







Review Article

Tools for assessing informal caregivers' self-efficacy in home care: integrative review

Instrumentos de avaliação da autoeficácia do cuidador informal na assistência domiciliar:
revisão integrativa

Instrumentos de evaluación de la autoeficacia del cuidador informal en la atención domiciliar:
revisión integrativa

Fernanda Gatez Trevisan dos Santos¹, Elaine Trevezanuto Correia¹,
Luana Cristina Bellini Cardoso¹, Mayara Almeida Martins¹, Aline Zulin¹, Cremilde
Aparecida Trindade Radovanovic¹

¹ Universidade Estadual de Maringá (UEM), Maringá, Paraná, Brasil

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Abstract

Objective: to identify the validated instruments for assessing informal caregivers' self-efficacy described in the literature. **Method:** integrative review, which analyzed primary research articles, without date restrictions, in the Medical Literature Analysis and Retrieval System Online, Latin American and Caribbean Health Sciences Literature, Cumulative Index to Nursing and Allied Health Literature, and Scopus and Cochrane Library databases. The search was performed in October 2022; double-blind selection was developed in Rayyan®. Data were submitted to critical analysis and qualitative synthesis and presented in a descriptive form. **Results:** Twenty-nine self-efficacy assessment instruments were found within 41 articles. These can be used in different contexts, such as patients with chronic diseases, cancer, dementia, among others. **Conclusion:** the study enabled the identification of 29 validated instruments for assessing self-efficacy to be applied on informal caregivers in different care contexts.

Descriptors: Self Efficacy; Caregivers; Surveys and Questionnaires; Home Nursing; Family

Resumo

Objetivo: identificar os instrumentos validados de avaliação da autoeficácia em cuidadores informais descritos na literatura. **Método:** revisão integrativa, que analisou artigos de pesquisas primárias indexados nas bases de dados Medical Literature Analysis and Retrieval System Online, Literatura Latino Americana e do Caribe em Ciências da Saúde, Cumulative Index to Nursing and Allied Health Literature, Scopus e Cochrane Library, sem restrição de data. A busca foi realizada em outubro de 2022; a seleção duplo-cega foi desenvolvida no Rayyan®. Os dados foram submetidos à análise crítica e síntese qualitativa e apresentados de forma descritiva. **Resultados:** em 41 artigos, foram encontrados 29 instrumentos de avaliação da autoeficácia. Estes podem ser utilizados em diferentes contextos; como pacientes com adoecimento por doenças crônicas, câncer, demência, entre outros. **Conclusão:** o estudo possibilitou a identificação de 29 instrumentos validados de avaliação da autoeficácia para serem aplicados com cuidadores informais em diferentes contextos de cuidado.

Descritores: Autoeficácia; Cuidadores; Inquéritos e Questionários; Assistência Domiciliar; Família

Resumen

Objetivo: identificar instrumentos validados de evaluación de autoeficacia en cuidadores informales descritos en la literatura. **Método:** revisión integrativa, analizado artículos de investigaciones primarias indexados en las bases de datos Medical Literature Analysis and Retrieval System Online, Literatura Latino Americana y de Caribe en Ciencias de la Salud, Cumulative Index to Nursing and Allied Health Literature, Scopus y Cochrane Library, sin restricción de fecha. La búsqueda realizada en octubre de 2022; la selección doble ciega fue desarrollada en Rayyan®. Los datos fueron sometidos al análisis crítico y síntesis cualitativa y presentados de manera descriptiva. **Resultados:** en 41 artículos, fueron encontrados 29 instrumentos de evaluación de la autoeficacia. Estos pueden ser utilizados en diferentes contextos; como pacientes con enfermedad por enfermedades crónicas, cáncer, demencia, entre otros. **Conclusión:** el estudio permitió la identificación de 29 instrumentos validados de evaluación de la autoeficacia para ser aplicados con cuidadores informales en diferentes contextos de atención.

Descriptor: Autoeficacia; Cuidadores; Encuestas y Cuestionarios; Atención Domiciliar de Salud; Familia

Introduction

Chronic noncommunicable diseases (NCDs) are the leading cause of morbidity and mortality in the world and account for approximately 75% of deaths in Brazil, with cardiovascular problems, cancer, diabetes, and chronic respiratory diseases standing out. Besides premature mortality, the advance of NCDs causes disabilities and, consequently, requires the presence of a caregiver.¹⁻²

In general, the responsibility for caring for a sick family member falls on one or more family members and is performed at home.³ In this context, the informal caregiver (IC) is defined as a family or community member who voluntarily provides some assistance to the dependent person without receiving remuneration for the service; most of the time, the care is performed by women, spouses, and children.⁴⁻⁵ It can be affirmed that the role of the family is

indispensable in the context of care dependence, and support is necessary for ICs so that they can carry out home care safely and effectively.³ According to Bandura's social cognitive theory, self-efficacy (SE) is defined as the belief one has about one's own abilities to organize and successfully perform an intended action, which can be influenced by external factors such as the environment and the social support received.⁶⁻⁷ This belief plays a role in the choices that will be made by the caregiver, since his or her goals are based on how much effort and time he or she is capable of putting into these actions, of persevering in the face of difficulties and failures, and whether or not there is the possibility of giving up, how much stress and depression they experience with demands of the environment and, finally, the level of achievement they reach.⁸⁻¹⁰

Caregivers with low SE are more likely to develop depressive symptoms, anxiety, and health problems. They also present feelings of hopelessness and disbelief in being able to deal with complex situations and believe that they have little chance of changing their own reality. The overburden experienced by the caregiver and intensified by the negative feelings also influences the quality of the care provided.^{7,11-12} On the other hand, caregivers with a high degree of SE are more susceptible to acquiring new behaviors, learn to solve problems, use their knowledge and skills, and adjust more easily to the care routine. Thus, SE is associated with greater caregiver well-being, hope, and quality of life.⁹⁻¹¹

Interventions directed at the family have shown to be effective in promoting SE and trust, with improvements observed in the quality of patient care and in the caregiver's life. It was also verified that the interventions to improve SE have greater effectiveness when considering the caregiver's trajectory, knowledge, and skills.^{6,11-13} In this context, the use of validated questionnaires is suggested to help in the evaluation of SE for care, which enables the production of scientifically robust and reliable data. Therefore, the present study aims to identify literature-validated instruments to evaluate SE in informal caregivers.

Method

This is an integrative literature review organized in six stages, namely: 1) elaboration of the research question; 2) establishment of criteria for inclusion and exclusion of studies and literature search; 3) definition of the information to be extracted from selected studies; 4) critical analysis of the studies included in the review; 5) interpretation of results; 6) presentation of the synthesis of the gathered knowledge.¹⁴

The research question was elaborated according to the PICO (Population, Interest, Context) strategic model, considering the following structure: P - informal caregiver; I - use of questionnaires that assess self-efficacy; Co - home care. In this way, the following question was constructed: "What are the questionnaires for assessing informal caregivers' self-efficacy in home care available in the scientific literature?"

We selected open access, primary research articles, with full texts available, without date or language restriction, which used some form of questionnaire to measure self-efficacy of the IC in home care. We excluded editorials, letters, event proceedings, research protocols, reviews, monographs, dissertations and theses, and those studies that presented SE as a secondary outcome.

The search was conducted in October 2022, in the Periodical Portal of the *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior* (CAPES) [Coordination for the Improvement of Higher Education Personnel], in the Medical Literature Analysis and Retrieval System Online (MEDLINE) and Latin American and Caribbean Literature on Health Sciences (LILACS) databases by access to the Virtual Health Library (VHL) portal, and in the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus, and Cochrane Library.

The expression used in the review combined the terms present in the Medical Subject Headings (MeSH) and their corresponding terms in the Health Sciences Descriptors (DeCS). The cross-referencing of the descriptors was done in English and Portuguese as follows: "Self-Efficacy (DeCs/MeSH)". Two researchers conducted the selection steps independently, and divergences were discussed among the authors.

The Rayyan® platform was used to help with pre-analyzing the articles, selecting duplicates, and analyzing the titles and abstracts of the studies that met the inclusion criteria.¹⁵ A flowchart was used for providing transparency of the selection process of the corpus of the review. Subsequently, the articles were read in full, and the studies that used instruments for assessing IC's SE were selected. For the extraction of information, we prepared a Microsoft Excel® spreadsheet containing the following data: year of publication, country where the research was conducted, journal, study objective, methodology, participants, instruments used for measurement, outcome, and level of evidence.

For categorizing the level of evidence, the following classification was considered: level I, systematic review or meta-analysis of randomized controlled clinical trials; level II, well-designed randomized controlled clinical trial; level III, well-designed clinical trials without randomization; level IV, well-designed cohort and case-control studies; level V, systematic review of descriptive

and qualitative studies; level VI, descriptive or qualitative study; level VII, evidence derived from opinions of authorities and/or expert committee reports.¹⁶ The fifth stage of the integrative review - interpretation of results - corresponded to the discussion phase of the main research findings. The theoretical foundation was based on the critical evaluation of the studies included, allowing for the identification of conclusions, and pointing out gaps in knowledge. In the sixth and last stage - presentation of the synthesis of the review/knowledge - the manuscript was written containing the description of the stages taken by the reviewer and the most relevant outcomes evidenced by the analysis of the selected articles.¹⁴ As this was an integrative review, the research was not submitted to the Research Ethics Committee, but the ideas from the authors of the publications used in the development of this study were kept.

Results

A total of 342 articles were found in the databases, of which 95 were duplicates. Fifty articles were selected for reading in full, of which nine were excluded for not meeting the inclusion criteria. Thus, 41 articles comprised this review (Figure 1).

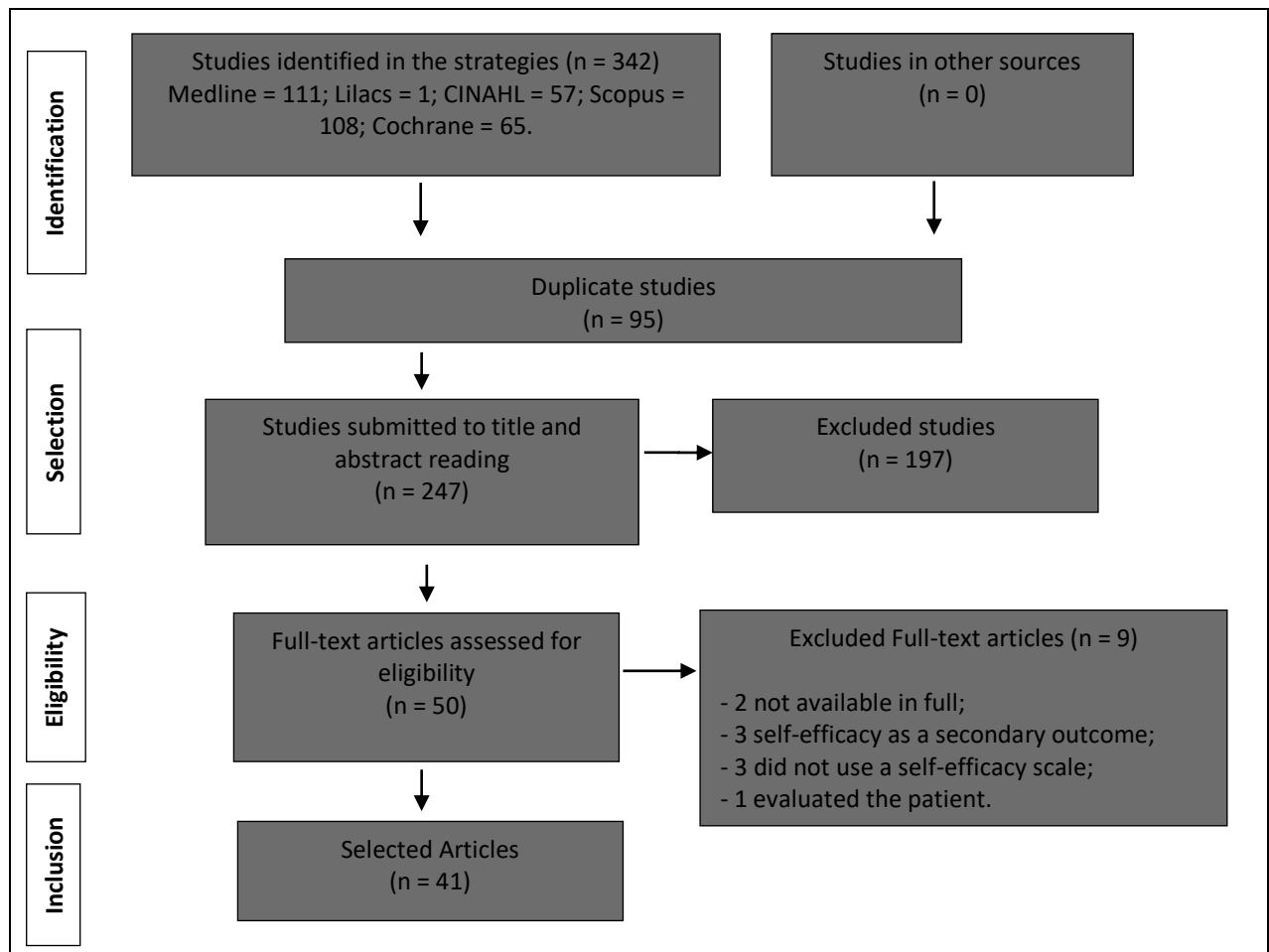


Figure 1 - Flow of the selection process of studies included in the integrative review, 2022.

The selected articles (n = 41) were from 16 countries, published in English and in the official language of the country of publication. The sample size of the analyzed articles ranged from 10 to 542 participants, and 34 of these included only the IC, five worked with the caregiver-patient dyad, and two included professionals and caregivers.

As per the methodology, 20 were cross-sectional studies of quantitative approach; 10 were methodological, of instrument construction and validation; five were quasi-experimental; three were controlled and randomized clinical trials; two were cohort studies; and one was a mixed method research. Regarding the level of evidence, the number of studies per level was: level II, 3; level III, 6, level IV, 1; level VI, 31.

Twenty-nine instruments for assessing informal caregivers' self-efficacy in home care were identified (Chart 1).

Chart 1 - Characterization of the informal caregiver's self-efficacy assessment instruments present in the review

Instruments/Studies	Scale structure	Context for using the scale
CAH Survey ¹⁷	32 items, of which 10 assess SE, with a four-point Likert response scale.	Family members of patients with congenital adrenal hyperplasia
Cancer Self-Efficacy Scale-transplant (CASE-t) ¹⁸⁻¹⁹	Scale adapted from Lewis, 1996. ¹⁸ Responses from 0 to 10; $\alpha = 0.96$.	Assesses care management for cancer patients who have received stem cell transplantation.
Caregiver Empowerment Scale ²⁰	59 items, four factors. Five-point Likert response scale. Alpha ranged from 0.79 to 0.88.	Family members of patients with traumatic brain injury
Caregiver Confidence in Medical Sign/Symptom Management ³	25 items, four factors; $\alpha = 0.92$.	Assesses signs/symptoms management.
Caregiver Self-Efficacy ^{7,21-22}	Six items, five-point Likert response scale; $\alpha = 0.77$.	ICs of adults with developmental disabilities.
Caregiver Self-Efficacy Scale (CSES) ²³	21 items and four factors. Five-point Likert response scale. Alpha ranged from 0.73 to 0.94.	ICs of people with cancer.
Caregiver Self-Efficacy Scale (CSES-8) - Short version ²⁴⁻²⁵	Short version of the CSES, with eight items, maintaining response scale. $\alpha = 0.89$.	General measurement of SE.
Caregiver Self-Efficacy Scale for Transfers (CEST) ²⁶⁻²⁷	14 items, two domains. 11-point response scale; $\alpha = 0.96$.	Caregivers of children with movement dysfunction
Chronic Disease Self-Efficacy Scale ^{11,28}	Seven items, which can be answered with a ten-point scale; $\alpha = 0.89$.	Family members of patients with chronic diseases
Chronic Pain Self-Efficacy Scale (CPSS) ^{8,29}	16 items, three factors. 10-point Likert scale. F1 $\alpha = 0.88$; F2 $\alpha = 0.87$; F3 $\alpha = 0.90$.*	Family members of adult cancer patients in handling pain

Communication Self-Efficacy Scale (CSES) ^{10,30}	16 items categorized into three factors; each item can be answered on a scale of 0 to 10; $\alpha = 0.93$.	Assesses the caregiver's SE for communicating with the person with aphasia.
Coping Self-Efficacy Scale (short version) ³¹⁻³²	13 items, three factors. 11-point response scale; $\alpha = 0.87$.	Assesses SE for coping.
Epilepsy Self-Efficacy Scale (ESES) ³³⁻³⁴	33 items. 11-point response scale; $\alpha = 0.92$.	Original scale assesses self-care of children and adolescents with epilepsy. Wagner et al. adapted it for assessing parent's SE.
Family Caregiver Inventory ^{9,35}	Composed of two structured interview instruments: one for the caregiver and one for the receiver of care. Five-point Likert response scale.	General measurement of SE.
Family Caregiver Self-Efficacy Scale ³⁶⁻³⁸	Composed of nine items and two factors. 11-point response scale. F1* - symptom management, $\alpha = 0.78$; F2* - community support, $\alpha = 0.77$.	Family members of patients with dementia
Family Caregiver Self-Efficacy Scale in Terminal Cancer Patients at Home ³⁹⁻⁴⁰	Eight items, arranged in two domains, $\alpha = 0.80$. 4-point Likert response scale.	Family members of patients with terminal cancer
Family-Carer Diabetes Management Self-Efficacy Scale (DMSSES) ⁶	14 items, four factors; $\alpha = 0.89$. Five-point Likert response scale.	Family members of patients with diabetes mellitus
General Self-Efficacy Scale ^{13,41-44}	Adaptations with 12 and 10 items, four-point response scale, $\alpha > 0.75$ were used.	General measurement of SE.
LVAD Caregiver Self-Efficacy Scale (LCSS) ⁴⁵	21 items, categorized in two factors; $\alpha = 0.93$.	Family members of patients with ventricular assist device
Parenting Sense of Competence Scale (PSOC) ⁴⁶⁻⁴⁷	Seven items, which can be answered with a six-point scale; $\alpha = 0.71$.	Assessment of parents
Parents Versus Anorexia Scale ⁴⁸⁻⁴⁹	Seven items, five-point Likert response scale; $\alpha = 0.78$.	Parents who care for children with eating disorders
Parents'/Guardians' Self-Efficacy in Management of Asthma ⁵⁰	17 items, categorized in two factors. F1 $\alpha = 0.90$; F2 $\alpha = 0.82^*$	SE of parents/caregivers in the control of asthma
Parent Efficacy for Child Healthy Weight Behavior Scale (PECHWB) ⁵¹⁻⁵²	four factors. F1 $\alpha = 0.96$; F2 $\alpha = 0.96$. F3 $\alpha = 0.93$. F4 $\alpha = 0.95^*$	Assesses the SE of parents to promote healthy weight behaviors.
Revised Scale for Caregiver Self-Efficacy (RSCSE) ⁵³⁻⁵⁹	15 items, three factors. F1 $\alpha = 0.75$; F2 $\alpha = 0.70$; F3 $\alpha = 0.75^*$. Analog response scale from 0 to 100.	Family members of patients with Alzheimer's and other dementia
Self-Efficacy Questionnaire ¹⁸	23 items, assessed in a four-point Likert response scale; $\alpha = 0.94$.	Family members of patients with mental illness
Self-Efficacy Questionnaire for Chinese Family Caregivers (SEQFC) ⁶⁰⁻⁶²	27 items and five domains, with $\alpha > 0.80$ for all domains.	Specific to Chinese caregivers
Self-Efficacy Scale ^{54,63}	15 items with a five-point Likert response scale.	Family members of patients with Alzheimer's
Food Allergy Self-Efficacy Scale for Parents (FASE-P) ⁶⁴	21 items, with five subscales, and each item is scored on a 100-point analog scale; $\alpha = 0.89$.	Parents who care for children with food allergies

*F1, F2, F3, and F4, respectively, Factor 1, Factor 2, Factor 3, and Factor 4. SE - self-efficacy, IC - informal caregiver.

The instruments found in this review can be used in different situations. Three instruments are configured as general measures of the informal caregiver's self-efficacy. However, as the care for each disease has its specificities, there were specific instruments to evaluate the care for patients with cancer, chronic diseases, Alzheimer's and/or other related dementias, mental diseases, diabetes mellitus, and others.

There were also questionnaires aimed at parents and/or guardians of children with asthma, epilepsy, movement dysfunction, eating disorders, among others. In addition, studies were found that specifically evaluate the management of signs and symptoms, pain control, communication skills, and coping of caregivers.

The instruments that appeared more than once in this review were the following: Revised Scale for Caregiver Self-Efficacy,⁵³ found in six studies;⁵⁴⁻⁵⁹ General Self-Efficacy Scale,⁴¹ four studies;^{13,42-44} Self-Efficacy Questionnaire for Chinese Family Caregivers,⁶⁰ three studies;⁶⁰⁻⁶² Caregiver Self-Efficacy,²¹ two studies;^{7,22} Caregiver Self-Efficacy Scale for Transfers,²⁶ two studies;²⁶⁻²⁷ Family Caregiver Self-Efficacy Scale,³⁶ two studies.³⁷⁻³⁸ The remaining instruments appeared only once.

Revised Scale for Caregiver Self-Efficacy (RSCSE) – Specific scale for caregivers of people with Alzheimer's or related dementias. The questionnaire was developed in 2002 in California, United States.⁵³ The RSCSE assesses caregivers' confidence in responding to 15 items, distributed across three highly challenging domains of caregiving in dementia: getting rest; managing disruptive patient behaviors; and managing unpleasant thoughts. The domains reflect distinct and common behavioral and cognitive challenges for family caregivers of people with dementia.⁵³ The analog scale of responses ranges from 0 to 100, in which 0 represents an absolute inability to perform the activity, and a rating of 100% means that the caregiver is absolutely certain that they can perform the activity whenever they want.⁵³ This instrument has been translated and adapted into several languages; and, in this research, its use is reported in Canada,^{54,57} China,⁵⁵ Hong Kong,⁵⁶ and the United States.⁵⁸⁻⁵⁹

General Self-Efficacy Scale (GSES) – The instrument was developed in 1982, in the United States.⁴¹ It is a general scale for assessing informal caregivers' SE; and it addresses topics such as goal setting, ability to face difficulties, giving up or not on goals, ability/interest in making friends, among others. It was originally organized into two factors: the General Self-Efficacy Subscale, with 17 items; and the Social Self-Efficacy Subscale, with 6 items.⁴¹ The GSES has also been validated in many countries; after adaptations for other cultures, it presented shorter

versions, with 10 and 12 items. The response scale used is a four-point scale ranging from 1 (not at all true) to 4 (exactly true), where higher sum scores indicate greater SE. The instrument showed good internal consistency, always with an alpha value greater than 0.75. In this review, it was found to be used in China,⁴⁴ Singapore,¹³ Turkey,⁴² and Australia.⁴³

Self-Efficacy Questionnaire for Chinese Family Caregivers - The instrument was designed specifically for Chinese informal caregivers.⁶⁰ The three studies available in this review correspond, respectively, to the construction, validation, and application of the instrument in China.⁶⁰⁻⁶² Initially, the instrument was composed of 35 items, which, after analyses of validity and reliability, were reduced to 27 in the final version.⁶¹ The items were distributed into five domains, all of which showed Cronbach's alpha values greater than 0.80.

Caregiver Self-Efficacy - Developed in 1999, in Chicago, United States.²¹ With six items, which include, in the response options, statements such as "I honestly believe I have the necessary skills to be a good caregiver for my family member" and "I can find the answer to what is bothering my family member". A five-point Likert scale ranging from 1 (completely disagree) to 5 (completely agree) was used, with a summation of the responses performed for the total score. The original version had an $\alpha = 0.77$. Two studies in this review used this instrument: one was conducted in Switzerland;²² the other was conducted in the United States.⁷

Caregiver Self-Efficacy Scale for Transfers (CSEST) - The instrument has 14 items that measure the perceived self-efficacy of adult caregivers of dependent children. Its main objective is to assess the skills and challenges perceived by ICs when helping a child with limited transfer ability. The tasks include activities such as moving the child from a chair to the bathroom or relocating the chair to a car or van.²⁷ Both studies present in this review were developed in the United States,²⁶⁻²⁷ one of which proceeded to the construction and psychometric evaluation of the CSEST instrument. Its 14 items were distributed in two domains; and initially the response scale had 11 points, from 0 to 10, in which higher scores indicate greater SE.²⁶ The subsequent research, developed in 2012, tested the instrument using a smaller range of categories for responses. The number of items were maintained, and the psychometric properties were confirmed. The five-category response scale produced data with evidence of reliability and validity.²⁷

Family Caregiver Self-Efficacy Scale - Instrument developed in 2002, also in the United States.³⁶ Its application is exclusive for informal caregivers of people with dementia. The Family Caregiver Self-Efficacy Scale was composed of nine items and two factors. The first factor refers

to symptom management and had $\alpha = 0.78$. The second factor, community support, scored an $\alpha = 0.77$. Respondents, indicating on a scale from 1 (not at all sure) to 10 (very sure), answer questions such as "How certain are you now that you can...", followed by a certain situation related to care. The total sum of the answers corresponds to the SE score. In this review, the instrument was found to be used in the country of origin³⁸ and in Australia.³⁷

Discussion

Having a quality tool readily available is important to support the caregiver as it guides actions both in clinical practice for increasing the IC's confidence and health-related outcomes for the family member³ and in developing effective interventions and monitoring changes over time.⁶ To fully determine whether strategies/interventions are effective, it is necessary to be able to measure the IC's SE.³

SE is a subjective construct; it is not a stable measure, but a dynamic one that can be modified according to current environmental circumstances, as well as individual aspects of the IC - for example, his/her emotional state.^{3,6} Thus, identifying the factors that positively and negatively interfere with care enables health professionals to deliver interventions to strengthen SE.⁷

Of the articles included in this review, 20 studies were cross-sectional, of quantitative approach, which aimed to test hypotheses and verify the factors positively or negatively associated with informal caregiver's self-efficacy, in different contexts. They assessed levels of self-efficacy and caregiver burden,⁴² depressive symptoms,⁵⁵ level of caregiver knowledge,¹⁷ informal caregiver coping strategies,³⁴ among other items.

It has been shown that internal and external resources can be important for caregiving experiences. Among the individual aspects that interfere in SE, the IC's physical and mental health status, age, internal coping strategies, and problem-solving capacity stand out.^{7,11,13,40}

It was observed that elderly caregivers often resort to religious beliefs, which are configured as a source of spiritual support and a significant part of their coping strategy.¹³ Resignification consists of facing a problem situation or stressful event in a positive way in order to make it more manageable.^{13,54}

The problem-solving capacity is associated with the IC's potential of acquiring, applying, and maintaining new behaviors; therefore, it is an important strategy of adapting to care. The individual learns to use this knowledge and skills to solve the problem, consequently gaining a

sense of mastery, promoting greater well-being and quality of life.¹¹

As for the environmental aspects that interfere in SE, the formal and informal support networks are highlighted, meaning: satisfaction with health services, professional support, quality training, presence of secondary caregivers, help from other family members, and community involvement.^{8,40} The presence of the secondary caregiver can serve both as instrumental support to assist in daily tasks and as quality emotional support, reducing negative impacts on the primary caregiver, such as anxiety and fear. It also allows the primary IC more time for fun and social activities.⁴⁰ Furthermore, the greater the IC's involvement in the community, the more he/she will feel competent to care and will have more opportunities to make choices, provoking a positive relationship with SE.⁷

Caregivers who had more financial resources felt empowered to access services outside their informal support network (family, friends, and neighbors), allowing them to feel both effective and satisfied with their caregiving roles. It is noteworthy that younger ICs may be more inclined to pay for formal help.^{7,54}

Unfulfilled service needs and dissatisfaction with home care were associated with greater IC stress and burden. Difficulties in access to health services also implied lower caregiver effectiveness.^{7,40} A study developed in the United States showed that more than 20% of the ICs of people with Alzheimer's and other dementias had difficulties with medical or nursing tasks, such as medication administration, wound care, blood pressure monitoring, or oxygen tank operation; thus, the need for professional support for ICs to perform care safely and effectively is emphasized.³

The results obtained in this review allowed the identification of five studies with interventions, which included randomized clinical trials and quasi-experimental studies. In this sense, the importance of using instruments to evaluate the caregiver's SE before and after the intervention was evidenced. Studies that offered training to the ICs reveal the importance of formal support networks.^{9,12,49} Research developed in the Netherlands investigated the impact of an Interaction Skills Training program on levels of SE and burden experienced by ICs that care for severe mental illness. The training, consisting of seven three-hour sessions over a ten-week period, met caregivers' need to acquire effective communication and interactive skills when dealing with patients' disruptive behaviors; thus, proved effective in increasing caregivers' SE and mitigating burden.¹²

A study conducted in the United States examined the association between the IC's

perception of the adequacy of training received and their SE to care for colorectal cancer patients. Due to the high demand for care for these patients, several states require hospitals to train caregivers prior to discharge, but many of the participants reported that they were not satisfied with the training received and had low SE in managing bowel problems. Further, it is noted that additional training may be beneficial in improving the quality of home care.⁹

In the United Kingdom, a one-day intervention for ICs of people with eating disorders was delivered through an interactive workshop lasting approximately seven hours. Improvements were observed across the group: after the workshop, the ICs showed increased levels of SE and confidence in their role in the recovery of their loved ones living with eating disorders.⁴⁹

A study conducted in Australia evaluated the effects of using an MP3 player for four weeks in caregivers of people with dementia, which significantly increased caregivers' mental health and well-being, as well as their SE in dealing with dementia symptoms.³⁷ It is worth mentioning that the aging of the population has led to more and more cases of dementia; in 2016, Brazil had the second highest prevalence of the disease, with about 1,037 cases per 100,000 inhabitants.⁶⁵ Therefore, it becomes relevant to foster research focused on this population and their caregivers.

As a limitation, no instrument validated in Brazil was identified with the objective of assessing caregiver's SE. Therefore, for future research, the construction or adaptation of questionnaires on this theme considering the Brazilian context is suggested. In addition, it was demonstrated a low level of evidence (VI) of most studies referred in the results. However, the categorization does not indicate the exclusion of these studies since the objective of the review was to survey the instruments in use, described in the literature.

As for the contributions to the nursing practice, it will serve as a basis for the construction or adaptation of questionnaires on this theme for caregivers residing in Brazil.

Conclusion

The present study allowed the identification of 29 instruments to evaluate the SE of ICs in home care. They can be used in different contexts, such as illness due to chronic diseases, cancer, dementia, parents and/or guardians who care for their children, among others.

The importance of using quality instruments to guide actions in clinical practice and in the development of effective interventions was highlighted. Furthermore, it was evidenced that

SE is a subjective construct, which can be modified according to the caregiver's own circumstances, such as physical and mental health status, age, coping strategies, and problem-solving skills, in addition to environmental factors, such as family, community, and professional support network.

References

1. Gomes CS, Bernal RTI, Moreira AD, Teixeira RA, Cardoso LSM, Ribeiro ALP, et al. Estimates of prevalence of hypertension and diabetes mellitus according to Health Vulnerability Index in Belo Horizonte, Brazil. *Rev Bras Epidemiol.* 2021;24 Suppl 1:e210015. doi: 10.1590/1980-549720210015.supl.1
2. Ministério da Saúde (BR), Secretaria de Atenção à Saúde, Departamento de Atenção Básica. Caderno de atenção domiciliar. Brasília (DF): Ministério da Saúde, Secretaria de Atenção à Saúde, Departamento de Atenção Básica; 2012.
3. Piggott CA, Zimmerman S, Reed D, Sloane PD. Development and testing of a measure of caregiver confidence in medical sign/symptom management. *Am J Alzheimers Dis Other Demen.* 2017;32(7):373-81. doi: 10.1177/1533317517711247
4. Instituto da Segurança Social, I.P. (PT). Guia prático estatuto do cuidador informal: cuidador informal principal e cuidador informal não principal. Lisboa (PT): Instituto da Segurança Social; 2020.33 p.
5. Jütten LH, Mark RE, Sitskoorn MM. Empathy in informal dementia caregivers and its relationship with depression, anxiety, and burden. *Int J Clin Health Psychol.* 2019;19(1):12-21. doi: 10.1016/j.ijchp.2018.07.004
6. Wichit N, Mnatzaganian G, Courtney M, Schulz P, Johnson M. Psychometric testing of the family-carer diabetes management self-efficacy scale. *Health Soc Care Community.* 2018;26(2):214-23. doi: 10.1111/hsc.12511
7. Burke M, Heller T. Individual, parent and social-environmental correlates of caregiving experiences among parents of adults with autism spectrum disorder. *J Intellect Disabil Res.* 2016;60(5):401-11. doi: 10.1111/jir.12271
8. Kizza IB, Maritz J. Family caregivers for adult cancer patients: knowledge and self-efficacy for pain management in a resource-limited setting. *Support Care Cancer.* 2019;27(6):2265-74. doi: 10.1007/s00520-018-4504-7
9. Havyer RD, Van Ryn M, Wilson PM, Griffin JM. The effect of routine training on the self-efficacy of informal caregivers of colorectal cancer patients. *Support Care Cancer.* 2017;25(4):1071-7. doi: 10.1007/s00520-016-3494-6
10. Tatsumi H, Nakaaki S, Satoh M, Yamamoto M, Chino N, Hadano K. Relationships among communication self-efficacy, communication burden, and the mental health of the families of persons with aphasia. *J Stroke Cerebrovasc Dis.* 2016;25(1):197-205. doi: 10.1016/j.jstrokecerebrovasdis.2015.09.018
11. Erlen JA, Sereika SM, Sun R, Tamres LK, Tang F, Lingler JH. Outcomes of a problem-solving medication management intervention for informal caregivers. *West J Nurs Res.* 2019;41(11):1642-57. doi: 10.1177 / 0193945919825844
12. Gharavi Y, Stringer B, Hoogendoorn A, Boogaarts J, Van Raaij B, Van Meijel B. Evaluation of an interaction-skills training for reducing the burden of family caregivers of patients with severe mental illness: a pre-posttest design. *BMC Psychiatry.* 2018;18(1):84. doi: 10.1186/s12888-018-1669-z
13. Tay KCP, Seow CCD, Xiao C, Lee HMJ, Chiu HFK, Chan SWC. Structured interviews examining the burden, coping, self-efficacy, and quality of life among family caregivers of persons with dementia in Singapore. *Dementia (London).* 2016;15(2):204-20. doi: 10.1177/1471301214522047

14. Mendes KDS, Silveira RCCP, Galvão CM. Revisão integrativa: método de pesquisa para a incorporação de evidências na saúde e na enfermagem. *Texto Contexto Enferm.* 2008;17(4). doi: 10.1590/S0104-07072008000400018
15. Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan – a web and mobile app for systematic reviews. *Systematic Reviews.* 2016;5:210. doi: 10.1186/s13643-016-0384-4
16. Galvão CM. Níveis de evidência. *Acta Paul Enferm.* 2006;19(2). doi: 10.1590/S0103-21002006000200001
17. Fleming LK, Rapp CG, Sloane R. Caregiver knowledge and self-confidence of stress dosing of hydrocortisone in children with congenital adrenal hyperplasia. *J Pediatr Nurs.* 2011;26(6):e55-60. doi: 10.1016/j.pedn.2011.03.009
18. Lewis FM. Family home visitation study final report. Bethesda (MD): National Cancer Institute, National Institutes of Health; 1996.
19. Bevans M, Wehrlen L, Castro K, Prince P, Shelburne N, Soeken K, et al. A problem-solving education intervention in caregivers and patients during allogeneic hematopoietic stem cell transplantation. *J Health Psychol.* 2014;19(5):602-17. doi: 10.1177/1359105313475902
20. Degeneffe CE, Dunlap L, Chan F, Man D, Sung C. Development and validation of the caregiver empowerment scale: a resource for working with family caregivers of persons with traumatic brain injury. *Rehabil Psychol.* 2011;56(3):243-50. doi: 10.1037/a0024465
21. Heller T, Miller AB, Hsieh K. Impact of a consumer-directed family support program on adults with developmental disabilities and their family caregivers. *Fam Relat.* 1999;48(4):419-27. doi: 10.2307/585250
22. Rudelli N, Straccia C, Petitpierre G. Fathers of children with autism spectrum disorder: their perceptions of paternal role a predictor of caregiving satisfaction, self-efficacy and burden. *Res Autism Spectr Disord.* 2021;83:101744. doi: 10.1016/j.rasd.2021.101744
23. Ugalde A, Krishnasamy M, Schofield P. Development of an instrument to measure self-efficacy in caregivers of people with advanced cancer. *Psychooncology.* 2013;6:1428-34. doi: 10.1002/pon.3160
24. Ritter PL, Sheth K, Stewart AL, Gallagher-Thompson D, Lorig K. Development and evaluation of the 8-item Caregiver Self-Efficacy Scale (CSES-8). *Gerontologist.* 2020;28;62(3):e140-9. doi: 10.1093/geront/gnaa174
25. Sheth K, Lorig K, Stewart A, Parodi JF, Ritter PL. Effects of COVID-19 on informal caregivers and the development and validation of a scale in english and spanish to measure the impact of COVID-19 on caregivers. *J Appl Gerontol.* 2021;40(3):235-43. doi: 10.1177/0733464820971511
26. Thomas JJ, Shuford DM, Duke JC, Cipriani 3rd DJ. Development and psychometric properties of the self-efficacy scale for transfers for caregivers of children requiring transfer assistance. *Arch Phys Med Rehabil.* 2007;88(4):481-8. doi: 10.1016/j.apmr.2007.01.019
27. Cipriani DJ, Hensen FE, McPeck DL, Kubec GLD, Thomas JJ. Rating scale analysis and psychometric properties of the caregiver self-efficacy scale for transfers. *Phys Occup Ther Pediatr.* 2012;32(4):404-15. doi: 10.3109/01942638.2012.694993
28. Lorig K, Stewart A, Ritter P, González V, Laurent D, Lynch J. Outcome measures for health education and other health care interventions. Thousand Oaks (CA): SAGE Publications; 1996.
29. Anderson KO, Dowds BN, Pelletz RE, Edwards TW, Peeters-Asdourian C. Development and initial validation of a scale to measure self-efficacy beliefs in patients with chronic pain. *Pain.* 1995;63(1):77-83. doi: 10.1016/0304-3959(95)00021-J
30. Hiroshi T, Masahiko Y, Shutaro N, Kazuo H. Development of communication Self-Efficacy Scale (CSE) for caregivers of adults with aphasia. *High Brain Func Res.* 2012;32(3):514-24. doi: 10.2496/hbfr.32.514
31. Chesney MA, Neilands TB, Chambers DB, Taylor JM, Folkman S. A validity and reliability study of the Coping Self-Efficacy Scale. *Br J Health Psychol.* 2006;11(3):421-37. doi: 10.1348/135910705X53155
32. Harmell AL, Mausbach BT, Roepke SK, Moor RC, Von Kanel R, Patterson TL, et al. The relationship

- between self-efficacy and resting blood pressure in spousal Alzheimer's caregivers. *Br J Health Psychol.* 2011;16(2):317-28. doi: 10.1348/135910710X504932
33. Caplin D, Austin JK, Dunn DW, Shen J, Perkins S. Development of a self-efficacy scale for children and adolescents with epilepsy. *Child Health Care.* 2002;31(4):295-309. doi: 10.1207/S15326888CHC3104_3
34. Wagner JL, Smith G, Ferguson P. Self-efficacy for seizure management and youth depressive symptoms: caregiver and youth perspectives. *Seizure.* 2012;21(5):334-9. doi: 10.1016/j.seizure.2012.02.009
35. Archbold PG, Stewart BJ. Family caregiving inventory. Portland (OR): Oregon Health Sciences University, Department of Family Nursing, School of Nursing; 1986.
36. Fortinsky RH, Burant CJ, Kercher K. Measurement and correlates of family caregiver self-efficacy for managing dementia. *Aging Ment Health.* 2002;6(2):153-60. doi: 10.1080/13607860220126763
37. Lewis V, Bauer M, Winbolt M, Chenco C, Hanley F. A study of the effectiveness of MP3 players to support family carers of people living with dementia at home. *Int Psychogeriatr.* 2015;27(3):471-9. doi: 10.1017/S1041610214001999
38. Fortinsky RH, Unson CG, Garcia RI. Helping family caregivers by linking primary care physicians with community-based dementia care services. *Dementia.* 2002;1(2):227-40. doi: 10.1177/147130120200100208
39. Miyazaki E, Tadaka E. Development of the family caregiving self-efficacy scale in terminal cancer patients at home. In: 17th Annual Meeting of the Japan Academy of Community Health Nursing; 2014; Okayama (Japan).
40. Ito E, Tadaka E. Quality of life among the family caregivers of patients with terminal cancer at home in Japan. *Jpn J Nurs Sci.* 2017;14(4):341-52. doi: 10.1111/jjns.12164
41. Sherer M, Maddux JE, Mercadante B, Prentice-Dunn S, Jacobs B, Rogers RW. The Self-Efficacy scale: construction and validation. *Psychol Rep.* 1982;51(2):663-71. doi: 10.2466/pr0.1982.51.2.663
42. Durmaz H, Okanl A. Investigation of the effect of self-efficacy levels of caregiver family members of the individuals with schizophrenia on burden of care. *Arch Psychiatr Nurs.* 2014;28(4):290-4. doi: 10.1016/j.apnu.2014.04.004
43. Khan F, Pallant J, Brand C. Caregiver strain and factors associated with caregiver self-efficacy and quality of life in a community cohort with multiple sclerosis. *Disabil Rehabil.* 2007;29(16):1241-50. doi: 10.1080/01443610600964141
44. Jia Y, Shi J, Sznajder KK, Yang F, Cui C, Zhang W, et al. Positive effects of resilience and self-efficacy on World Health Organization Quality of Life Instrument score among caregivers of stroke in patients in China. *Psychogeriatrics.* 2021;21(1):89-99. doi: 10.1111/psyg.12635
45. Casida J, Wu HS, Harden J, Carie A, Chern J. Evaluation of the psychometric properties of self-efficacy and adherence scales for caregivers of patients with a left ventricular assist device. *Prog Transplant.* 2015;25(2):116-23. doi: 10.7182/pit2015556
46. Johnston C, Mash EJ. A measure of parenting satisfaction and efficacy. *J Clin Child Psychol.* 1989; 18(2):167-75. doi: 10.1207/s15374424jccp1802_8
47. Lamb AE, Biesecker BB, Umstead KL, Muratori M, Biesecker LG, Erby KH. Family functioning mediates adaptation in caregivers of individuals with Rett syndrome. *Patient Educ Couns.* 2016;99(11):1873-9. doi: 10.1016/j.pec.2016.06.018
48. Rhodes P, Baillie A, Brown J, Madden S. Parental efficacy in the family-based treatment of anorexia: preliminary development of the Parents Versus Anorexia Scale (PVA). *Eur Eat Disord Rev.* 2005;13:399-405. doi: 10.1002/erv.661
49. Jenkins PE, Bues S, Cottrell J, Hawkins J, Pinder L, Price S, et al. A collaborative care skills workshop for carers: Can it be delivered in 1 day? *Clin Psychol Psychother.* 2018;25(1):130-7. doi: 10.1002/cpp.2119
50. Wood MR, Price JH, Dake JA, Telljohann SK, Khuder AS. African American parents'/guardians' health

- literacy and self-efficacy and their child's level of asthma control. *J Pediatr Nurs.* 2010;25(5):418-27. doi: 10.1016/j.pedn.2009.05.003
51. Nelson M, Davis MC. Development and preliminary validation of the Parent Efficacy for Child Healthy Weight Behaviour Scale. *J Health Psychol.* 2013;18(2):282-91. doi: 10.1177/1359105312439732
52. Palmer F, Davis MC. Reliability and validity of the Parent Efficacy for Child Healthy Weight Behaviour (PECHWB) scale. *Child Care Health Dev.* 2014;40(3):398-404. doi: 10.1111/cch.12069
53. Steffen AM, McKibbin C, Zeiss MA, Gallagher-Thompson D, Bandura A. The revised scale for caregiving self-efficacy: reliability and validity studies. *J Gerontol B Psychol Sci Soc Sci.* 2002 Jan;57(1):P74-86. doi: 10.1093/geronb/57.1.p74
54. Ducharme F, Lachance L, Kergoat MJ, Coulombe R, Antoine P, Pasquier F. A comparative descriptive study of characteristics of early- and late-onset dementia family caregivers. *Am J Alzheimers Dis Other Demen.* 2016 Feb;31(1):48-56. doi: 10.1177/1533317515578255
55. Cheng ST, Lam LCW, Kwok T, Natalie SS, Fung AWT. Self-efficacy is associated with less burden and more gains from behavioral problems of alzheimer's disease in hong kong chinese caregivers. *Gerontologist.* 2013;53(1):71-80. doi: 10.1093/geront/gns062
56. Kwok TC, Au A, Wong B, Ip I, Mak V, Ho F. Effectiveness of online cognitive behavioral therapy on family caregivers of people with dementia. *Clin Interv Aging.* 2014 Apr 11;9:631-6. doi: 10.2147/CIA.S56337
57. Marziali E, McCleary L, Streiner DL. Evaluation of an assessment battery for estimating dementia caregiver needs for health and social care services. *Am J Alzheimers Dis Other Demen.* 2010;25(5):446-54. doi: 10.1177/1533317510370958
58. Robinson-Lane SG, Zhang X, Patel A. Coping and adaptation to dementia family caregiving: A pilot study. *Geriatr Nurs.* 2021; ;42(1):256-61. doi: 10.1016/j.gerinurse.2020.08.008
59. Noel MA, Lackey E, Labi V, Bouldin ED. Efficacy of a virtual education program for family caregivers of persons living with dementia. *J Alzheimers Dis.* 2022; 86(4):1667-78. doi: 10.3233/JAD-215359
60. Zhang SY, Edwards H, Yates P, Ruth E, Guo QH. Development of Self-Efficacy Questionnaire for Chinese Family Caregivers. *Int J Ment Health Nurs.* 2012 Aug;21(4):358-65. doi: 10.1111/j.1447-0349.2011.00791.x
61. Zhang SY, Edwards H, Yates P, Ruth E, Guo Q. Preliminary reliability and validity testing of a self-efficacy questionnaire for Chinese family caregivers. *Aging Ment Health.* 2013;17(5):630-37. doi: 10.1080/13607863.2013.771615
62. Zhang SY, Edwards H, Yates P, Li C, Guo Q. Self-Efficacy partially mediates between social support and health-related quality of life in family caregivers for dementia patients in Shanghai. *Dement Geriatr Cogn Disord.* 2014;37(1-2):34-44. doi: 10.1159/000351865
63. Kuhn D, Fulton BR. Efficacy of an educational program for relatives of persons in the early stages of Alzheimer's disease. *J Gerontol Soc Work.* 2004;42(3/4):109-30. doi: 10.1300/J083v42n03_07
64. Pappalardo AA, Herbert L, Warren C, Lombard L, Ramos A, Asa´ ad A, et al. Self-Efficacy among caregivers of children with food allergy: a cohort study. *Pediatr Psychol.* 2022;47(6):674-84. doi: 10.1093/jpepsy/jsab137
65. GBD 2016 Dementia Collaborators. Global, regional, and national burden of Alzheimer's disease and other dementias, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol.* 2019 Jan;18(1):88-106. doi: 10.1016/S1474-4422(18)30403-4

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Authorship Contributions

1 – Fernanda Gatez Trevisan dos Santos

Corresponding Author

Nurse, PhD student - Email: fer.gatez@gmail.com

Conception and development of the research, writing of the manuscript; review and approval of the final version.

2 – Elaine Trevezanuto Correia

Nurse, PhD student - Email: elaine_trevezanuto@hotmail.com

Conception and development of the research, writing of the manuscript; review and approval of the final version.

3 – Luana Cristina Bellini Cardoso

Nurse, PhD student - Email: luana.bellini@hotmail.com

Conception and development of the research, writing of the manuscript; review and approval of the final version.

4 – Mayara Almeida Martins

Nurse, master's student - E-mail: mayara.martins@live.com

Conception and development of the research, writing of the manuscript; review and approval of the final version.

5 – Aline Zulin

Nurse, PhD student - Email: aline_zulin@hotmail.com

Conception and development of the research, writing of the manuscript; review and approval of the final version.

6 – Cremilde Aparecida Trindade Radovanovic

Nurse, PhD - Email: catradovanovic@uem.br

Conception and development of the research, writing of the manuscript; review and approval of the final version.

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