OPEN

# **Measuring Self-Care**

## A Description of the Family of Disease-Specific and Generic Instruments Based on the Theory of Self-Care of Chronic Illness

Barbara Riegel, PhD, RN, FAAN; Maddalena De Maria, PhD, RN; Claudio Barbaranelli, PhD; Michela Luciani, PhD, RN; Davide Ausili, PhD, RN; Victoria Vaughan Dickson, PhD, RN, FAAN; Tiny Jaarsma, PhD, RN, FAAN; Maria Matarese, MSN, RN; Anna Stromberg, PhD, RN, FAAN; Ercole Vellone, PhD, RN, FAAN

Background: In recent years, there has been an exponential increase in attention paid to the patient-reported outcome of self-care. Many investigators have used one of the families of self-care instruments freely available on the website www.self-care-measures.com. These self-care measures have been translated into many languages, which are also available on the website. The measures include both disease-specific and generic instruments, which are based on a common theoretical framework, the Middle Range Theory of Self-Care of Chronic Illness. Purpose: The purpose of this article is to illustrate similarities among the instruments and to standardize their scoring, analysis, and use. We describe the Self-Care of Heart Failure Index, the Self-Care of Coronary Heart Disease Inventory, the Self-Care of Hypertension Inventory, the Self-Care of Diabetes Inventory, the Self-Care of Chronic Obstructive Pulmonary Disease Inventory, the Self-Care of Chronic Illness Inventory, and the Self-Care Inventory. Detailed guidance on scoring, translation, and analysis is provided. Complementary measures of self-care self-efficacy and those used to measure caregiver contributions to patient self-care are briefly described. Conclusions: Many of the common questions of instrument users are answered in this article. Following this guidance will facilitate consistent use of the instruments, which will enable users to compare their results to those of others worldwide and facilitate future reviews and meta-analyses. Clinical Implications This review, emphasizing standard scoring and interpretation, is useful for clinicians and researchers across various populations and settings.

## **KEY WORDS**: self-care, self-management, caregivers, chronic disease, patient-reported outcome measures, psychometrics

#### Barbara Riegel, PhD, RN, FAAN

University of Pennsylvania, Philadelphia; and Center for Home Care Policy & Research at VNS Health, New York, New York.

Maddalena De Maria, PhD, RN Link Campus University, Rome, Italy.

Claudio Barbaranelli, PhD

Sapienza University, Rome, Italy. Michela Luciani, PhD, RN University of Milano-Bicocca, Italy.

**Davide Ausili, PhD, RN** University of Milano-Bicocca, Italy.

Victoria Vaughan Dickson, PhD, RN, FAAN University of Connecticut, Storrs, CT.

Tiny Jaarsma, PhD, RN, FAAN Linkoping University, Sweden.

Maria Matarese, MSN, RN Campus Bio-medico University of Rome, Italy.

Anna Stromberg, PhD, RN, FAAN Linkoping University, Sweden.

#### Ercole Vellone, PhD, RN, FAAN

University of Rome Tor Vergata, Italy. Wroclaw Medical University, Poland.

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#### Correspondence

Barbara Riegel, PhD, RN, FAAN, University of Pennsylvania School of Nursing, Center for Home Care Policy & Research at VNS Health, 418 Curie Blvd. Philadelphia, PA 19104-4217 (briegel@nursing.upenn.edu). DOI: 10.1097/JCN.000000000001146 Abbreviations: HF—heart failure, SCHFI—Self-Care of Heart Failure Index, SC-CHDI—Self-Care of Coronary Heart Disease Inventory, SC-HI—Self-Care of Hypertension Inventory, SCODI—Self-Care of Diabetes Inventory, SC-COPDI—Self-Care of Chronic Obstructive Pulmonary Disease Inventory, COPD—chronic obstructive pulmonary disease, SC-CII—Self-Care of Chronic Illness Inventory, SCI—Self-Care Inventory, CC—caregiver contributions, PCA—principal component analysis, EFA—exploratory factor analysis, CFA—confirmatory factor analysis, ME—measurement equivalence

S elf-care is widely recognized as a core element of successful health maintenance and illness management. With this recognition comes the need for valid instruments to assess self-care. Our international research group has developed and psychometrically tested several measures of self-care that are freely distributed on our website https://self-care-measures.com/ and used by interdisciplinary clinicians and researchers worldwide. This article addresses the questions we commonly receive from instrument users. The purpose of this article is to illustrate similarities among the instruments and to standardize their scoring, analysis, and use.

The instruments discussed in this article are based on the Middle Range Theory of Self-Care of Chronic Illness.<sup>1</sup> This theory was developed to capture a holistic view of patients—those with varied or multiple chronic conditions. Self-care is the overarching construct built from the 3 core concepts of self-care maintenance, self-care monitoring, and self-care management. We defined selfcare as a process of maintaining health through healthpromoting practices and managing illness.<sup>1</sup> Self-care is performed in both healthy and ill states.

Self-care maintenance refers to the behaviors that individuals adopt to maintain physical and emotional stability (eg, physical activity). These practices help them manage their health effectively. Self-care monitoring reflects the ongoing assessment of health status. These behaviors involve paying attention to signs and symptoms and tracking progress. Self-care management captures the response to signs, symptoms, and changes as they occur. These are the steps individuals take to adjust their self-care practices and manage their condition. Self-care management behaviors include the thoughtful choice of treatment options or reflection. Reflection influences self-care so the final item in most instruments asks how sure the respondent is about the effectiveness of recent self-care management behaviors.

The Middle Range Theory of Self-Care of Chronic Illness recognizes that various factors influence self-care, including experience, skill, motivation, culture, confidence, habits, functional and cognitive abilities, and support from others. One of the factors most influential in stimulating self-care is the presence of symptoms.<sup>2</sup> Symptom detection, interpretation, and response are central elements of the self-care process. Yet, many people with chronic physical disease have less insular gray matter and abnormal insular activity, which can affect interoception or the ability of the brain to perceive, elaborate, and respond to internal signals such as symptoms.<sup>3</sup> For this reason, the

theory was updated in 2019 to describe how symptoms influence self-care.<sup>4</sup> In 2022, we suggested that symptom recognition mediates the influence of symptoms on the adoption of self-care behaviors.<sup>5</sup> This suggestion influences the scoring and analysis of the self-care instruments, as described hereinafter.

### Existing Self-Care Instruments

The instruments described hereinafter have been used in a wide variety of situations, countries, and settings. Five are disease-specific measures that capture the selfcare behaviors recommended for a particular chronic condition (ie, heart failure [HF], coronary heart disease [CHD], hypertension, diabetes, and chronic obstructive pulmonary disease [COPD]), and 2 are generic measures that capture common self-care behaviors regardless of condition (ie, populations with and without chronic illness). Responses are usually self-reported, but the instruments can be administered by interview when necessary. Most instruments can be completed in 10 minutes. The only limitation is administration at the time of the diagnosis because self-care is a learned skill; presumably, a newly diagnosed patient may not yet have learned what to monitor and how to manage symptoms. Many include a measure of self-care self-efficacy because confidence influences self-care, as discussed hereinafter. Most include a final item addressing reflection.

A generic self-care instrument may be useful if a diseasespecific instrument is unavailable, when the sample has more than 1 chronic condition, when the investigator is not interested in disease-specific behaviors, or to minimize subject burden.<sup>6</sup> In a secondary analysis of data from 896 Italian patients with multiple chronic conditions, participants completed the Self-Care of Chronic Illness Inventory (SC-CII) and a disease-specific Self-Care of HF Index (SCHFI), Self-Care of Diabetes Inventory (SCODI), or Self-Care of Chronic Obstructive Pulmonary Disease Inventory (SC-COPDI).<sup>7</sup> Differences were found in the level of self-care measured by the generic and disease-specific self-care instruments. Specifically, multimorbid patients scored lower in self-care maintenance and self-care management on the generic instrument compared with the disease-specific instrument.<sup>7</sup>

#### Self-Care of Heart Failure Index

The disease-specific SCHFI was the first self-care instrument we developed. This instrument was based on an early version of the Situation-Specific Theory of HF Self-Care<sup>8</sup> and updated intermittently as the theory was updated. In 2016, the Situation-Specific Theory was revised to reflect the Middle Range Theory of Self-Care of Chronic Illness with a new concept: symptom perception.<sup>9</sup> Symptom perception is an HF-specific version of self-care monitoring.

Currently, version 7.2 of the SCHFI is available and version 8.0 is in testing. Version 7.2 includes 29 items rated on a 5-point Likert response scale.<sup>10</sup> The items address self-care maintenance (10 items), self-care monitoring or symptom perception (11 items), 2 of which address symptom recognition, and self-care management (8 items). In psychometric testing with 631 US adults, the SCHFI Self-Care Maintenance scale had 2 moderately correlated (r = 0.51) dimensions: consulting behaviors and dietary behaviors. Reliability, tested with the global reliability index for multidimensional scales, which accommodates structural complexity, was 0.75. The Symptom Perception scale also had 2 dimensions: monitoring behaviors and symptom recognition. Reliability tested with the global reliability index for multidimensional scales was 0.85. The Self-Care Management scale had 2 moderately correlated (r = 0.67) dimensions: recommended behaviors and problem-solving behaviors. The global reliability index was 0.70. When stability (ie, test-retest) was tested in 50 subjects who completed the SCHFI v7.2 two weeks after the first administration, scores were correlated at 0.89 for Self-Care Maintenance, 0.70 for Symptom Perception, and 0.84 for Self-Care Management. Construct validity has been supported with confirmatory factor analysis (CFA) supporting the 3 scales as theoretically related. Predictive validity was demonstrated in testing with the Short-Form 36 v2. The SCHFI has been shown to be valid and reliable in numerous countries.<sup>11–16</sup>

Version 6.2 is still widely used, although it is limited because it does not include the Symptom Perception scale, so little can be said about self-care monitoring. In a recent study, 2 items of the Self-Care Maintenance scale measuring monitoring of weight and ankle swelling were used to compute a Self-Care Monitoring scale score,<sup>7</sup> with the justification that these 2 items load on a single factor.<sup>12</sup> Because scores are standardized, as discussed below, Self-Care Maintenance and Self-Care Management scores from version 6.2 can be compared with scores on later versions.

#### Self-Care of Coronary Heart Disease Inventory

The Self-Care of Coronary Heart Disease Inventory (SC-CHDI) is a disease-specific instrument developed from clinical guidelines and standards of care for CHD.<sup>17</sup> Version 2 of the SC-CHDI<sup>18</sup> included only Self-Care Maintenance and Self-Care Management scales, but v3 includes 23 items reflecting all 3 theoretical concepts.<sup>19</sup> The Self-Care Maintenance scale includes 9 items, the Self-Care Monitoring scale includes 7 items plus 1 item on symptom

recognition, and the Self-Care Management scale has 6 items. In version 3, all response scales were revised from a 4-point Likert scale to a 5-point Likert scale.

In a sample of 205 US adults with CHD, the Self-Care Maintenance scale had 2 moderately correlated (r = 0.62) dimensions: *illness-related behaviors* and health-promoting behaviors. Reliability tested with the global reliability index for multidimensional scales was 0.94. The Self-Care Monitoring scale yielded a single factor. Reliability, tested with Cronbach  $\alpha$ , was 0.83. The Self-Care Management scale had 2 dimensions of autonomous and consulting behaviors, which were moderately strongly correlated (r = 0.68). Reliability tested with the global reliability index was 0.87. Stability has not been tested. Construct validity was supported when CFA demonstrated that the 3 scales are theoretically related and through testing hypotheses related to self-care self-efficacy. The SC-CHDI v3 has been translated into numerous languages; reliability and validity of translations have been published in 3.<sup>20–22</sup>

#### Self-Care of Hypertension Inventory

The Self-Care of Hypertension Inventory (SC-HI) is a disease-specific instrument developed for use in adults with chronic hypertension. Hypertension is relatively asymptomatic, so self-care monitoring becomes even more important in hypertension than other symptomatic conditions. Self-care management can only occur if changes in blood pressure, medication side effects, body weight, etc are detected. Version 3<sup>23</sup> includes 24 items reflecting the theoretical concepts of self-care maintenance (9 items), self-care monitoring (7 items) plus 1 addressing symptom recognition, and self-care management (7 items). The response scales were revised from a 4-point Likert scale to a 5-point scale in version 3.

In psychometric testing of the SC-HI v3 in a sample of 200 US adults, the Self-Care Maintenance scale had 2 dimensions, *autonomous* and *consultative behaviors*.<sup>23</sup> Reliability tested with factor determinacy was 0.80. Reliability of the single-factor Self-Care Monitoring scale was 0.94 when tested with Cronbach  $\alpha$ . The Self-Care Management scale also had a single-factor solution, with adequate reliability (0.84) tested with Cronbach  $\alpha$ . Construct validity of version 2 was demonstrated with the Medical Outcomes Study General Adherence Scale and the Decision-Making Competency Inventory.<sup>24</sup> The SC-HI v3 is available in 7 languages. Several translations have been tested for reliability and validity.<sup>25–32</sup>

#### Self-Care of Diabetes Inventory

The SCODI is a disease-specific instrument used to assess self-care behaviors of people with type 1 or type 2 diabetes mellitus.<sup>33</sup> After a review of international guidelines, self-care recommendations were translated into 29 items distributed among 3 scales: Self-Care Maintenance (12 items), Self-Care Monitoring (6 items) plus 2 on symptom recognition, and Self-Care Management (9 items). This instrument does not include the final item measuring reflection on treatment effectiveness. Items are scored on a 5-point Likert scale.

The Self-Care Maintenance scale has 4 moderately correlated ( $r \le 0.35$ ) dimensions: (1) health-promoting exercise behaviors, (2) disease prevention behaviors, (3) health-promoting behaviors, and (4) illness-related behaviors.33 Self-Care Monitoring has 2 highly correlated (r = 0.72) dimensions: body listening and symptom recognition. Self-Care Management has 2 moderately correlated (r = 0.55) dimensions: *autonomous* and *consultative* behaviors. When reliability was assessed in a sample of 200 Italian adults using the global reliability index for multidimensional scales, reliability was adequate: 0.81 for Self-Care Maintenance, 0.84 for Self-Care Monitoring, and 0.86 for Self-Care Management. Construct validity was confirmed by testing hypotheses about self-care confidence, glycated hemoglobin, diabetes complications, and body mass index.<sup>33</sup> The SCODI can be used in both type 1 and type 2 diabetes mellitus, as its psychometric performance has been tested in mixed<sup>33</sup> and separate samples.<sup>34</sup>

The SCODI is available in 15 different languages. Translations have been tested for reliability and validity in several countries.<sup>33–38</sup> A revised version of the SCODI reflecting recent changes in clinical guidelines is currently in testing.

#### Self-Care of Chronic Obstructive Pulmonary Disease Inventory

The SC-COPDI is a disease-specific self-care instrument for people with COPD.<sup>39</sup> Version 2.1 has 32 items, with 13 in the Self-Care Maintenance scale, 8 in the Self-Care Monitoring scale plus 1 addressing symptom recognition, and 10 in the Self-Care Management scale. This instrument does not include the final item measuring reflection on treatment effectiveness.

When tested in a sample of 498 Italian adults, the Self-Care Maintenance scale had 4 moderately correlated (r = 0.33) dimensions: (1) disease prevention, (2) improving breathing, (3) physical activity promotion, and (4) treatment adherence behaviors.<sup>39</sup> The global reliability index for multidimensional scales was 0.78. The Self-Care Monitoring scale had 2 moderately correlated (*r* = 0.49) dimensions: *respiratory symptom mon*itoring and extra-respiratory symptom monitoring. The global reliability index for multidimensional scale was 0.92. The Self-Care Management scale had 3 dimensions: (1) autonomous behaviors, (2) consulting behaviors, and (3) problem-solving behaviors. The global reliability index was 0.87. When stability was tested in 50 patients with stable COPD after 2 weeks, intraclass correlation coefficients were 0.88, 0.84, and 0.77 for Self-Care Maintenance, Monitoring, and Management. Construct validity was supported by testing hypotheses about COPD severity, dyspnea, and health status, with results similar to those in Chinese<sup>40</sup> and US samples.<sup>41</sup> The SC-COPDI has been translated into 10 languages, and more translations are in process.

#### Self-Care of Chronic Illness Inventory

The SC-CII is a generic instrument used to assess an individual's ability to manage 1 or more chronic illness(es) with self-care.<sup>42</sup> The SC-CII has 19 items divided into 3 scales: Self-Care Maintenance with 7 items, Self-Care Monitoring with 5 items plus 1 measuring symptom recognition, and Self-Care Management with 6 items.

In psychometric testing with 407 US adults, the Self-Care Maintenance scale had 2 moderately correlated (r = 0.50) dimensions: *illness-related* and *health-promoting* behaviors. Reliability, assessed with the global reliability index for multidimensional scales, was 0.67. The Self-Care Monitoring scale had a single dimension. Reliability, tested with Cronbach  $\alpha$ , was 0.86. The Self-Care Management scale had 2 moderately correlated (r = 0.51) factors: autonomous and consulting behaviors. Reliability, assessed with the global reliability index for multidimensional scales, was 0.71. Construct validity was supported with CFA supporting the theoretical model. In a cross-cultural validation study of Italian, US, and Swedish samples of chronically ill patients, the SC-CII had strong factorial validity, obtaining partial scalar invariance for all scales.<sup>43</sup> The SC-CII has been shown to be reliable and valid in US,<sup>42</sup> Chinese,<sup>44</sup> Italian and Swedish,<sup>43</sup> and Albanian patients.<sup>45</sup> The SC-CII has been translated into 14 languages, and more translations are in process.

#### Self-Care Inventory

The Self-Care Inventory (SCI) can be used to measure self-care in adults of any age, with or without a chronic condition. The Middle Range Theory of Self-Care of Chronic Illness specifies that self-care is performed in healthy and ill states, and everyone performs some level of self-care daily.<sup>1</sup> The SCI was based on the SC-CII,<sup>42</sup> because even healthy people monitor themselves and manage symptoms. Items from the SC-CII were adapted by focusing on general health-promoting and illness management behaviors.

The SCI has 20 items distributed among the 3 scales: Self-Care Maintenance (8 items), Self-Care Monitoring (5 items) plus 1 on symptom recognition, and Self-Care Management (6 items). In a US sample of 294 adults (58% without a chronic condition), the Self-Care Maintenance scale had 2 dimensions: *health-promoting* and *illness-related* behaviors. Reliability, tested with the global reliability index for multidimensional scales, was 0.85.<sup>46</sup> The Self-Care Monitoring scale was unidimensional. Reliability, tested with Cronbach  $\alpha$ , was 0.88. The Self-Care Management scale had 2 moderately correlated (r = 0.39) dimensions: *autonomous* and *consulting behaviors*. Reliability, tested with the global reliability index for multidimensional scales, was 0.88. Stability was tested after 10 days in 125 volunteers from the US sample.<sup>46</sup> Test-retest reliability was 0.81 for Self-Care Maintenance, 0.76 for Self-Care Monitoring, and 0.91 for Self-Care Management. Cross-cultural validation is currently in testing.

Construct validity was supported through testing that supported the theoretical model as well as correlations between self-efficacy, positivity, stress, and selfcare scores.<sup>47</sup> The SCI has been translated into 10 languages, and several other translations are in process. Psychometric testing has been done in samples from the United States<sup>46</sup> and Jordan.<sup>48</sup> It is currently in testing in an Italian sample.

#### **Complementary Instruments**

Complementary instruments are those often used with one of the self-care instruments because they provide information commonly used to interpret results (eg, mediating mechanisms). The complementary instruments described below include the Self-Care Self-Efficacy scale (SCSES) and instruments measuring how caregivers contribute to patient self-care.

#### Self-Care Self-Efficacy

In our early work studying self-care, we recognized the importance of self-efficacy in the performance of selfcare during interviews with patients. Self-efficacy can be defined as confidence in one's ability to successfully carry out a particular task, so we originally named this the Confidence scale. We later added questions about persistence in the face of setbacks to reflect Bandura's theory of behavioral change and began calling these measures of self-care self-efficacy.<sup>49</sup> Self-efficacy is not a core element of self-care, but it has been shown repeatedly to influence self-care behavior as a mediator or a moderator.<sup>50</sup> Thus, users are strongly encouraged to measure self-care self-efficacy.

There are several versions of this scale available on the website: disease specific, generic, and caregiver versions. Most instruments include 10 items embedded at the end of the instrument, but there are several differences among the various self-efficacy scales, which are enumerated in Table 1. At this time, we are transitioning from using separate, embedded self-efficacy scales and recommend that users measure this important concept with the generic SCSES, which is available on the website.<sup>47</sup>

#### **Caregiver Contribution to Self-Care**

Many collectivistic cultures view health issues as a family matter, and many individualistic cultures rely on family caregivers to support patient health in the context of progressive declines. Therefore, we developed a situationspecific theory of caregiver contributions (CC) to HF self-care<sup>51</sup> and a set of instruments measuring CCs to patient self-care defined as "the provision of time, effort, and support in behalf of another person who needs to perform HF self-care" (p 246).<sup>52</sup> Items in the patient instruments were modified to measure the extent to which caregivers help the patient perform self-care through making recommendations or performing activities for the patient. There are now CC versions of several instruments (ie, CC-SCHFI, CC-SC-CHDI, CC-SC-OPDI, CC-SC-CII, and Caregiver Self-Efficacy scale), with more currently in review.<sup>53–55</sup> Development of the instruments measuring CC to patient self-care has stimulated several dyadic analyses in the study of self-care.

## **Standardized Scoring Methods**

All the self-care instruments discussed here are scored in the same fashion. Responses are rated on a 5-point Likert-type scale with response anchors chosen based on how the question is phrased (ie, How often? How likely? How sure?). Scores standardized 0–100 are computed separately for each individual scale. Higher scores indicate higher self-care maintenance, self-care monitoring, and/or self-care management. Do *not* compute a total self-care score in which the scales are added together. The scoring method cannot be revised because doing so would make your study results unable to be compared with those of other studies.

Begin by cleaning the data to deal with missing data. You can impute values or change the denominator in the transformation formula provided below to accommodate missing items. We recommend that if the respondent answers  $\geq$ 50% of the items in a multiitem scale (eg, Self-Care Maintenance scale), the score can be calculated. If the respondent answered fewer than 50% of the items, the score for that scale should be considered missing. Early versions of some Self-Care Management scales could not be computed unless the patient had symptoms, but the directions were revised in later versions to ask "how likely are you to ...." This allows patients who are not currently symptomatic to respond to the scale questions.

To compute a standardized score, first compute a raw scale score. The raw scale score is a simple algebraic sum of responses for all items in each scale. For example, the raw scale score for the Self-Care Maintenance Scale is the sum of responses to items in section A. This simple scoring method is possible because items in the same scale have roughly equivalent relationships to the underlying concept being measured and no item is used in more than 1 scale. Thus, it is not necessary to weight items. These assumptions are used in calculating scores for other commonly used instruments such as the Short-Form 36.<sup>60</sup>

News	Is Self-Efficacy Embedded in the SCI?	No.	later du tem Cantonna	Comment
Name	the SCI?	Items	Introductory Sentence	Comment
SCSES v.1	No	10	In general, how confident are you that you can:	This is the generic self-care self-efficacy measure that we recommend using with all the self-care instruments.
SCHFI v.7.2	Yes	10	In general, how confident are you that you can:	The SCSES is included in the SCHFI
SC-CHDI v.3	No			Not included but advocated
SC-HI v.3	No			Not included but advocated
SCODI v.1	Yes	11	People with diabetes have to develop skills to take care of themselves and to maintain their health. How confident do you feel doing the following activities?	Section D addresses self-care self-efficacy. All items are focus on diabetes activities and blood sugar. Item 33 is the only one shared with the SCSES (3). Section D will be deleted in SCODI v.2 but users are encouraged to use the SCSES instead.
SC-COPDI v.2.1	Yes	7	Indicate how much confidence you feel in your ability to carry out the activities listed below.	Items are focused on chronic lung disease and phrased differently than the SCSES. Some items are combined (eg, item 4 "Take medicines properly, following the instructions given even if it difficult").
SC-CII v.4c	Yes "Self-Care Confidence scale"	10	In general, how confident are you that you can:	<ul> <li>Very similar to the SCSES with minor wording differences:</li> <li>(1) Item 23 "monitor your <i>health</i> condition routinely" vs Item 4 "monitor your condition routinely"</li> <li>2) Item 24 "Persist in routinely monitoring your <i>health</i> condition even when difficult" vs Item 5 "Persist in routinely monitoring your condition even when difficult"</li> </ul>
SCI v.1	Yes	10	In general, how confident are you that you can or could:	<ul> <li>Questions are the same as the SCSES, except items 2, 3, 4, and 5, which have been adapted for those who might not have a chronic condition.</li> <li>2. Follow the treatment plan you have been given? Follow the plan <i>if you have been given a treatment</i>?</li> <li>3. Persist in following the treatment plan even when difficult? Persist in following the plan <i>if you have been given a treatment</i>?</li> <li>4. Monitor your condition routinely? Monitor your <i>health status</i> routinely?</li> <li>5. Persist in routinely monitoring your condition even when difficult? Persist in routinely monitoring your <i>health status</i> even when difficult?</li> </ul>

#### TABLE Comparison of the Self-Care Self-Efficacy Measures Across Self-Care Scales

To transform raw scale scores into standardized scores, use the formula shown in Figure 1. Table 2 shows an example of this process. The table provides the information necessary to apply this formula to each scale in the SC-CII as an example. Use the same principle when computing scores for the other scales. This transformation converts the lowest and highest possible scores to 0 and 100, respectively. Scores between these values represent the percentage of the total possible score achieved. Figure 2 provides an example of transforming a Self-Care Maintenance raw score of 21 to a standardized score of 50.

### Symptom Recognition

Each instrument has 1 or 2 items measuring how quickly symptoms were recognized and interpreted. As symptom

recognition is not a behavior but a signal to engage in selfcare behavior, we suggest that these items not be used in calculating scale scores or in factor analyses. Instead, we advocate analyzing these items descriptively.<sup>5</sup> Symptom recognition can be tested as a mediator of the relationship between self-care monitoring and self-care management.

#### Interpreting Scores

Early mixed-method studies were used to identify a cutpoint in the standardized score that best reflects adequate self-care behavior. Briefly, a cut-point of  $\geq$ 70 is considered adequate self-care based on congruence between descriptions of adequate self-care in qualitative and quantitative data from the SCHFI.<sup>11</sup> Although these studies were performed with patients with HF, this cut-point is widely used in other conditions,<sup>61-63</sup> [(Actual raw score - lowest possible raw score)]

Possible raw score range

Transformed Scale =

\* 100

**FIGURE 1.** Formula for transforming raw scale scores into standardized scores. Use this principle when computing scores for any of the scales. This transformation converts the lowest and highest possible scores to 0 and 100, respectively. Scores between these values represent the percentage of the total possible score achieved.

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and we continue to define "adequate" self-care as  $\geq$ 70 for most of the scales based on the rationale that a T-standard point of 70 is 2 standard deviations above the mean of 50. If the distribution is normal, this approach is appropriate. However, if the distribution is substantially skewed, a cut-point of 70 may be misleading. Work is ongoing to develop normative scores that are disease- and country-specific.

We are frequently asked how much of a change in score is considered clinically relevant. We use the convention of a half standard deviation, which can be used in the absence of an established minimally important difference.<sup>64,65</sup> In prior self-care studies using this half standard deviation criterion, the change in standardized scores was typically approximately 8 points. However, we encourage users to precisely calculate the half standard deviation of scores in their sample at baseline and use that number to evaluate the clinical relevance of a change in scores.

## **Psychometric Evaluation Across Samples**

Because of the increasing practice of translating and validating self-report measures, the issue of replicability of psychometric results has become crucial. Relying on valid measures is crucial for facilitating result comparisons across diverse countries and cultural groups. However, it is neither the mere translation of a scale into another language nor the collection and standard analysis of data in a different country that guarantees the comparability of results across countries. Differences might result from genuine group differences or measurement problems. Assessing measurement equivalence (ME) or invariance ensures valid cross-cultural comparisons of health assessments. An approach to ME that we use is based on CFA. Following the seminal work of Meredith,66 different levels of comparability across diverse populations can be tested on the parameters of the factorial model to demonstrate the same configuration of a factor structure, the same meaning of factors, and the

same use of the scale scores across different countries. An extension of ME to longitudinal design allows testing for constancy and comparability of instruments across different time lags.

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#### **Translation**

The instruments discussed previously and their translations are freely available on the website. We advocate that translators use a process based on Brislin's method.<sup>67</sup> Brislin's approach is the classic method for translation and validation of instruments for cross-cultural research. The English language version is used as the basis of the translation. Two translators are recruited to translate the English version into the new language. We recommend that these translators have the new language as their mother tongue. Ideally, 1 translator should have expertise in the topic (eg, a nurse) and the second translator should be a language expert who is naïve about illness self-care. The translators should work independently and be instructed to stay close to the English version. The 2 translations are discussed and integrated, choosing words that are closest to the original English version as possible. Next, 2 new translators are recruited to back-translate the new language version into English. Again, these back-translations are melded into one and discussed to rectify differences. Back-translations are returned to the instrument developer who personally reviews the back-translation to assure semantic equivalence before giving permission to the translator to use the instrument translation. We ask all translators to freely share their translations with others who speak the same language and we post the translations on the website to facilitate this process.

#### **Testing the Measurement Model**

Because of its crucial role in psychometric testing, factor analysis must be conducted properly and principal component analysis (PCA) is not the correct technique.

Scale	las for Scoring and Transforming Scales Sum Final Item Values	Lowest and Highest Possible Raw Scores	Possible Raw Score Range
Self-Care Maintenance (Section A)	Items 1 + 2 + 3 + 4 + 5 + 6 + 7	7, 35	28
Self-Care Monitoring (Section B)	ltems 8 + 9 + 10 + 11 + 12*	5, 25	20
Self-Care Management (Section C)	Items 14 + 15 + 16 + 17 + 18 (note item 13 is scored separately, as described below)	5, 25	20

8 The Journal of Cardiovascular Nursing | Month 2024

$$\frac{[(21-7)]}{[28]} * 100 = 50$$

**FIGURE 2.** Example of how to transform a Self-Care Maintenance Scale raw score of 21 to a standardized score of 50. In this example, the patient responses were added together to total 21. The lowest possible score (ie, 7, is deleted from that total and then divided by the possible raw score range (ie, 28 in this example, see Table 4). This result (14/28 = 0.5) is multiplied by 100 to yield a score of 50 for this Self-Care Maintenance Scale score.

Users studying the dimensionality of self-care instruments are strongly encouraged to avoid using PCA. PCA assumes that all the observed variance in items is common variance; thus, it blurs true variance (the reliable variance explained by the factors shared by the items) with unique variance (which is not shared by items and is mainly due to measurement error). The result is inflated factor loadings, something that makes the naïve scientist happy, but these loadings contain both true and error variance.

To test the dimensionality of self-care scales, we advocate either exploratory factor analysis (EFA) or CFA. When items are measured with at least a 5-point ordered response option and the distribution does not deviate from normality, maximum likelihood estimators are best. When variables show moderate non-normality, maximum likelihood robust estimators are recommended when the response format uses at least a 5-point scale. When fewer than 5 ordered categories are used as response options or when non-normality is strong, distribution-free estimators such as WLS-MV are the optimal choice.68 All these estimators are available in commercial (eg, Mplus) and open-source software (eg, R) for EFA or CFA or for a hybrid of both such as exploratory structural equation modeling. When WLS-MV is used, correct formulas for adapting model-based reliability estimates are available in different software. We strongly encourage the use of CFA whenever possible to replicate the factorial structure of published self-care scales. We recommend EFA or exploratory structural equation modeling only when model trimming is needed because of misfit of the confirmatory model, or when a totally new scale is developed.

Note that estimating the sample size needed for factorial analyses and structural equation modeling is challenging. The literature abounds with "rules of thumb" related to how large of a sample is enough for conducting these analyses.<sup>69</sup> Recently an approach was developed to address this problem within a power analysis framework.<sup>70</sup> These authors developed an interactive Shiny app (https://sjak.shinyapps.io/power4SEM/) that makes power analysis easy to perform.

## Reliability Assessment and the Decline of Cronbach Alpha

Cronbach  $\alpha$  is probably the most used coefficient for estimating instrument reliability. Although many scientists

persist in using  $\alpha$ , its use is based on "hidden" or inexplicit assumptions that (1) the scale is unidimensional, and (2) all scale items reflect the construct in the same way or that they all have the same "true score." If these assumptions are violated,  $\alpha$  is a biased estimate of reliability. The true score is not observable. Thus, psychometricians use EFA and/or CFA to estimate how much an item (an observed variable) reflects the construct (a latent, unobservable variable). In these analyses, factor loadings provide a hint at the true variance of an item.

Factor analysis should be performed before testing reliability. This analysis sheds light on the assumptions on which  $\alpha$  relies. If the scale is multifactorial (ie, more than 1 factor is responsible for item correlations),  $\alpha$  cannot be used as an index of scale reliability. One possible solution is to compute different  $\alpha$  coefficients for the different clusters of items identified in the factor analysis. However, this solution is undesirable when we are not interested in subscales. In the self-care measures, we are interested in measuring self-care maintenance, self-care monitoring, and self-care management, not their specific dimensions.

What if a scale is multifactorial? As noted previously,  $\alpha$  gives an accurate and unbiased estimate of reliability only if all items have the same level of true score or the same factor loading, referred to as (Tau) equivalent. Factor analysis is crucial to test the assumption of  $\tau$  equivalence. Because  $\alpha$  is based on 2 very stringent (and usually unrealistic) assumptions, we believe that it is time for scientists to abandon the old coefficient  $\alpha$  in favor of coefficients that are unaffected by violations of these assumptions and are more directly linked to the factorial model.<sup>71</sup> Because their estimates are derived from the parameters of the factorial mode, they can be referred to as "model-based" coefficients. Among them, (omega) is the most well-known and used coefficient.

ω is derived from factor loadings and the residual variances estimated from a factor solution. Different from α, ω provides an unbiased estimate of reliability when item loadings are unequal and is well suited for monodimensional scales.<sup>71</sup> When a scale is composed of multiple factors, other model-based coefficients such as the model-based internal consistency index<sup>72</sup> and the global reliability index for multidimensional scales<sup>73</sup> can be used to derive proper estimates of reliability of a multidimensional global construct.<sup>74–76</sup>

## **Clinical Implications and Conclusion**

Self-care is widely recognized as fundamental to success in dealing with illness. The instruments measuring self-care behaviors described in this article are used by both clinicians and researchers. Clinicians seek to identify where their patients are struggling in the

#### What's New and Important

The self-care instruments discussed in this article are used across the world, but users commonly seek advice about how to score, analyze, and report their results. This article illustrates the following:

- The similarity among the various self-care instruments, which will facilitate using them in a consistent fashion.
- All the instruments are based on a common theory, so all the instruments are scored, analyzed, and reported in the same way.
- Understanding the theoretical basis of the instruments and the relationship among the instruments will promote consistent, comparable use, which will allow investigators across the world to compare their results and will facilitate future meta-analyses.

self-care process, realizing that time can be saved by focusing education on areas that patients have not yet mastered. Researchers use the instruments to measure the effectiveness of their interventions. Our goal in writing this article is to provide users of the various self-care instruments with the background needed to understand how the self-care instruments were developed and tested. Seeing how they are related makes them easier to understand and interpret. Information on scoring and analysis is provided to promote consistent use of the instruments across studies, populations, and settings. A standardized approach to scoring and interpretation facilitates comparison among patients and studies. Consistent use will facilitate future reviews and meta-analyses, which will support future efforts to promote self-care.

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