

Development and psychometric evaluation of the self-care of informal caregivers inventory

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ARTICLE INFO

Keywords:

Informal caregivers
Self-care
Questionnaire design, Psychometrics
Outcome assessment
Caregiver burden
Prevention and control

ABSTRACT

Background: In recent years, a growing body of literature on informal caregivers' health and well-being has emerged, highlighting the need for a tool to measure their self-care practices.

Objective: The aim of the study was to develop a theory-based instrument measuring the self-care behaviors of informal caregivers and test its psychometric properties.

Design: The initial phase of instrument development entailed a detailed, six-step process (conceptualization, theoretical adaptation, back-translation and cultural adaptation, cognitive interviewing, item enhancement, and content validity), followed by formal psychometric testing (participant engagement, validity, internal consistency reliability, test-retest reliability).

Setting: Study conducted at a hospital located in Tehran, Iran.

Participants: A sample of 234 informal caregivers of cancer outpatients receiving treatment in oncology wards was enrolled. Caregivers had to be 18 years or older, recognized as the primary caregiver by the patient, and willing to provide informed consent.

Methods: The Self-Care of Informal Caregivers Inventory items comprise three dimensions: self-care maintenance (11 items), self-care monitoring (7 items), and self-care management (9 items), which achieved a content validity index rating of 100 % in a panel of experts. Data were collected from caregivers during routine clinic visits. Construct validity was verified through exploratory structural equation modelling and reliability was verified using Cronbach's α and multidimensional model-based reliability. Test-retest reliability was evaluated using the Intra-class Correlation Coefficient.

Results: All three dimensions showed good model fit indices (self-care maintenance: Comparative Fit Index = 1.00, Tucker-Lewis Index = 0.99, Root Mean Square Error of Approximation = 0.044; self-care monitoring: Comparative Fit Index = 1.00, Tucker-Lewis Index = 1.00, Root Mean Square Error of Approximation = 0.027; self-care management: Comparative Fit Index = 0.99, Tucker-Lewis Index = 0.99, Root Mean Square Error of Approximation = 0.048) and Cronbach's α of 0.88, 0.88, and 0.91, respectively. The overall multidimensional model-based reliability was 0.93. The Intra-class Correlation Coefficient values for the three dimensions were 0.94, 0.60, and 0.51, respectively.

Conclusion: Preliminary testing provides support for use of the Self-Care of Informal Caregivers Inventory in research. Using this theory-based instrument to assess the self-care practices of informal caregivers can assist in identifying topics to discuss and opportunities for guidance.

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<https://doi.org/10.1016/j.ijnsa.2024.100237>

Received 28 April 2024; Received in revised form 12 August 2024; Accepted 4 September 2024

Available online 12 September 2024

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Tweetable Abstract: The Self-Care of Informal Caregivers Inventory: A validated tool for informal caregivers is useful for research. #Informalcaregivers #SelfCare

What is already known

- The demanding nature of caregiving often leads to neglect of the informal caregivers' health practices, as they prioritize the needs of their loved ones over their own, potentially resulting in a decline in their well-being over time.
- The healthcare system increasingly acknowledges the substantial contribution and the pivotal role of informal caregivers. Hence, preserving informal caregivers' health has become essential for healthcare providers.
- While self-care is a fundamental behavior for promoting and preserving health, the literature lacks a standardized assessment of self-care practices among informal caregivers.

What this paper adds

- This study presents the first theory-based inventory for assessing the self-care of informal caregivers, offering a new tool in caregiver research.
- The Self-Care of Informal Caregivers Inventory, fundamentally rooted in the Middle-Range Theory of Self-Care of Chronic Illness, categorizes self-care into maintenance, monitoring, and management for a comprehensive evaluation.
- Psychometric analysis supports the reliability and validity of the Self-Care of Informal Caregivers Inventory.
- The study's findings enhance our understanding of informal caregivers' self-care practices and underscore the practical applications of this inventory in research and clinical settings.

1. Introduction

Informal caregivers provide physical and emotional support to a family member or a friend coping with a debilitating condition (Jika et al., 2021; Kim et al., 2023; Lung et al., 2022). From being an informal caregiver to a child with special needs to caring for a loved one experiencing a chronic illness, caregivers encounter many challenges due to caregiving responsibilities. These obstacles may vary due to the care recipient's unique circumstances (i.e., disease-related factors), the informal caregiver's characteristics (i.e., sociodemographic factors), and the duration and intensity of the caregiving episode (Alshammari et al., 2021; Durante et al., 2022; Peng et al., 2022).

Caregiving is stressful, with emotional exhaustion, physical demands, and poor health habits when caregiving tasks take precedent over personal care (Benko Meštrović et al., 2023; Gottschalk, 2021). Research over the past few decades illustrates how these challenges contribute to health deterioration in various informal caregiver populations (Zheng et al., 2023). It has been well-documented that caregiving strains the health of caregivers, manifesting as physical burdens and emotional exhaustion (Kaschowitz et al., 2017; Zheng et al., 2023). The emotional exhaustion of caregiving is associated with an increased risk of anxiety and depression, which may be due to profound feelings of caregiving stress and fatigue among informal caregivers (Jika et al., 2021). The complexity of managing healthcare routines, especially for those providing care for patients with multimorbidity, often amplifies this stress and contributes to further emotional distress (Kim et al., 2023). Disrupted sleep patterns and sleep deprivation are common, as informal caregivers may need to check frequently on their loved ones during the night (Byun et al., 2016; Hoyt et al., 2020).

It is widely acknowledged that informal caregivers prioritize the health requirements of care recipients over their own self-care, leading to neglect of their daily health needs (Lin et al., 2023). Health-promoting behaviors such as a balanced diet, adequate rest, stress management, personal time, physical activity, and social interactions can help caregivers cope with the demands of caregiving (Brito et al., 2022, Kim and Woo, 2022, Mochari-Greenberger and Mosca, 2012, Ross et al., 2020). Yet, a growing number of studies suggest that these health-promoting behaviors are ignored, leaving informal caregivers with physical sequelae (Sulaimani et al., 2023; Dionne-Odom et al., 2017; Oliveira et al., 2019). Consequently, the lack of health-promoting behaviors and poor self-care practices has become a universal language among informal caregivers.

The Middle-Range Theory of Self-Care of Chronic Illness defines self-care as "a process of maintaining health through health promoting practices and managing illness". Self-care is said to be performed in both healthy and ill states, with health-promoting behaviors (self-care maintenance) and self-care monitoring and self-care management performed to manage illness (Riegel et al., 2012; Sales de Brito et al., 2022; Riegel et al., 2019a, 2021). Self-care maintenance involves behaviors to improve or sustain one's health, such as regular physical activity and a balanced diet. Self-care monitoring consists of observing oneself for new or changing signs and symptoms, employing methods such as regular health screenings. Self-care management involves responding to changes in health status and making necessary adjustments to treatment plans or lifestyle choices to manage these changes effectively (Riegel et al., 2012, 2018). It should be noted that while self-care maintenance, self-care monitoring, and self-care management are distinct within the self-care spectrum, their interaction is dynamic. The Middle-Range Theory of Self-Care for Chronic Illness highlights each component's significant role, complementing and enhancing the effectiveness of the other components for optimal health outcomes and overall well-being (Lee et al., 2022; Luciani et al., 2022; Page et al., 2022).

Self-care practices are crucial for informal caregivers who need to balance the demands of caregiving with their own health needs (Riegel et al., 2019b, 2021). Studies indicate the vital role of self-care among informal caregivers; however, despite its significance, self-care practices often go unnoticed among informal caregivers and healthcare providers (Oliveira et al., 2019; Van Roij et al., 2021). By classifying self-care practices into the three dimensions of self-care maintenance, monitoring, and management, the theory highlights the logical interconnections of the behaviors and illustrates a comprehensive understanding of how self-care behaviors affect the individual (Fig. 1). Notably, this classification provides valuable insight to healthcare providers in determining where an individual struggle with self-care so as to identify what types of assistance and intervention are needed (Riegel et al., 2012).

Many instruments, questionnaires, and scales have been developed to assess different health-related aspects of caregiving (Deeken et al., 2003; Van Durme et al., 2012). As shown in Table 1, most existing instruments assess informal caregivers' physical and mental health to evaluate the impact of caregiving on overall well-being, highlighting different concerns and areas of focus (Family Caregiver Alliance, 2022). Despite the meaningful scientific contributions made to understanding caregiver well-being, there is a significant gap in measurement as no instrument focuses explicitly on the self-care practices of informal caregivers. The availability of a theory-based, reliable, and valid instrument tailored to assess the self-care practices of informal caregivers can provide more insight into the informal caregiver population and their self-care practices, promote preventive healthcare and evidence-based interventions by healthcare providers. This study aimed to develop and evaluate the psychometric properties of the Self-Care of Informal Caregivers' Inventory (SC-ICI) based on the Middle-Range Theory of Self-Care of Chronic Illness.

2. Methods

The study was conducted in two phases. In Phase 1 we examined content validity of instrument items through a six-step process: conceptualization and item generation, theoretical adaptation and content development, back-translation and cultural adaptation, cognitive interviewing, item enhancement, and content validity. In Phase 2 formal psychometric testing was done to assess reliability and construct validity, including participant engagement (Fig. 2). The instrument was developed in English, a shared language, and psychometrically tested in Farsi.

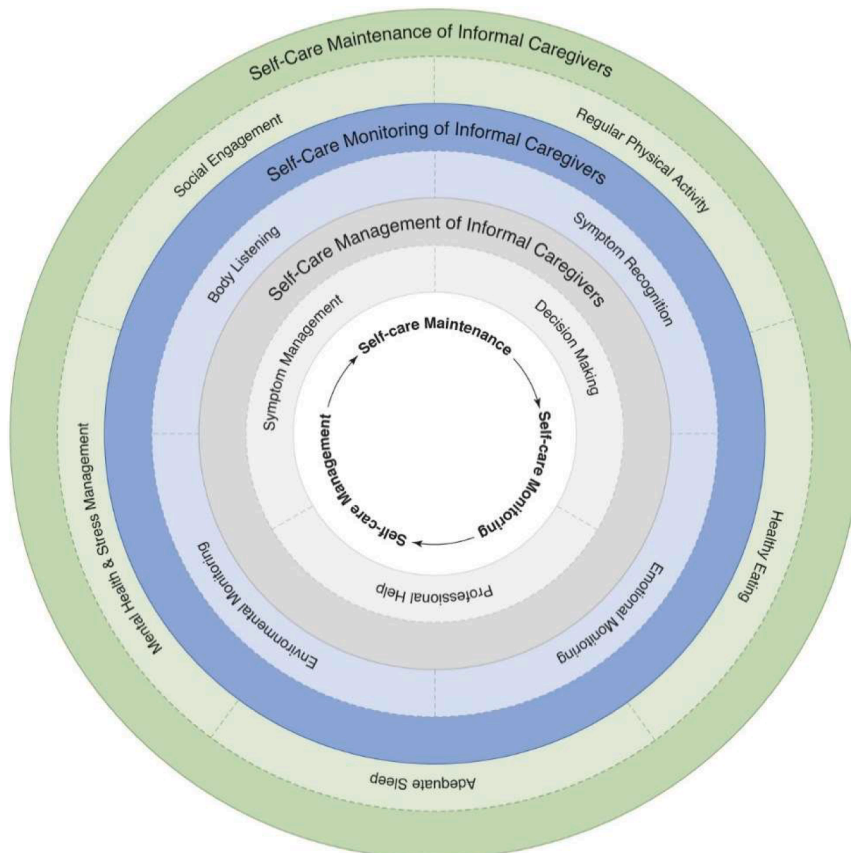


Fig. 1. The centrality of the dynamic process of self-care in health-promoting behaviors.

Table 1

Summary of measures for informal caregivers and limitations in measuring self-care practices. Note: The measures sourced from the Family Caregiver Alliance; "Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners (2012)" are marked with a superscript "**".

Measure	Author(s) and Year	Description	Limitation
Zarit Burden Interview (ZBI)	Steven H. Zarit, Judy M. Reever, & Joseph Bach-Peterson, 1980.	29-item tool evaluates a caregiver's emotional well-being, financial difficulties, and social interactions.	The ZBI does not explicitly address detailed self-care behaviors.
Caregiver Well-Being Scale (CWBS)	Sandra G. Tebb, 1995.	45 items (simplified to 14 in 2013) assessing basic needs and daily activities based on Maslow's hierarchy; physiological, safety, love and belonging, esteem and self-actualization.	The CWBS is initially broad; however, it lacks a specific focus on detailed self-care practices.
Caregiver Self-Assessment Questionnaire	The American Medical Association. Validated in 2010 by Epstein-Lubow et al.	18-item questionnaire measures caregivers stress levels and highlights several health concerns.	Provides a general assessment of stress without a comprehensive examination of all self-care aspects.
Caregiver Well-Being: Physical Health*	Linda K. George & Ladson Hinton Gwyther, 1986.	2-item measure assesses the number of physician visits and self-rated health.	Provides limited insight into self-care as it focuses on health outcomes rather than behaviors.
General Health Perceptions Scale*	John E. Ware, 1993.	5-item scale provides a self-reported measure of physical health.	Broadly assesses health perceptions however it is not specifically tailored for caregivers and lacks self-care focus.
General Health Survey Questionnaire, Short Form 36 (SF-36)*	John E. Ware Jr, 1993–1996.	36-item questionnaire measures eight health domains of physical functioning, social functioning, role limitations caused by physical problems, general mental health, energy and fatigue, bodily pain, and general health.	The SF-36 is a comprehensive outcome measure instrument, however it is not specifically tailored for caregivers and does not directly address self-care practices.
General Health Survey Questionnaire, Short Form 12 (SF-12)*	John E. Ware Jr, 1993–1996.	12-item scale covers major health domains affecting physical and emotional well-being	The SF-12 focuses on the general health and not specifically tailored to caregivers' self-care needs.
Perceived Health Index*	Gary T. Deimling & Diane Bass, 1986.	4-item scale measures worry, exhaustion, aches, and pains related to health perception.	It measures perceptions rather than concrete self-care practices.
Aspects of the Caregiving Role: c. Health*	Hal Kendig Schofield, 1997.	5-item scale that rates major health problems and self-reports overall health.	The Aspects of the Caregiving Role focuses on general health status rather than specific self-care strategies.
Caregiver WellBeing Scale	Steven H. Zarit & Carol J. Whitlatch, 1992.	7-item scale that measures caregiver's feelings such as sadness and lack of interest in activities.	The scale does not provide detailed self-care behaviors.
Activities of Living	Susan S. Tebb, 1995.	A 23-item measuring non-basic needs essential for a healthy life, including exercise, skill development, relaxation, personal growth, and social support, across three areas: time for self, home, and family.	The scale focuses on overall satisfaction with activities of living rather than specific self-care strategies.
Bakas Caregiving Outcomes Scale	Tamilyn Bakas and Valerie L. Champion, 1999.	A 10-item measuring life changes resulting from caregiving, with a focus on physical and mental health, relationships with others, and relationship with the care recipient.	The scale addresses general life changes rather than specific self-care strategies for caregivers.

2.1. Phase one: instrument development

2.1.1. Step one: conceptualization and item generation

First we conducted a comprehensive review of the construct of self-care, encompassing various theoretical frameworks, and chose the Middle-Range Theory of Self-Care of Chronic Illness as the theoretical frame. We also reviewed studies of self-care among informal caregivers, considering their unique challenges. A comprehensive review revealed a wide range of the biological, psychological, and social challenges that could impact the health of informal caregivers. Drawing from the challenges reported by informal caregivers, the most common barriers to health-promoting behaviors, and the overlooked self-care practices identified, we formulated 35 initial items for the Self-Care of Informal Caregivers Inventory.

2.1.2. Step two: theoretical adaptation and content development

The Middle-Range Theory of Self-Care for Chronic Illness was used to classify the 35 initial items as self-care maintenance, monitoring, or management. The authors carefully considered each item before finalizing a set of 27 items for inclusion. The 27 items included 11 on self-care maintenance, seven on self-care monitoring, and nine on self-care management. Items measuring self-care maintenance reflect behaviours that promote physical and emotional stability, aiming to preserve health and enhance well-being (Bunsuk et al., 2023). Items were designed to assess personal hygiene practices, physical activity, eating essential meals, a balanced diet, water intake, alcohol intake, sleep, and medication taking. Smoking habits included vaping (electronic cigarettes) due to its increasing prevalence and associated health risks.

Self-care monitoring items reflect 'body listening' with prompt recognition of bodily changes and interpreting of symptoms so that decisions can be made about when action is needed. These self-care monitoring items for informal caregivers were designed to assess

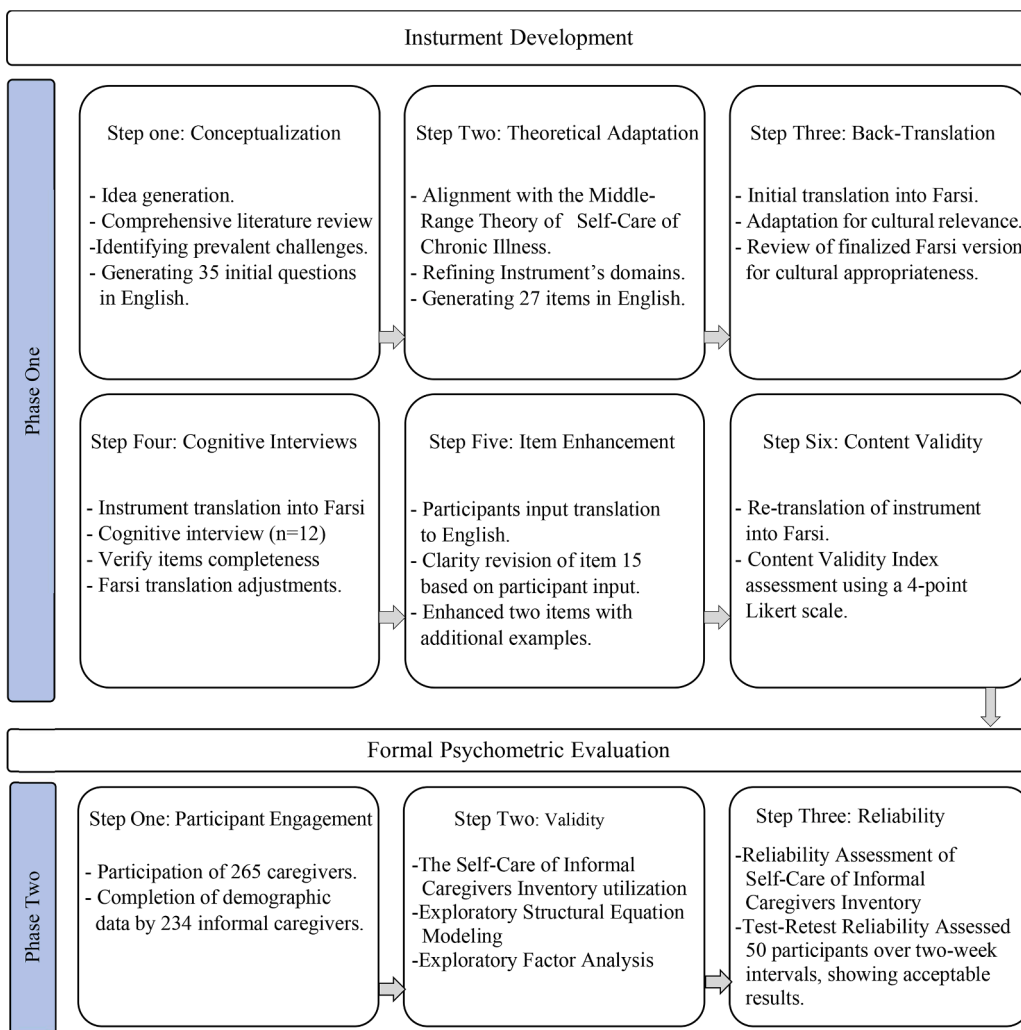


Fig. 2. Instrument development and formal psychometric evaluation stages.

awareness of behaviors that are crucial in preventing potential physical and mental health declines due to caregiving burden. The items included in this section address monitoring of physical health, changes in eating patterns and emotional state, and feelings of being overwhelmed, fatigued, and physical discomfort thereby covering the broad range of issues reported by informal caregivers.

Self-care management requires one to evaluate changes detected during self-care monitoring, conclude whether an action is needed, and then do something to address the changes (Riegel et al., 2012). Therefore, caregivers are asked about the actions taken towards changes in their physical and emotional status. Additionally, items address various actions taken towards the changes to manage physical and emotional issues and find a balance between personal life, work, and caregiving roles. Other items assess whether the caregiver asks and accepts help from others. For these items, we separated seeking help from relatives and friends on simple tasks such as everyday errands and accepting help from palliative care providers. We intended to highlight the importance of the burden that even the simplest tasks, such as grocery shopping, might bring to informal caregivers and address the potential cultural stigma experienced by some informal caregivers associated with accepting help from palliative care providers.

2.1.3. Step three: back-translation and cultural adaptation

Although instrument development was a collaborative effort initially designed in English by one native and one fluent English speaker, the initial psychometric analysis was conducted in a Farsi-speaking population in Iran. Therefore, after the items were finalized in English, the first author and an Iranian language expert unfamiliar with the scientific construct of self-care translated the instrument into Farsi. Both translators worked independently to create two Farsi versions. These versions were combined by discussing differences and selecting the wording that most closely matched the original English meaning.

To ensure cultural relevance and reflect Iranian cultural practices, some items were given additional examples. For instance, the item “Give yourself a break and make time to relax (e.g., rest, watch TV series, read a book, meditate)” was adapted by adding “praying” to the examples. The final Farsi version of the inventory was then reviewed again to ensure that it was linguistically accurate,

making it suitable for cognitive interviewing.

2.1.4. Step four: cognitive interviewing

In this step cognitive interviewing was used to assess the comprehensibility and usefulness of items and identify problems such as lack of clarity and missing questions (Balza et al., 2022). Twelve informal caregivers were interviewed. Since the Self-Care of Informal Caregivers Inventory is designed for informal caregivers, regardless of condition, the interviews were done with caregivers caring for loved ones with different debilitating conditions to ensure the inventory's inclusivity and applicability. Three informal caregivers were caring for patients with chronic obstructive pulmonary disease, seven informal caregivers of adults with cancer, and two caring for children with diabetes or cancer. Eligibility criteria for informal caregivers participating in the cognitive interviews included age ≥ 18 years and having been a caregiver to a family member or a friend with a chronic condition for at least one month. Caregivers were excluded if they were not living in the same household as the patient. Participants were selected based on their visit time in the waiting room, choosing those who spent the most time there and could leave their loved one alone while waiting to see their doctor. The first author conducted each interview in a private room over a two week period, with each interview lasting approximately 45–60 min. The informal caregivers were informed about the study's aim and provided verbal consent to be interviewed.

The informal caregivers were given the inventory and a pencil. After completing the inventory independently, caregivers were asked to read each item aloud. The interviewer asked open-ended questions: 'How can you relate to this item?' and 'From your experience, do you feel anything should be included in this item?' The caregivers were encouraged to give feedback, discuss their relation to the item, and suggest changes or additions. The interviews were recorded with the participant's permission. The recordings were reviewed by the first author and feedback was summarized in English for discussion with the second author.

2.1.5. Step five: item enhancement

Based on these cognitive interviews, several changes were made to enhance the clarity and applicability of the instrument. In Section A: self-care maintenance, the item 'Give yourself a break and make time to relax (e.g., rest, meditate),' was expanded to 'Give yourself a break and make time to relax (e.g., rest, watch TV series, read a book, meditate, pray)' to acknowledge diverse relaxation methods. In Section B: self-care monitoring 'Pay attention to your emotional well-being,' was changed to 'Pay attention to your emotional state.' This shift encourages informal caregivers to be aware of their current emotions. It enhances the focus on real-time emotional monitoring, a vital component of self-care monitoring in the theory. In Section C: self-care management the item 'Ask for assistance from others,' was modified to provide examples of the types of assistance to encourage caregivers to seek help in caregiving tasks and routine daily activities (e.g., caregiving responsibilities, everyday errands). This process concluded in the refinement of three items and the final selection of the 27 items in the inventory.

2.1.6. Step six: content validity

After finalizing the instrument in English, it was translated again into Farsi for the Content Validity Index assessment. Content validity refers to the extent to which an instrument's items adequately represent the specific construct it aims to measure, ensuring comprehensive coverage of the domain of interest (Shi et al., 2012). To assess the Content Validity Index, each inventory item was given a 4-point Likert scale ranging from 'not relevant' to 'very relevant.' Then a panel of Iranian experts, including one physician, two nurses, four health psychologists, and one clinical psychologist judged each item. Four of the 12 expert team members conducting content validation were also providing informal care to loved ones at the time of the study. Each expert independently reviewed the items and rated their relevance. Then, all 12 panel members participated in a series of three collaborative meetings with the first author. These sessions were designed to address any discrepancies and foster a collective consensus on the appropriateness of each item. The instrument achieved a CVI of 100 %, indicating unanimous expert agreement on the relevance and appropriateness of each item.

2.2. Phase two: formal psychometric evaluation

2.2.1. Sampling and data collection

Primary caregivers of cancer outpatients receiving treatment in oncology wards were sampled. The cancer patients had been undergoing treatment in the hospital for more than one month. The decision to enroll cancer patient caregivers was driven by practical considerations of accessibility and availability in the chosen setting among the Farsi-speaking population of Iran. The informal caregivers had to be 18 years of age or older, recognized as the primary caregiver by the patients, and interested in participating after learning about the research. Participants completed a study-specific sociodemographic questionnaire designed to collect data on caregiver age, education, relationship to the patient, employment, and marital status and the Self-Care of Informal Caregivers Inventory. Data collection occurred during routine clinic visits. Survey completion was overseen by the primary author or two nurse research assistants who were thoroughly briefed on the study protocol.

A sample of 234 caregivers was enrolled. Guidelines for factor analysis typically recommend a ratio of 5–10 participants per item, and given our 27-item inventory, this sample size is sufficient for a robust psychometric evaluation. Our sample size choice is validated by findings from a systematic review (White, 2022). Furthermore, to ensure the adequacy of our sample size, we referenced power calculation methods for structural equation models (SEMs) proposed by Satorra and Saris (1985). These methods, detailed in Jak et al.'s tutorial, confirm that our sample size is sufficient (Jak et al., 2020).

To evaluate the stability of the Self-Care of Informal Caregivers Inventory over time, test-retest reliability was assessed in a randomly selected subset of 50 caregivers from the total sample of 234. This sample size aligns with established standards (Kishore

et al., 2021). These 50 caregivers completed the inventory twice, with a two-week interval between assessments. This interval was chosen to coincide with the caregivers' return visits accompanying the patients.

The final Self-Care of Informal Caregivers Inventory used in subsequent testing uses a 5-point Likert format with response options ranging from 'Never,' 'Rarely,' 'Sometimes,' 'Often,' to 'Always' for each item. Each scale within the inventory is scored separately to reflect self-care maintenance, self-care monitoring, and self-care management. Scores are standardized 0 to 100, with higher scores indicating greater self-care. The inventory requires approximately 10 min to complete.

2.2.2. Ethical approval

Approval to approach caregivers was obtained from oncologists seeing outpatients for their scheduled follow-up appointments, despite the absence of a formal Institutional Review Board system in Iran. The investigators used several ethical safeguards, including the safe handling of data, the voluntary nature of participation, the right to withdraw at any time, confidentiality of personal information, discussion of associated risks and benefits, obtaining informed consent from all participants, and a commitment to providing participants with the study results. Participants provided their written consent before receiving the inventory for completion. These ethical protocols were diligently followed to ensure the welfare and rights of all participants.

2.3. Data analysis

Participants who did not fully complete the self-care inventory and demographic information were excluded from the analysis. In this study, 31 subjects were excluded from the analysis because they responded to less than 95 % of the questions in the demographic survey and the self-care inventory. Those who responded to a sufficient number of questions and those who did not were compared, and there were no significant differences between these two groups. All those who provided complete responses to the self-care inventory were included. However, some included participants skipped some demographic questions. Categorical variables were expressed as frequencies and percentages, while continuous variables were represented by mean values \pm standard deviation (SD).

Exploratory Structural Equation Modeling (ESEM) was used to evaluate the fit of concepts to the construct of self-care. The use of ESEM in our analysis served a unique purpose, allowing us to address both exploratory and confirmatory parts of our research simultaneously. Despite its conceptual focus, the flexibility of ESEM allowed us to investigate potential latent components that were not explicitly stated in the initial model. This method is especially useful when working with a diverse and culturally specific participant pool (Marsh et al., 2020; Prokofieva et al., 2023). Fit indices, including Chi-square, degrees of freedom (Df), p-values, Comparative Fit Index (CFI), Tucker Lewis Index (TLI), Standardized Root Mean Square Residual (SRMR), and Root Mean Square Error of Approximation (RMSEA), were computed for each scale.

Following the ESEM, Exploratory Factor Analysis (EFA) was conducted separately for each scale (self-care maintenance, self-care monitoring, and self-care management) (Riegel et al., in press). The rationale for performing EFA, even after a theory-driven development process, was to assess for multidimensionality, which requires a different approach to assessing reliability. EFA was executed using Varimax rotation to enhance the interpretability of the factor structure. Items with factor loadings below 0.4 were excluded to retain only those items with substantial contributions to their respective factors. Additionally, we reported key metrics, including the cumulative variance explained, the Kaiser-Meyer-Olkin Measure of Sampling Adequacy, and Bartlett's Test of Sphericity, to support

Table 2
Sociodemographic of the Study Sample ($n = 234$).

Sample characteristics	Frequency (%) / Mean \pm SD
Gender	
Female	190 (81.20)
Male	44 (18.80)
Age, mean (SD) / Min - Max	45.5 \pm 15.5 / [18 - 73]
Relationship of the caregiver to the patient	
Parent	59 (25.2)
Child	110 (47.1)
Spouse	42 (19.9)
Sibling	23 (9.8)
Education	
Middle school or less	53 (22.6)
High School	75 (32.1)
University Degree	100 (42.7)
Not Provided	6 (2.6)
Employment Status	
Employed	115 (49.1)
Unemployed	77 (32.9)
Retired	34 (14.5)
Not Provided	8 (3.4)
Marital Status	
Single	95 (40.6)
Married	102 (43.6)
Divorced	30 (12.8)
Widowed	7 (3.0)

the appropriateness and robustness of our factor analysis results.

All scales exhibited a multidimensional structure so internal consistency reliability was assessed using a multidimensional model-based reliability. Reliability coefficients exceeding 0.7 were considered acceptable.

Pearson correlation coefficient (r) was calculated to examine the correlation between self-care maintenance and self-care monitoring, self-care maintenance and self-care management, and self-care monitoring and self-care management to ensure that each dimension individually contributes to the overall construct of self-care. Confidence intervals for all Pearson correlation coefficients were reported, determined through Fisher’s r-to-z transformation with bias adjustment. The Intraclass Correlation Coefficient (ICC) was computed to assess the test-retest reliability of measurements, encompassing both within-subject consistency (Single Measures ICC) and between-subject agreement (Average Measures ICC) for self-care maintenance, self-care monitoring, and self-care management. Analyses were performed using R (version 4.3.1) and SPSS (version 27). Statistical significance was defined as a p-value less than 0.05.

3. Results

3.1. Characteristics and demographic of participants

A sample of 234 informal caregivers completed the Self-Care of Informal Caregivers’ Inventory (Table 2). The sample predominantly consisted of women (81.2 %) with a mean age of 45.5 years. This group included many adult children and parents caring for their loved ones. Participants were generally well-educated and nearly half were employed. Marital status varied, with a balanced distribution between single and married individuals.

3.2. Fit indices for concepts derived from ESEM

In ESEM (Table 3), the fit indices for Self-Care Maintenance were excellent, with a non-significant chi-square test ($p= 0.11$), a CFI of 1.00, a TLI of 0.99, and a RMSEA of 0.04. The SRMR was particularly low at 0.03, indicating minimal discrepancies between the observed and model-predicted correlations. The fit indices for Self-Care Monitoring were also good, as evidenced by a non-significant chi-square test ($p = 0.55$), perfect CFI and TLI values of 1.00, and an RMSEA of 0.00. The SRMR value of 0.03 further supported the model’s close fit to the data. For Self-Care Management, despite a significant chi-square test ($\chi^2 = 68.35, p= 0.01$) suggesting some model misfit, the CFI and TLI values were high at 0.99. The RMSEA was 0.05, indicating an acceptable fit, and the SRMR was 0.05, suggesting a good fit in terms of residuals. The overall model fit was examined using the chi-square test, which was non-significant ($\chi^2 = 298.23, p= 0.17$). The CFI and TLI values were excellent at 0.99, the SRMR was 0.04, and the RMSEA was 0.02, indicating a well-fitting model.

3.3. Exploratory factor analysis and item factor loadings

Table 4 illustrates the factor loadings derived from EFA and ESEM for each item within the self-care scales. The EFA factor loadings, ranging from 0.57 to 0.79, indicate robust associations between the items and their respective concepts. This range signifies that each item substantially contributes to its scale’s overall variance. Similarly, the ESEM loadings, shown in parentheses, ranged from 0.47 to 0.77, further corroborating the strong relationships within the construct. The total variance explained by the model was 54.43 %, demonstrating that our factors account for a substantial portion of the variance in caregivers’ self-care behaviors. The KMO measure was 0.93, indicating excellent sampling adequacy and supporting the suitability of the data for factor analysis. Bartlett’s Test of Sphericity yielded a chi-square value of 3029.86 (df = 351, $p < 0.001$), indicating that the correlations among items were sufficiently large for EFA.

Table 3

Fit indices for all the concepts derived from Exploratory Structural Equation Modeling.

Indices		Total	Concept		
			Self-care maintenance	Self-care monitoring	Self-care management
Chi-square	Value	298.23	21.76	26.36	68.35
	Df	276	15	28	45
	p-value	0.171	0.114	0.553	0.014
CFI	Value	0.99	0.99	1.00	0.99
TLI	Value	0.99	0.99	1.00	0.99
SRMR	Value	0.036	0.031	0.027	0.048
RMSEA	Value	0.019	0.044	0.000	0.047
	Lower 95 % CI	0.00	0.000	0.000	0.022
	Upper 95 % CI	0.033	0.082	0.043	0.069
	P-value (RMSEA < 0.05)	1.000	0.557	0.970	0.558

Note. DF degree of freedom, TLI Tucker Lewis Index, CFI comparative fit index, RMSEA Root Mean Square Error of Approximation.

Table 4
Exploratory factor analysis and item factor loadings for the self-care maintenance, self-care monitoring, and self-care management.

Items	Factor Loading		
	Self-care Maintenance	Self-care Monitoring	Self-care Management
Self-care Maintenance			
1. Maintain daily personal hygiene (e.g., oral, skin, hair care)?	0.69 (0.56)		
2. Do physical activities (e.g., brisk walking, cycling)?	0.61 (0.50)		
3. Eat all the essential meals of the day (breakfast, lunch, dinner)?	0.65 (0.51)		
4. Keep a healthy, balanced diet (combination of whole grains, lean proteins, fruits, and vegetables)?	0.62 (0.50)		
5. Drink enough water (e.g., 6 to 8 glasses daily)?	0.57 (0.50)		
6. Avoid smoking or vaping (cigarettes, electronic cigarettes)?	0.7 (0.55)		
7. Avoid or limit alcohol intake daily (no more than one drink for women and two for men)?	0.67 (0.53)		
8. Make sure to get enough sleep during the night?	0.64 (0.51)		
9. If/when prescribed, take the medications or supplements on time (e.g., setting reminders)?	0.67 (0.53)		
10. Give yourself a break and make time to relax (e.g., rest, watch TV series, read a book, meditate)?	0.63 (0.50)		
11. Keep contact with friends and engage in social activities (e.g., attending the movies and gatherings)?	0.64 (0.50)		
Self-care Monitoring			
12. Monitor your physical health?		0.71 (0.57)	
13. Monitor your weight (e.g., regular weigh-ins, notice changes in clothing fit)?		0.79 (0.70)	
14. Monitor your daily eating habits (e.g., notice changes in eating patterns, loss or increase in appetite)?		0.73 (0.61)	
15. Pay attention to your emotional state (e.g., recognizing constant feelings such as sadness, anxiety, guilt)?		0.76 (0.65)	
16. Pay attention to signs of being overwhelmed (e.g., frequent irritability)?		0.71 (0.58)	
17. Pay attention to signs of fatigue (e.g., unusual tiredness throughout the day)?		0.67 (0.54)	
18. Pay attention to signs of discomfort (e.g., trouble sleeping, back pain, uncommon headaches)?		0.74 (0.60)	
Self-care Management			
19. Change your caregiving efforts based on your physical status (e.g., not pushing yourself)?			0.71 (0.76)
20. Avoid or limit unhealthy snacks, meals, and drinks (e.g., chips, deep-fried/ fast food, sweetened beverages)?			0.74 (0.75)
21. Increase regular sports activities?			0.76 (0.74)
22. Adopt techniques to enhance your emotional well-being (e.g., meditation, listening to music)?			0.7 (0.71)
23. Find harmony and balance between your personal life, work, and caregiving roles?			0.73 (0.69)
24. Change your sleep habits (e.g., make a regular sleep schedule and comfortable environment)?			0.61 (0.65)
25. Seek professional counseling or join support groups (e.g., attending caregiver support meetings)?			0.74 (0.75)
26. Ask for assistance from others (e.g., caregiving responsibilities, everyday errands)?			0.75 (0.77)
27. Accept help from others (e.g., relatives, friends, palliative care providers, hospice care team)?			0.74 (0.73)
Cumulative Variance Explained	54.43 %		
Kaiser-Meyer-Olkin Measure of Sampling Adequacy	0.93		
Bartlett's Test of Sphericity [Chi-Square, DF, P-value]	Chi-square = 3029.86, DF = 351, P-value < 0.001		

Note: Factor loadings are shown for both Exploratory Factor Analysis and Exploratory Structural Equation Modeling (ESEM). ESEM loadings are provided in parentheses. Extraction. Rotation Method: Varimax with Kaiser Normalization. Small coefficients with an absolute value below 0.4 were suppressed.

3.4. Internal consistency reliability of scales

We assessed the internal consistency reliability of the scales using Cronbach's alpha because each scale was shown in EFA to be unidimensional. The Alpha coefficients of self-care maintenance, self-care monitoring, and self-care management were 0.88, 0.88, and 0.91, respectively.

We explored the relationships between the different self-care components using correlation analysis. The analysis revealed significant positive correlations between self-care maintenance and self-care monitoring ($r = 0.43, p < 0.001$), self-care maintenance and self-care management ($r = 0.51, p < 0.001$), and self-care monitoring and self-care management ($r = 0.45, p < 0.001$). Test-retest reliability is assessed to determine the consistency of a measure over time, ensuring that the results are stable and reproducible. Accordingly, test-retest reliability for self-care maintenance was excellent ($ICC = 0.94, p < 0.001$). For self-care monitoring ($ICC = 0.43, p = 0.001$) and self-care management ($ICC = 0.34, p = 0.008$), reliability was moderate indicating acceptable consistency.

4. Discussion

This study aims to fill a void in the existing scientific literature by developing and evaluating the psychometric properties of the Self-Care of Informal Caregivers Inventory. Based on the Middle-Range Theory of Self-Care of Chronic Illness, we designed an instrument to assess self-care maintenance, self-care monitoring, and self-care management of informal caregivers and demonstrated that it is reliable and valid.

This effort is particularly significant given the challenges faced by informal caregivers in providing care and support, which can lead to neglect in self-care behaviors and a potential decline in mental and physical health. The sudden shift from everyday life routines to adjusting to caregiving responsibilities can impact health behaviors, making it crucial for informal caregivers to be more conscious of their health and self-care practices (Liu et al., 2022). In addition, by evaluating self-care behaviors among informal caregivers, healthcare providers can address self-care needs and identify specific areas where caregivers struggle. This targeted approach enables healthcare professionals to provide tailored support. Notably, with life expectancy increasing due to advancements in medical treatments, the role of informal caregivers in the healthcare system is growing more vital than ever. By providing patient care, informal caregivers form a vital bridge between professional healthcare services and individuals with debilitating conditions (Stephenson et al., 2022). Hence, empowering informal caregivers by addressing the often-overlooked self-care practices and acknowledging their contribution can enhance health outcomes across a spectrum of conditions.

An important advantage to this instrument is its focus on the self-care of a specific population - informal caregivers. Generic measures of self-care are available and have been used in other caregiver studies (Riegel et al., 2024), but others have demonstrated that generic measures may inflate scores (Maria et al., 2024). This focused instrument is anticipated to increase the precision with which self-care is measured in caregivers and thereby enhances the generalizability and applicability of the measure to a broader informal caregiver population.

Our assessment of the Self-Care of Informal Caregivers Inventory demonstrated a strong psychometric profile in this sample. The solid psychometric properties underscore its potential as a standard measure in caregiver assessments to support informal caregiver's health. These metrics indicate the tool's potential as a reliable and valid measure in caregiver assessments and its potential contribution to understanding and improving the self-care practices of informal caregivers.

The analysis revealed a strong, statistically significant relationship between different aspects of self-care, including maintenance, monitoring, and management. However, multiple factors may influence these correlations so future users may find different relationships. Differences in study participants, such as demographics and cultural backgrounds, might affect the observed relationships in future research. Furthermore, differences in research methodologies, including study design, data collection, and analysis techniques, can lead to inconsistent future findings. These contrasting results highlight the complexity of self-care and underscore the need for further research to understand the underlying factors contributing to the associations among different self-care dimensions in informal caregivers.

4.1. Practical implications of the findings

The primary usefulness of this inventory will be to researchers interested in designing and testing interventions to improve the self-care of informal caregivers. In addition, though, having a valid measure of caregiver self-care can contribute to positive caregiving dynamics and the broader community by helping healthcare professionals to identify poor self-care in caregivers. Self-Care matters, even while caring for others. The inventory plays a key role in promoting health literacy among informal caregivers. It illustrates that while maintaining a healthy diet and regular exercise are essential parts of self-care, noticing physical and emotional changes (self-care monitoring) and taking action toward those changes (self-care management) are just as crucial for self-care. Notably, by providing structured, actionable items, the inventory aids informal caregivers in incorporating practical self-care strategies into their daily routines, ultimately enhancing their well-being.

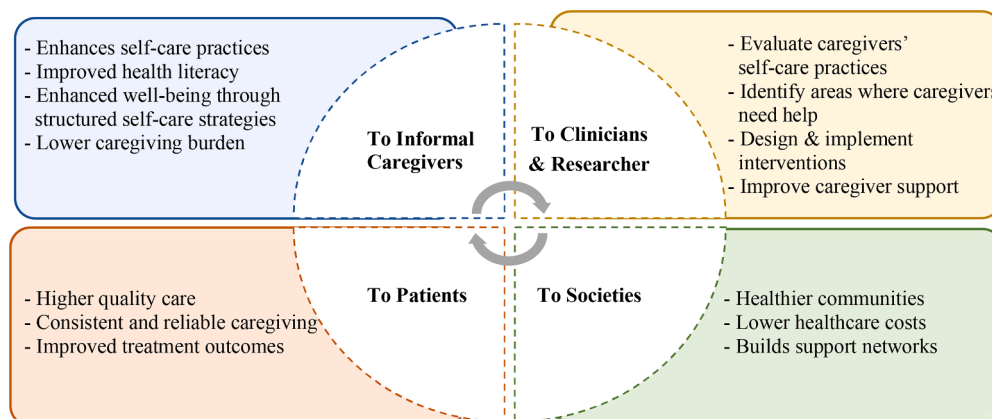


Fig. 3. The practical implications of the self-care of informal caregivers inventory.

In addition, the Self-Care of Informal Caregivers Inventory has the potential to foster a more resilient and healthier society. This focus is particularly timely and significant given the increasing prevalence of informal caregiving. Hence, recognizing the significant role of informal caregivers, we emphasize that by evaluating their self-care practices, we benefit not only them but also their loved ones, the healthcare providers, and society as a whole (Fig. 3).

4.2. Strengths and limitations

This instrument is based on the Middle-Range Theory of Self-Care of Chronic Illness, providing a solid theoretical framework. A strength of the study was the rigorous approach used in instrument development and testing. However, there are also some limitations.

Our study was conducted in one country and a single setting, which may restrict the generalizability of our findings to other healthcare environments. Additionally, while our study was performed in Farsi, the translation into English was not subjected to psychometric evaluation. To address some of these limitations, the inventory is currently being tested in the United States with English-speaking participants. While the study employed robust statistical analyses, the reliance on self-report measures and the limited diversity in informal caregiver demographic characteristics may have introduced response bias and affect the external validity of the results.

5. Conclusion

In conclusion, in this study we demonstrated that the Self-Care of Informal Caregivers Inventory has robust validity and reliability, making it a valuable tool for assessing self-care of informal caregivers. The instrument bridges a gap in caregiving literature and is applicable in clinical settings and research studies. The study also highlights the potential generalizability of the Self-Care of Informal Caregivers Inventory across various health conditions. The results highlight the importance of assessing the self-care of informal caregivers and provides a means of doing so. The Self-Care of Informal Caregivers Inventory can assist health care providers to determine where intervention is useful and necessary for informal caregivers and sets the stage for future studies to improve its usefulness and develop support measures for informal caregivers.

Future research should investigate the factors contributing to the only fair test-retest reliability of self-care monitoring and self-care management and ways to enhance the consistency of responses over time. Such modifications could enhance the instrument's reliability in evaluating these aspects of self-care.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

Data availability statement

The instrument is freely available at www.self-care-measures.com. Data from this study is accessible from the corresponding author upon reasonable request.

CRedit authorship contribution statement

Negin Dorri: Writing – original draft, Visualization, Methodology, Formal analysis, Data curation, Conceptualization. **Barbara Riegel:** Writing – review & editing, Supervision, Conceptualization.

Declaration of competing interest

The authors declare that they have no conflicts of interest, financial or personal, that could have influenced this article's research, writing, or publication.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.ijnnsa.2024.100237](https://doi.org/10.1016/j.ijnnsa.2024.100237).

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