research Institute (QCRI) system was used to screen the imported references.<sup>32</sup> A blinded screening process was performed separately by two members of the study group, meaning that each person was unaware of the choices made by the other. Three screening options are available in the Rayyan QCRI system: include, exclude, or maybe. During the blind-off phase, the two authors discussed the “conflicting” and “maybe” articles, and agreed on which of the articles should proceed to a full-text reading. In addition to the selection through Rayyan QCRI system, we conducted manual searches from reference lists and performed updated searches at regular intervals. Quality assessment is not a mandatory step in a scoping review, and we did not consider it necessary for the purpose of current study.<sup>31</sup>

## Data Extraction and Synthesis

Based on the five sub-goals, we extracted the following data from each study:

Sub-goal 1: Study design and characteristics, including author name, country, cancer stage, number of participants, setting (eg hospital, home health care), the study’s objective and whether the 19-or –20-item version of the scale was used. Sub-goal 2: Information regarding the scale’s structural validity was assessed, specifically whether the assessment was based on a) an evaluation through testing and analysis conducted within the study itself, b) prior studies or c) no information regarding the scale’s structural validity was assessed. Sub-goal 3: Information on whether the researchers provided a justification for the choice of score type reported. By “justification of score reported”, we mean: a) if the reason is obvious, based on the method (eg factor-analysis), b) if the reason for chosen score is directly explained by the researchers, or c) if no justification for the choice of score type reported. Sub-goal 4: Information on whether mean of overall scores, subscores, and/or single-item scores were used to present the results. Sub-goal 5: Information on the values of the highest and lowest ranked single-item mean scores (in studies that reported mean of single-item scores) and the value of the overall mean score (if reported in studies that also reported mean of single-item scores).

In studies that reported the mean of single-item scores but did not report the mean overall score of all items, we calculated this to address sub-goal 5 as effectively as possible (Sum the scores of all mean single-item scores and divided by either 19 or 20). Reverse scoring, where a score of “1” indicated “very dissatisfied”, was reported in 6 of the 13 studies that reported single-item scores. This differs from the Likert scale used in Kristjanson’s study,<sup>2</sup> where a score of “1” indicated “very satisfied”. Thus, we recoded the values to enable comparison. Additionally, studies that presented results as percentages were also recoded to align with means derived from the Likert scale (1–5) for the sake of comparability.

The first author thoroughly read the articles, extracted the information needed, and structured and organized the sampled data into tables and figures. The last author reviewed the first author’s extraction and synthesis afterward.

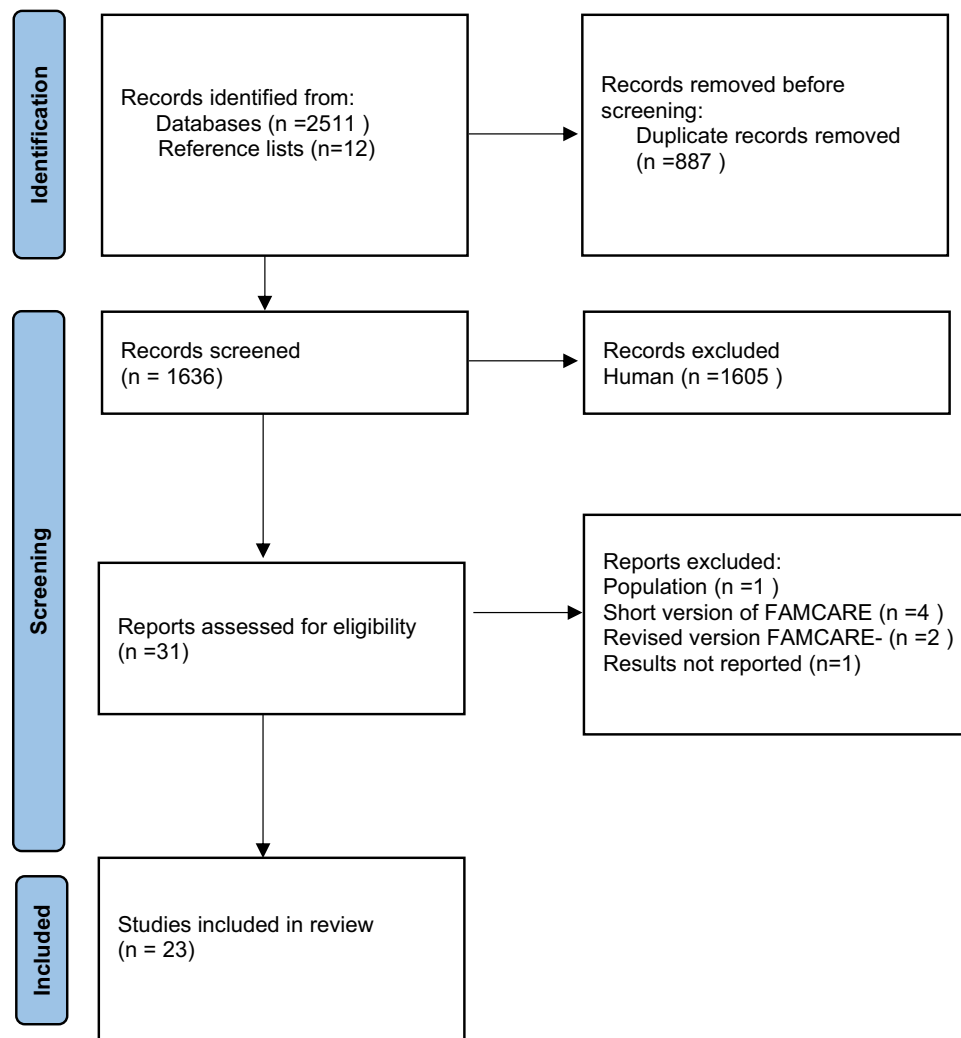
## Results

### Study Selection

The literature search yielded 1636 references after duplicates were removed. During the blinded phase, one of the authors included 50 references for full-text reading, the other author included 27, and 17 were in conflict. The author with the lowest number of included articles had categorized more of them as “maybe”. During the blind-off phase, the two authors discussed the “conflicting” and “maybe” articles, and agreed on which of the articles should proceed to a full-text reading. The majority of articles were excluded because the population did not meet the inclusion criteria, did not report results from the FAMCARE Scale, or used a shortened or modified version of the FAMCARE Scale. After including the manually searched articles from the reference lists and updated searches, we included 31 articles for full-text readings. The first author reviewed these, and after excluding articles that did not meet the inclusion criteria, 23 articles were included (see [Figure 1](#)). The included articles were reviewed independently by the first and last authors.

### Study Design and Characteristics

The characteristics of the included studies are presented in [Table 1](#). Seven studies investigated intervention effects<sup>33–39</sup> and four of the studies were randomized controlled trials (RCTs). None of the interventions were designed specifically for



**Figure 1** Flow diagram outlining the selection of studies for the scoping review.

**Notes:** Adapted from Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*. 2021;372.<sup>30</sup>

caregivers, and their satisfaction was examined based on their experience of the care given in the intervention (treatment) or control arm (standard care) of the study. Four studies used a retrospective analysis, in which the bereaved recalled their satisfaction with care at 1 month,<sup>37</sup> 3 months,<sup>34</sup> 2–12 months,<sup>40</sup> or 5.5 years<sup>41</sup> after the patient's death. One study<sup>42</sup> used a pre-/post-design, where satisfaction with care was measured at least six months after the patient's death. Fourteen studies used a cross-sectional design. In four of these,<sup>22–24,43</sup> the main aim was to develop a method for short versions of the original scale<sup>24,43</sup> or to validate the scale in another language.<sup>22,23</sup> These studies were included in the review because they also reported results of the FAMCARE-20. Three of the 23 studies<sup>33,39,44</sup> were longitudinal studies and three<sup>35,45,46</sup> were mixed-methods studies with quantitative and qualitative data. Two studies collected data using face-to-face interviews,<sup>40,47</sup> and a third conducted telephone interviews.<sup>43</sup>

## Reporting of the Scale Structure of the FAMCARE Scale

Most studies utilized the FAMCARE scale with 20 items, three used scale with 19 items,<sup>33,38,48</sup> while one validation study reported results from the analysis of both 19 and 20 items.<sup>37</sup> Thirteen of the 23 studies described the scale structure of the FAMCARE Scale with varying degrees of specification. The majority based their descriptions on previous studies, and only five studies<sup>22–24,28,46</sup> referred to scale structure based on the proprietary analyses derived from their original data sources. We observed a clear pattern: results concerning scale structure were typically found in studies that either employed a method and validation design or aimed to test the scale's structure<sup>22–24,28</sup> (see [Table 2](#) for more details).

**Table 1** Overview and Characteristics of the Included Articles (n = 23)

Study (Author, Year, Country)	Patients (Number, Phase of Cancer, Setting)	Study Design, Items in FAMCARE Scale	Aim
Augustussen et al (2017), <sup>45</sup> Greenland	N=30, Advanced cancer, Hospital	Cross-sectional, FAMCARE-20	To assess relatives' level of satisfaction with advanced cancer care and to bring to light their current main concerns.
Bergerød et al (2020), <sup>46</sup> Norway	N=238, Different stages, Hospital	Cross-sectional, FAMCARE-20	Explore next of kin satisfaction with cancer care, map their suggestions for involvement, and combine this information to establish a basis for improving quality and safety.
Can et al (2011), <sup>23</sup> Turkey	N=100, All stages, Hospital	Cross-sectional/ Method-validation, FAMCARE-20	To assess the psychometric validation of the QoL and FAMCARE Scales of Turkish family caregivers of cancer patients.
Carter et al (2011), <sup>24</sup> Australia	N=230, All stages, Outpatient Oncology service	Cross-sectional/ Method-validation, FAMCARE-20	To evaluate caregivers' experience of oncology services for ambulatory patients and develop a short instrument suitable for computerized administration in the clinical setting.
Castilla-Soto et al (2021), <sup>48</sup> Spain	N=147, Beginning of palliative care, Primary care health centers	Cross-sectional, FAMCARE-19a	To describe the QoL, burden, and satisfaction with care of family caregivers of cancer patients at the beginning of palliative care.
Chattat et al (2016), <sup>22</sup> Italy	N=132, All stages, Hospice, outpatient or inpatient setting	Cross-sectional/ Method-validation, FAMCARE-20	To prepare and validate an Italian version of the FAMCARE Scale.
Conlon M et al (2019), <sup>34</sup> Canada	N=96, End of life, Hospice	Retrospective, FAMCARE-20	To examine the impact of an ambulatory hospice palliative program on end-of-life care compared to care received by a matched control group of deceased patients. Caregiver satisfaction with care was measured after the patients' deaths.
Dhollander et al (2020), <sup>35</sup> Belgium	N=13, Advanced cancer, Home health care	Pilot study/ Longitudinal, FAMCARE-20 b	To determine the feasibility, acceptability, and perceived effectiveness of an early palliative homecare intervention.
Dudgeon et al (2008), <sup>36</sup> Canada	N=75, Palliative, Acute care, outpatient care and community residential care	Pre and post loss study, FAMCARE-20	To evaluate the effectiveness of implementation of assessment tools, collaborative care plans, and symptom management guidelines for cancer patients and their caregivers on symptom management, burden, and satisfaction with care.
Grunfeld et al (2004), <sup>44</sup> Canada	N=89, Terminal illness, Hospital	Cohort study, FAMCARE-20 b	To examine the psychosocial, occupational, and economic impact of caring for a person with advanced breast cancer over the course of the life-limiting illness.
Hanks et al (2002), <sup>39</sup> UK	N=127, Palliative, Hospital	RCT, FAMCARE-20 b	To evaluate a hospital specialist PCT. Compare outcomes of patients and their randomized caregivers who received one of two models of advice and support from a multidisciplinary specialist PCT.
Hwang et al (2003), <sup>49</sup> US	N= 100, Advanced cancer, Hospital	Cross-sectional, FAMCARE-20	To identify the caregiver characteristics and their unmet needs, association between caregiver unmet needs and caregiver satisfaction, and identify predictors of different caregiver outcomes.
Ito et al (2017), <sup>50</sup> Japan	N=74, Terminal cancer, Home	Cross-sectional, FAMCARE-20	To identify the factors associated with the quality of life of family caregivers with a terminal cancer patient at home.
Johnsen et al (2012), <sup>28</sup> Denmark	N= 467, Advanced cancer, Hospital	Cross-sectional, FAMCARE-20	To investigate the scale structure of the FAMCARE-20, to investigate satisfaction with care from the perspective of the relatives of cancer patients, and to investigate whether some subgroups of relatives were more dissatisfied than others.
Kebebew et al (2022), <sup>51</sup> Ethiopia	N=360, Advanced cancer, Hospital	Cross-sectional, FAMCARE-20	To evaluate the satisfaction of family caregivers of patients with advanced cancers.
Mah et al (2023), <sup>40</sup> Uganda	N=202, End of life, Hospice care	Cross-sectional, FAMCARE-20	To evaluate the quality of dying and death of patients with cancer in hospice care, according to bereaved caregivers of deceased patients.
McDonald et al (2017), <sup>33</sup> Canada	N=182, Advanced cancer, Hospital	Cluster-RCT, FAMCARE-19	To explore the effect on caregivers of an intervention of early referral of patients with cancer to palliative care versus standard care
Morishita-Kawahara et al (2022), <sup>42</sup> Japan	N=144, Terminal cancer, Hospital	Prospective pre-post loss study, FAMCARE-20	To clarify family caregivers' satisfaction with the care of terminal cancer patients and bereaved family caregivers' quality of life.
Naoki et al (2018), <sup>41</sup> Japan	N=23, Far advanced, Hospital	Cross-sectional, FAMCARE-20	To conduct a researcher-assisted questionnaire survey to clarify the impact of caregiver burden on family satisfaction in order to determine the types of burden that decrease family satisfaction.

(Continued)



**Table 1** (Continued).

Study (Author, Year, Country)	Patients (Number, Phase of Cancer, Setting)	Study Design, Items in FAMCARE Scale	Aim
Ornstein et al (2017), <sup>43</sup> US	N=1979, Advanced cancer, Hospital	Cross-sectional/ Method-testing, FAMCARE-20	To test the ability of a new short version (5-item) questionnaire on family satisfaction with care to accurately capture differences across hospital settings.
Ozcelik et al (2015), <sup>47</sup> Turkey	N=145, Advanced cancer, Hospital	Cross-sectional, FAMCARE-20	To determine the satisfaction levels of family members of patients with advanced-stage cancer.
Ringdal et al (2002), <sup>37</sup> Norway	N=183, Incurable, Hospital and Community care	RCT, FAMCARE-20 c	To examine similarities and differences in satisfaction with care between family members who were close to patients who had participated in an intervention with a comprehensive palliative care program and family members in conventional care.
Skorstengaard et al (2019), <sup>38</sup> Denmark	N=65, Severely ill patients, Hospital	RCT, FAMCARE-19	To investigate the effects of advanced care planning on patients with lung and heart diseases and cancer, as well as their caregivers.

**Notes:** a The number of items was not specified in the article; however, they referred the FAMCARE scale to a study where 19 items were employed. b The number of items was not specified in the article; however, they referred to Kristjanson's original 20-items FAMCARE scale. c Reported results for both 19 and 20 items.

**Abbreviations:** FAMCARE Scale, Family Satisfaction with End-of-Life Care Scale; PCT, palliative care team; QoL, quality of life; RCT, randomized controlled trial.

**Table 2** Presentation of What the Studies Reported Regarding Type of Scores, Justification for Chosen Scoring Type(s), and Whether Scale Structure Was Assessed or Tested

Authors, Year	Reported Overall Score	Reported Subscale Scores	Reported Single-Item Scores	Justification for Score Type Reported	Described the Scale Structure Derived from Previous Studies	Present Results of the Structural Validity in Own Study
Augustussen et al, (2017) <sup>45</sup>	No	No	Yes	No	Yes	No
Bergerød et al, (2020) <sup>46</sup>	Yes	Yes	Yes	No	Yes	Yes j
Can et al, (2011) <sup>23</sup>	Yes	Yes	Yes	Yes c	Yes	Yes i
Carter et al, (2011) <sup>24</sup>	Yes	Yes	Yes	Yes d	Yes	Yes j
Castilla-Soto et al, (2021) <sup>48</sup>	Yes	No	No	No	No	No
Chattat et al, (2016) <sup>22</sup>	Yes	Yes	Yes	Yes c	Yes	Yes i
Conlon et al, (2019) <sup>34</sup>	Yes	Yes	No	Yes e	Yes	No
Dhollander et al, (2020) <sup>35</sup>	Yes	No	No	No	No	No
Dudgeon et al, (2008) <sup>36</sup>	Yes	Yes	No	No	Yes	No
Grunfeld et al, (2004) <sup>44</sup>	Yes	No	No	No	No	No

(Continued)

**Table 2** (Continued).

Authors, Year	Reported Overall Score	Reported Subscale Scores	Reported Single-Item Scores	Justification for Score Type Reported	Described the Scale Structure Derived from Previous Studies	Present Results of the Structural Validity in Own Study
Hanks et al, (2002) <sup>39</sup>	No	Yes	No	No	No	No
Hwang et al, (2003) <sup>49</sup>	Yes	Yes	No	No	Yes	No l
Ito et al, (2017) <sup>50</sup>	Yes	No	No b	No	No	No
Johnsen et al, (2012) <sup>28</sup>	No	Yes	Yes	Yes f	Yes	Yes k
Kebebew et al, (2022) <sup>51</sup>	Yes	Yes	Yes	No	No	No
Mah et al, (2023) <sup>40</sup>	Yes	No	Yes	Yes f,g	No	No
McDonald et al, (2017) <sup>33</sup>	Yes	No	No a,b	Yes f,g	No	No
Morishita-Kawahara et al, (2022) <sup>42</sup>	Yes	Yes	No	No	No	No
Naoki et al, (2018) <sup>41</sup>	Yes	No	Yes	Yes f	Yes	No
Ornstein et al, (2017) <sup>43</sup>	Yes	No	No b	Yes d	Yes	No h
Ozcelik et al, (2015) <sup>47</sup>	Yes	Yes	No	No	Yes	No
Ringdal et al, (2002) <sup>37</sup>	Yes	No	Yes	Yes f	Yes	No h
Skorstengaard et al, (2019) <sup>38</sup>	Yes	No	No	No	No	No

**Notes:** Characteristics, a Described rankings of single item scores, but the numbers were not reported in a table, b Single score results shared by the author after request, c Due to psychometric validation, d Due to developing and testing a short-version of the FAMCARE Scale, e Used for composite subscales, f Used to report single-item score results, g Single-item score reported due to correlation or exploratory analyze, h The authors have performed and reported in a previous study, i Principal component analysis, j Exploratory factor analysis, k Confirmative factor analysis, l Conducted a principal component analysis to examine mutually orthogonal underlying dimensions between different tools, but not an analysis of the scale structure of the FAMCARE Scale itself.

**Abbreviation:** FAMCARE Scale, Family Satisfaction with End-of-Life Care Scale.

Examples of common statements from those who described their scale's structure without investigating it included: "The tool has a conceptual structure with four subscales", "The FAMCARE Scale has been validated in studies", and "To calculate composite scales, we followed recommendations by Kristjanson", among others.

## Structural Validity

In five of the studies, the results of the analysis revealed a pattern of items loading onto factors. A common characteristic was that the findings revealed different factors compared to the original four dimensions described in Kristjanson's study.<sup>2</sup>



Bergerød et al<sup>46</sup> conducted an exploratory factor analysis with 19 of 20 items, following a previous validation study,<sup>3</sup> in which item 14 (*Time required to make a diagnosis*) was excluded to strengthen the unidimensional scale. Bergerød et al<sup>46</sup> obtained only 2 factors in their analysis of the group of items that loaded > 0.6 (treatment-related items and Involvement-related items). Four items loaded < 0.6 and were not included in the subtotals, but were reported as single scores. Can et al<sup>23</sup> performed a principal component analysis in which the factor extraction resulted in three factors, and the content of the items in the three-factor structures of the scale was different from the results of Kristjanson's study.<sup>2</sup> Due to the eigenvalues in this scale of 10.21, 1.36, and 1.30, they decided that a one-dimensional scale might be formed from the 20 items. In the Carter et al<sup>24</sup> study, an exploratory factor analysis was conducted on both the four subscales and on the 20 individual items regarding the development of a 6-items version of the FAMCARE-20. In the first analysis, only one dimension had an eigenvalue over 1 (3.6), accounting for 80% of the variance. In the second analysis, there were two dimensions with eigenvalues >1, accounting for 52% and 7% of the variance. Based on these findings, they also suggested that the FAMCARE-20 had one primary underlying dimension of satisfaction with care, which formed the basis for reducing items that were highly representative of one another. Chattat et al<sup>22</sup> conducted a principal component factor analysis to explore the conceptual structure of an Italian version of the FAMCARE-20. Four factors were identified, and one of them differed from Kristjanson's original subscales.<sup>2</sup> All twenty items had high factor loadings, and based on these results they concluded that each item was necessary to measure the level of satisfaction. Johnsen et al<sup>28</sup> conducted a confirmative factor analysis to test the FAMCARE-20 Scale's dimensionality in their study. The analysis showed that their data did not fit well with Kristjanson's<sup>2</sup> proposed unidimensional scale structure; hence, the researchers performed the analysis at the single-item level. However, to allow for comparisons to other studies, they also reported subscale scores in accordance with Kristjanson's four-scale structure.<sup>28</sup> In the study by Ringdal et al,<sup>37</sup> the correlations of both 19 and 20 items were analyzed and reported in a previous validation study based on the same data set.<sup>3</sup> The factor analysis in this sample resulted in one strong factor with an eigenvalue of 10.95, and two weak factors with an eigenvalue of 1.52 and 1.08 when item 14 was removed. Because of these results, the researchers concluded that the 19 items tap into a single underlying dimension.

## Type of Score Reporting

Three studies<sup>22,24,51</sup> reported the mean of overall score, mean of subscale scores and single-item mean scores, whereas the remaining 20 studies reported one or two score types. The score reporting type of each study is presented in Table 2.

## Reporting the Mean of the Overall Score

Twenty of the 23 studies reported the mean of overall scores, but seven of them reported only this mean.<sup>35,36,38,39,43,44,48,50</sup> Of these seven studies, three<sup>35,36,38</sup> used the mean of overall scores to report the effects of an intervention; the other four<sup>43,44,48,50</sup> were observational studies.

## Reporting the Mean of the Subscale Scores

Twelve studies reported mean results for the subscale scores.<sup>22–24,28,34,36,39,42,46,47,49,51</sup> One study<sup>39</sup> reported only this type of score and the others reported mean subscale scores in addition to mean single-item scores,<sup>28</sup> mean overall scores<sup>34,36,42,47,49</sup> or both.<sup>22–24,51</sup> Studies that reported mean subscale score results were characterized by the following: conducting factor analyses of scale structures, reporting the validity of the FAMCARE Scale in another language or a short version of the questionnaire, evaluating interventions, or solely observed caregivers' satisfaction with care. Five of eleven studies that reported subscale scores, tested the correlations between the 20 items,<sup>22–24,28,46</sup> The other six studies calculated scores for the mean subscale results based on Kristjansen's<sup>2</sup> four original scale dimensions, without conducting their own factor analyses.

## Reporting the Mean of Single-Item Scores

Ten<sup>22–24,28,37,40,41,45,46,51</sup> of the 23 studies reported the mean scores of single-items. To examine the differences between the mean overall scores and mean single-item scores within the studies, we asked the authors of the studies who did not

report this scores to share these data if available. Three authors replied and sent us their results. Thus, we had a total of 13 articles with mean single-item scores available for this purpose. Only 11 of them could be used in the comparison due to the different reporting patterns and difficulty fitting them into the table. One study<sup>43</sup> had re-coded to less Likert scale response categories compared to those used in Kristjanson's<sup>2</sup> original FAMCARE-20, and another study had reported percentages in colored columns that were too inaccurate to include.<sup>41</sup>

## Justification for Score Reporting

Authors of ten studies<sup>22–24,28,33,34,37,40,41,43</sup> demonstrated the type of score they reported through their methodologies or elucidated reasons for their selections. Their reasons included psychometric validation, developing and testing a short version of the FAMCARE-20, facilitation of composite sub-scales, and reporting variation in single-item scores. When a reason was stated or was self-explanatory, the description of the justification was nevertheless given minimal space. [Table 2](#) provides an overview of the justifications for the score types reported for each study.

## Mean Scores Variations Within Each Study

We observed variations between the overall mean score of all items and the means of the best and worst-rated single items within each study. The extent of these differences varied among studies. Importantly, none of the studies reported an overall mean indicating caregiver dissatisfaction. Nevertheless, this analysis highlights the significant variability in the scores of the best and worst single items within each study. In five of these studies, there was a difference of 1 or more between the best and worst single-item scores. As an example, Augustussen et al<sup>45</sup> scored 2.4 as best for *the patient's pain relief* and 3.8 for *the time required to make a diagnosis and the way the family is included in treatment and care decisions* as the worst of the single-item scores. The variations in mean scores within each study are presented in [Table 3](#).

**Table 3** The Overall Score of the Mean of All Items and Item(s) with Best and Worst Scores in Each Study Reporting Single Item-Scores

Study	Overall Score, Mean <sup>a</sup>	Best Single-Item Score, (Mean) <sup>b</sup>	Worst Single-Item Score, (Mean)
Augustussen et al, (2017) <sup>45</sup>	3.0	Item 6: The patient's pain relief (2.4)	Item 14: Time required to make diagnosis (3.8), Item 15: The way the family is included in treatment and care decisions (3.8)
Bergerød et al, (2020) <sup>46</sup>	1.8	Item 6: Availability of a hospital bed (1.4)	Item 7: Family conferences held to discuss the patient's illness (2.9)
Can et al, (2011) <sup>23</sup>	2.1	Item 1: The patient's pain relief (1.8), Item 12: Availability of nurses to the family (1.8)	Item 4: Information given about side effects (2.4)
Carter et al, (2011) <sup>24</sup>	2.1	Item 10 The way tests and treatments are performed (1.8), Item 19: The way tests and treatments are followed up by the doctor (1.8)	Item 6: Availability of hospital be (2.4)
Chattat et al, (2016) <sup>22</sup>	1.5	Item 12: Availability of nurses to the family (1.2)	Item 7 Family conferences held to discuss the patient's illness (1.8)
Ito et al, (2017) <sup>50</sup>	2.5	Item 12: Availability of nurses to the family (2.1)	Item 5 Referrals to specialists (2.7), Item 6 Availability of hospital bed (2.7)

(Continued)

**Table 3** (Continued).

Study	Overall Score, Mean <sup>a</sup>	Best Single-Item Score, (Mean) <sup>b</sup>	Worst Single-Item Score, (Mean)
Johnsen et al, (2012) <sup>28</sup>	2.2	Item 12: Availability of nurses to the family (1.9)	Item 7 Family conferences held to discuss the patient's illness (2.5), Item 14: Time required to make diagnosis (2.5)
Kebebew et al, (2022) <sup>51</sup>	2.1	Item 12: Availability of nurses to the family (1.8)	Item 14 Time required to make diagnosis (2.8)
Mah et al, (2023) <sup>40</sup>	2.1	Item 16: Information given about how to manage the patient's pain (1.8)	Item 14 Time required to make diagnosis (2.8)
McDonald et al, (2017) <sup>33c</sup>	1.9	Item 9: Doctor's attention to patient's description of symptoms (1.7), Item 10: The way tests and treatments are performed (1.7)	Item 7 Family conferences held to discuss the patient's illness (2.3)
Ringdal et al, (2002) <sup>37d</sup>	2.2	Item 12: Availability of nurses to the family (1.6)	Item 14 Time required to make diagnosis (3.1)
Ringdal et al, (2002) <sup>37e</sup>	2.5	Item 12: Availability of nurses to the family (1.8)	Item 14 Time required to make diagnosis (3.1)

**Notes:** a:Overall mean score calculated by us, based on the reported single-item mean score results in the article, b:Scores ranged from 1 to 5 (Very Satisfied, Satisfied, Undecided, Dissatisfied and Very Dissatisfied), c:Item 14 excluded, d:Intervention, e:Control.

## Discussion

### Principal Findings

This scoping review identified varying reporting practices in studies that measured family caregivers' satisfaction with care in the context of cancer care, using the FAMCARE Scale. We observed variations in the descriptions of the scale's structure, in which only five of 23 studies reported results of structural validity based on their own data. We also found that justifications for the type of score reported were limited. Furthermore, a large variation in score types (single-item, subscale, or overall) reporting was detected, with a minority of studies reporting single-item scores. Our comparisons between the overall mean score and the means of the best and worst single-item-scores within each study show that caregivers sometimes varied widely in their responses to the FAMCARE items.

### How Designs and Characteristics of Studies Affect Reporting Practices

First, we observed that the design and purpose of the studies often appeared to influence the type of score and analysis reported by the researchers. A clear pattern was observed in which the results of analyses of scale structure were published in studies with a method and validation design or the objective of testing the scale's structure. We also found that both single-item and subscale score results were reported in a majority of studies with this type of design. This finding is expected and an obvious reason for presenting such scores, considering the methods commonly used to assess the reliability and validity of the construct.<sup>16,52</sup> Only two other studies<sup>28,46</sup> that did not have a typical method or validation design include and report their analyses of structural validity in their studies. Two other studies reported having performed scale structure validation in previous studies.<sup>37,43</sup> Among this review's RCTs, caregivers' satisfaction with care was most often a secondary outcome of the interventions; they were designed for patient care and were typically reported superficially, with only subscale and overall scores.<sup>38,39</sup> The RCTs that reported single-item scores<sup>33,37</sup> were secondary publications of data from the main RCT. Among the RCTs that reported and discussed single-item scores, the results favored the intervention, whereas the studies that did not find a significant effect of the intervention did not report single-item scores. None of the three non-randomized intervention studies<sup>34-36</sup> reported single-item scores, but two of them reported subscale scores based on Kristjanson's four original dimensions.<sup>34,36</sup> One possible explanation for

the limited emphasis on caregiver outcomes in the RCT studies can be attributed to constraints, such as word limits imposed by journals and the study's primary objectives. Another possible reason could be publication bias.<sup>53</sup> The fact that the interventions were aimed primarily at the patients and not the caregivers may also explain the limited focus on the caregivers in these publications. One could also speculate whether caregivers' satisfaction has been implemented as a measure without researchers having a solid rationale for including it as a measure, and thus, not focusing on its reporting. We found no pattern indicating that the other characteristics we examined, beyond design and purpose, influenced the reporting practices.

## Justification for Reporting and the Focus on the Scale's Structure

In a systematic review, de Vet et al<sup>54</sup> found that crucial information and results on the methods and factor analyses were missing in many publications, which supports our findings. We found that researchers rarely justify their choice of score types reported. Whether a tradition of justifying reasons for choosing score types is lacking or for other reasons, this behavior remains unclear, as noted by Crow et al.<sup>55</sup> A significant number of the included studies did not mention anything about the FAMCARE Scale's structure. The majority of studies simply contained a line or two stating that the instrument was developed by Kristjanson, validated in several studies, and that the scale was found to be unidimensional in previous research. However, we must also keep in mind that factor analysis may have been conducted but not reported in the publications we examined in this review. Another explanation for why factor analysis was not conducted is that there were too few participants included in the studies, compared to the recommended number of participants for this type of analysis.<sup>11</sup>

## Structural Validity of the FAMCARE Scale

By comparing and summarizing the results of the five studies in our review that performed factor analysis, the importance of conducting factor analysis to detect dimensions of the construct within a specific sample or context is apparent. This is especially true regarding the use of subscales. None of the five studies reported identical factor loadings during testing, resulting in a different scale structure and grouping of items compared to the original scale proposed by the developers of FAMCARE Scale. Differences in factor structures in other studies compared to Kristjanson's original proposal have also been noted in another study.<sup>20</sup> Summing items to form subscores would, in our opinion, not be accurate if based solely on other studies. The FAMCARE Scale has been described in the research literature as setting-dependent, with results potentially influenced by factors, such as culture, healthcare systems, norms, or the context in which the study is conducted.<sup>5,22,24,56</sup> Attention to the situation and setting is important during the analyses; therefore subscale scores should be based on factor analyses to confirm the scale's structure, especially when the measurement is used across different groups and in new settings.<sup>54</sup> Based on the results of this review, our recommendation is to present mean of single-item scores instead of mean of sub-scale scores unless a factor analysis has been conducted.

## FAMCARE Scale- A Reflective or Formative Measure or Somewhere Between?

The discussion about differences between reflective and formative indicators emerged in 2005, and researchers might not have been aware of this distinction at the time their research was conducted.<sup>12</sup> The current literature on formative measurement models is sparse compared with the more dominant classical test model, and as far as we know, it has not been prominent in the research on satisfaction with cancer care.

Kristjanson<sup>2</sup> developed the FAMCARE Scale in the early 1990s and encouraging further testing of the scale to expedite new knowledge. We have taken on the challenge and propose a different explanation for why the FAMCARE Scale structure does not always show unidimensionality. Could it be that the items in the scale represent different themes, and therefore, cannot be treated as a reflective measure? It has been suggested that a one-factor model in confirmatory factor analysis is likely due to a lurking variable causing items to correlate.<sup>57</sup> This argument has been given less attention in the research literature.<sup>12</sup> For example, the FAMCARE items related to the availability of a hospital bed and how thoroughly a doctor assesses a patient's symptoms cannot reflect the same unidimensional construct simply because they are not interchangeable. These items capture different facets of satisfaction and do not reflect one facet, as expected in a reflective measure.<sup>57</sup> The presence of several items with clearly different content in the FAMCARE Scale suggests that based on measurement theory,<sup>11</sup> the scale may function more like a formative measure. If this is true, the overall score of

items on the FAMCARE Scale might not accurately reflect family caregivers' unidimensional satisfaction with care. This result could lead to biased estimates of the structural relationship involving the construct.<sup>12</sup> However, some items on the FAMCARE Scale are more similar to each other than to others and may cluster, forming subdimensions. A multidimensional construct could incorporate a combination of reflective and formative items at various levels. Subscale scores may consist of multiple reflective items, contributing to the formative overall score.<sup>12</sup> Thus, the construct of cancer caregivers' satisfaction with care, as measured by the FAMCARE Scale, can be interpreted as a mix of both reflective and formative indicators. Hence, it could be appropriate to report both single-item and subscale scores (if based on factor analysis) while avoiding overall mean scores.

## Single-Item Mean Scores Can Inform Clinical Practice

Regardless of whether one understands the FAMCARE Scale as a reflective or formative measure, this scoping review found important differences between the overall mean score values, as well as the worst and the best mean single-item scores within each study. This knowledge is important if the researchers' goal is to yield findings to serve as a basis for guiding quality improvement in the clinical setting.<sup>55</sup> Even if the overall mean score is fairly good, some of the single-items may be experienced as problematic for some caregivers. Therefore, to improve the care provided to the caregivers, all aspects of satisfaction should be taken into consideration. The practice of reporting only the overall score of composite measures can mask individual items and, in turn, result in the loss of valuable information about specific aspects of family cancer caregivers' satisfaction.<sup>10,18</sup> For example, items might be discarded because they do not correlate or a conclusion might be based only on an overall mean score, even though some components deviate significantly from the average.<sup>13,58</sup> This challenge has been exemplified in this review; in some of the included studies, the results of single-item scores provided valuable information when evaluating the effects of interventions or differences identified in settings (phase) and locations (geographical).<sup>33,37,46</sup> Ringdal et al<sup>37</sup> found that the caregivers in the intervention group reported significantly higher satisfaction with items regarding information (eg pain relief and assessments of patients' symptoms) than the caregivers in the control group reported. In the McDonald et al RCT,<sup>33</sup> a difference in improvement over time was found at the item level in favor of the caregivers in the intervention group. Bergerød et al<sup>46</sup> compared caregiver satisfaction in two hospitals and analyzed differences based on the individual items. Similar differences between the means of single-item scores and the means of overall scores have also been observed and reported in studies conducted in intensive care units,<sup>59,60</sup> where satisfaction with care was measured with another multi-item instrument.

## Strengths and Limitations

The strength of this scoping review lies in our uncovering of diverse practices in calculating and reporting scores. Diverse practices in reporting are a challenge to comparisons of studies. Furthermore, our findings, particularly those about the limited attention given to the structure of the FAMCARE Scale, may stimulate reflection on the use of this instrument both in research and practice.

A limitation is that we did not include studies with short versions of the FAMCARE Scale, or studies conducted in other palliative care settings (eg for patients with heart or lung disease). The number of articles could have been higher and the dataset larger if we had not excluded them. Nevertheless, this exclusion made it possible to explore in depth, the status of reporting in family cancer caregiver settings.

## Conclusions

Based on this review's findings, we encourage future researchers to publish results that are more detailed, including single-item scores when using the FAMCARE Scale to measure cancer caregivers' satisfaction with care. Each aspect of the construct of the cancer caregiver's satisfaction with care could provide valuable insights. A transition to more reporting of single-item mean scores could provide nuanced insights into caregiver satisfaction. A testing of the scale structure that is more thorough could enhance the understanding of its structural validity in each study. We also urge researchers to clarify the intended use of the type of scores reported to promote transparency and facilitate comparability across studies. Finally, we hope researchers will engage in discussions and empirical testing regarding the claim that the

FAMCARE Scale could be best understood as a formative measure or a scale combining both formative and reflective characteristics.

## Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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