

# Health promoting behaviors by informal caregivers of older adults: an integrative review

Comportamentos promotores de saúde por cuidadores informais de idosos: revisão integrativa  
Comportamientos de cuidadores informales de adultos mayores que promocionan la salud: revisión integradora

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## Keywords

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## Abstract

**Objective:** To analyze the scientific evidence on health promoting behaviors adopted by informal caregivers of older adults.

**Methods:** This is an integrative review carried out on the following bases: Online Medical Literature Analysis and Retrieval System, SCOPUS, Web of Science, Health Sciences Bibliographic Index, Nursing Database and Latin American and Caribbean Health Sciences Literature. Twelve primary studies were surveyed that constituted the sample, without time or language limitations. The descriptive method was used for analysis and synthesis of results.

**Results:** Health promoting behaviors developed by informal caregivers of older adults constituted resources favorable to the maintenance of their overall health conditions, their well-being, the improvement of quality of life and personal satisfaction as a caregiver. Among the practices evidenced, the search for information, family counseling, support and social, emotional and spiritual support stood out. Also, compliance with community programs aimed at psychoeducation and physical activities, as well as the use of communication technologies and the enhancement of self-care stood out as strategies associated with coping with the negative repercussions resulting from care.

**Conclusion:** Health promoting behaviors capable of favoring quality of life and physical, mental and social well-being of informal caregivers of older adults were evidenced. Studies of this nature may arouse the need for public policies and comprehensive lines of care aimed at promoting caregivers' health.

## Resumo

**Objetivo:** Analisar as evidências científicas sobre os comportamentos promotores de saúde adotados por cuidadores informais de pessoas idosas.

**Métodos:** Revisão integrativa realizada nas seguintes bases: *Medical Literature Analysis and Retrieval System on-line*, *SCOPUS*, *Web of Science*, Índice Bibliográfico de Ciências da Saúde, Banco de Dados de Enfermagem e Literatura Latino Americana e do Caribe em Ciências da Saúde. Foram levantados 12 estudos primários que constituíram a amostra, sem delimitação de tempo ou de idioma. Utilizou-se o método descritivo para análise e síntese dos resultados.

**Resultados:** Os comportamentos promotores de saúde desenvolvidos pelos cuidadores informais de pessoas idosas constituíram recursos favoráveis à manutenção das suas condições globais de saúde, ao seu bem-estar, à melhoria da qualidade de vida e à satisfação pessoal enquanto cuidador. Dentre as práticas evidenciadas, destacaram-se a busca por informações, aconselhamento familiar, apoio e suporte social, emocional e espiritual. Ainda, a adesão aos programas comunitários voltados para psicoeducação e às atividades físicas,

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bem como o uso de tecnologias de comunicação e a valorização do autocuidado se destacaram como estratégias associadas ao enfrentamento das repercussões negativas decorrentes do cuidar.

**Conclusão:** Foram evidenciados comportamentos promotores da saúde capazes de favorecer a qualidade de vida e o bem-estar físico, mental e social do cuidador informal de pessoas idosas. Estudos dessa natureza podem despertar a necessidade de políticas públicas e de linhas integrals de cuidados voltados para promoção da saúde do cuidador.

## Resumen

**Objetivo:** Analizar las evidencias científicas sobre los comportamientos que promueven la salud adoptados por cuidadores informales de adultos mayores.

**Métodos:** Revisión integradora realizada en las siguientes bases: *Medical Literature Analysis and Retrieval System on-line*, *SCOPUS*, *Web of Science*, Índice Bibliográfico de Ciencias de la Salud, Banco de Datos de Enfermería y Literatura Latinoamericana y del Caribe en Ciencias de la Salud. Se verificaron 12 estudios primarios que constituyeron la muestra, sin delimitación de tiempo o de idioma. Se utilizó el método descriptivo para el análisis y la síntesis de los resultados.

**Resultados:** Los comportamientos que promueven la salud, desarrollados por los cuidadores informales de adultos mayores constituyeron recursos favorables para el mantenimiento de sus condiciones globales de salud, para su bienestar, para la mejora de la calidad de vida y para la satisfacción personal como cuidador. Entre las prácticas evidenciadas, se destacaron la búsqueda por informaciones, consejería familiar, apoyo y soporte social, emocional y espiritual. De igual forma, la adhesión a los programas comunitarios direccionados a la psicoeducación y a las actividades físicas, así como el uso de tecnologías de comunicación y la valoración del autocuidado se destacan como estrategias asociadas al enfrentamiento de las repercusiones negativas resultantes del cuidar.

**Conclusión:** Se evidenciaron comportamientos que promueven la salud, capaces de favorecer la calidad de vida y el bienestar físico, mental y social del cuidador informal de adultos mayores. Estudios de esa naturaleza pueden despertar la necesidad de políticas públicas y de líneas integrales de cuidados direccionados a la promoción de la salud del cuidador.

## Introduction

Changes in age structure and morbidity and mortality patterns are a complex, multidimensional, progressive and universal phenomenon that has great epidemiological, economic and social magnitude as it directly reflects on the health conditions of the population and results in a greater predisposition to chronic degenerative diseases, disabilities and conditions of dependency.<sup>(1-3)</sup>

In this context, the aging process on a global scale is constantly evidenced by population statistics from the most varied countries, which point to a significant increase in the number of older adults compared to the general population. Whilst representing a phase marked by legacies, experiences and learning, aging, when accompanied by chronic diseases, physical, functional, cognitive and social limitations, directly impacts the family organization in health services, which do not yet have favorable structure for meeting the common demands at this time of life.<sup>(3-5)</sup>

Amidst this, family participation is highlighted by taking on responsibilities as informal caregivers, even without professional training or technical preparation, thus constituting the main support and support network to manage disabilities and promote care. These are people with an affective bond and availability of time, who take care vol-

untarily, and are a mediating instrument for the physical, affective, social, psychological and spiritual well-being of older adults.<sup>(6,7)</sup>

Although informal care favors welcoming, security, comfort and emotional control for older adults, the literature considers it as a condition that generates morbidity because it requires physical, emotional, social and economic efforts, as well as for causing damage in quality of life, self-control, self-esteem and self-care, contributing to greater vulnerability of caregivers to overload, suffering and the fragility of their own health condition, requiring strategies to minimize the repercussions arising from the care process.<sup>(8,9)</sup>

Although many studies focus on the burden of informal caregivers, public policies aimed at the development of health promoting behaviors are still incipient, and the implementation of strategies and action plans has been constantly ignored or neglected in different contexts and levels of care.<sup>(10)</sup>

For the World Health Organization (WHO), health promotion comprises the empowerment of the community to act to improve their quality of life and health, including greater participation in the control of this process. In this sense, the need for professional support for the development of effective skills and competences that provide adaptation to their caregiver role and risk reduction is highlighted.<sup>(11)</sup>

In nursing, health promoting behaviors and models are multidimensional and seek to identify individual determinants and predictors for the adoption of self-care, allowing the assessment of results, the investigation of motivational factors and the satisfaction of needs as a mediating instrument for well-being.<sup>(12,13)</sup>

In Brazil, even though the need to value health promoting practices is referenced, most investigations focus on assessing the physical, mental and social impairments experienced during informal care for older adults, as well as seeking associated factors, predictors and determinants for the deterioration of caregivers' overall health status and quality of life.<sup>(9,10)</sup>

Considering the repercussions arising from care, as well as the need for interventions capable of promoting self-care and caregivers' quality of life, the objective of this study was to analyze the scientific evidence on health promoting behaviors adopted by informal caregivers of older adults.

## Methods

To achieve the proposed objective, an integrative literature review was carried out. This is a broad method that allows for the inclusion of different methodological approaches, resulting in the synthesis and analysis of knowledge and providing effective and cost-effective interventions.<sup>(14)</sup>

This investigation was based on six stages of investigation: elaboration of the research question; literature search and sampling; definition of the information to be extracted from the selected studies; critical assessment of the evidence included; interpretation of results; synthesis of knowledge; and presentation of the review.<sup>(14)</sup>

The research question was structured considering the PICO strategy domains. Population (P) refers to informal caregivers of older adults; Phenomenon of Interest (I), to behaviors; and Context (Co), to health promotion.<sup>(15)</sup> Thus, this study was conducted by the following question: What is the scientific evidence related to health promoting behaviors adopted by informal caregivers of older adults?

A bibliographic survey was carried out in October and November 2020 by consulting the Medical Literature Analysis and Retrieval System databases online (MEDLINE via PubMed<sup>®</sup>), SCOPUS, Web of Science<sup>™</sup>, Bibliographic Index of Sciences of Health (IBICS), Latin American and Caribbean Literature in Health Sciences (LILACS) and Database in Nursing (BDENF) via Virtual Health Library (VHL).

To operationalize the search, controlled and uncontrolled descriptors were selected, after consulting the Health Sciences Descriptors (DeCS) and Medical Subject Headings (MESH) vocabularies. The combination was performed using the Boolean operators OR and AND. Chart 1 presents the descriptors, as well as the strategy adopted in MEDLINE, which kept the same standardization for the other consulted databases.

**Chart 1.** Controlled and uncontrolled descriptors used to operationalize the search

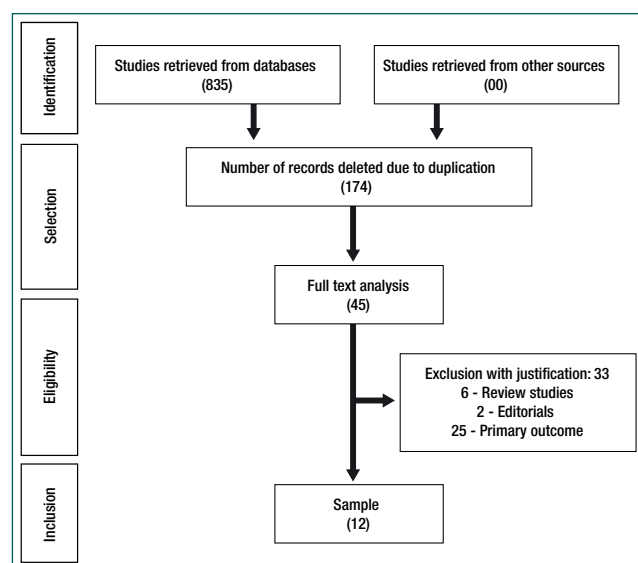
Health Sciences Descriptors		
P	Controlled	Cuidadores; Older adults.
	Uncontrolled	Cônjuges Cuidadores; Cuidador; Cuidador de Família; Cuidador Familiar; Cuidadores Cônjuges; Cuidadores de Família; Cuidadores Familiares; Familiar Cuidador; Familiares Cuidadores; Caregivers; Cuidadores; Older adults; Pessoa de Idade; Pessoa Idosa; Pessoas de Idade; Pessoas Idosas; População Idosa; Aged; Anciano.
I	Controlled	Comportamento
	Uncontrolled	Conduta; Behavior; Conducta.
Co	Controlled	Promoção da Saúde
	Uncontrolled	Promoção do Bem Estar; Promoção em Saúde; Health Promotion; Promoción de la Salud.
Medical Subject Headings		
P	Controlled	Caregivers; Aged.
	Uncontrolled	Caregiver; Carers; Carer; Care Givers; Care Giver; Spouse Caregivers; Spouse Caregiver; Family Caregivers; Family Caregiver; Elderly.
I	Controlled	Behavior.
	Uncontrolled	Behaviors; Acceptance Processes; Acceptance Process.
Co	Controlled	Health Promotion.
	Uncontrolled	Promotion of Health; Health Promotions.
P AND I AND Co		
((((((((((((("Caregivers"[Mesh]) OR ("caregivers"[All Fields]) OR ("caregiver"[All Fields]) OR ("carers"[All Fields]) OR ("carer"[All Fields]) OR ("care givers"[All Fields]) OR ("care giver"[All Fields]) OR ("spouse caregivers"[All Fields]) OR ("spouse caregiver"[All Fields]) OR ("family caregivers"[All Fields]) OR ("family caregiver"[All Fields]) AND (((("Aged"[Mesh]) OR ("aged"[All Fields]) OR ("elderly"[All Fields])) AND (((("Behavior"[Mesh]) OR ("behavior"[All Fields]) OR ("acceptance processes"[All Fields]) OR ("acceptance process"[All Fields])) AND (((("Health Promotion"[Mesh]) OR ("health promotion"[All Fields]) OR ("promotion of health"[All Fields]) OR ("health promotions"[All Fields]))		

Primary source studies that presented the health promoting behaviors adopted by informal caregivers of older adults, without temporal or language delimitation were included. Reviews, editorials,

articles that did not involve the primary outcome of this investigation and those that were duplicate were excluded, being considered only once when prioritizing specific health and nursing bases, followed by multidisciplinary.

The search, selection and inclusion were carried out by two reviewers, independently, who, after standardizing terms and crossings, as well as reading titles and abstracts, obtained a degree of agreement above 80%. Disagreements were managed by a third reviewer, who issued an opinion to decide on the inclusion. It is noteworthy that the retrieved references were imported into Endnote Web management, in order to sort, identify and exclude duplicate records between the consulted databases.

Thus, 835 articles were retrieved and after applying the eligibility criteria, the sample composition was obtained, consisting of 12 studies. The route taken for identification, selection, eligibility, inclusion and sample followed PRISMA recommendations (Preferred Reporting Items for Systematic Reviews and Meta-Analyses),<sup>(16)</sup> as shown in Figure 1.



**Figure 1.** Selection path of primary studies in the investigated bases

Data extraction was performed with the aid of a validated and adapted instrument, considering variables related to the identification of studies (main author, title, journal, year of publication and coun-

try), methodological aspects (design and level of evidence), health promoting behaviors, main results and conclusions.<sup>(17)</sup>

The Level of Evidence (LoE) was determined from the recommendations proposed by the Oxford Center for Evidence-based Medicine, which classifies the evidence according to the methodological design: 1A - systematic review of randomized controlled clinical trials; 1B - randomized controlled clinical trial with narrow confidence interval; 1C - therapeutic results of the “all-or-nothing” type; 2A - systematic review of cohort studies; 2B - cohort study; 2C - observation of therapeutic results or ecological studies; 3A - systematic review of case-control studies; 3B - case-control study; 4 - case report; 5 - expert opinion.<sup>(18)</sup>

The descriptive method was used for analysis and synthesis of results, being presented in charts structured according to the variables of interest for this investigation.

## Results

The descriptive analysis of results showed that seeking promotion and compliance with health promoting behaviors among caregivers of older adults is a constant target of scientific investigation in multiple contexts in the national and international scenario. In this regard, it was found that the studies, in their entirety, were published in English and developed in different countries such as the United States of America (USA), Norway and Portugal, which stood out for concentrating the largest number of investigations. The growing interest of researchers in the topic was evidenced, showing the need for support and support as a protective and inducing factor of physical, mental and social well-being and the quality of life of caregivers, as well as an indicator for reducing the risk of psychopathological comorbidities in this population segment. In this sense, there was a predominance of studies published between the years 2003 to 2019. Regarding the methodological design, clinical trials prevailed, level of

**Chart 2.** Summary of studies included in the review

Author and journal	Title	Year	Country	Design	LoE
Bjorge H <sup>(19)</sup> BMC Health Serv Res	The effect of psychosocial support on caregivers' perceived criticism and emotional over-involvement of persons with dementia: an assessor-blinded randomized controlled trial	2019	Norway	Randomized clinical trial (RCT)	1B
Paul C <sup>(20)</sup> Community Mental Health Journal	Effects of a community intervention program for dementia on mental health: the importance of secondary caregivers in promoting positive aspects and reducing strain	2019	Portugal	Clinical trial	1B
Clauss E <sup>(21)</sup> J Occup Health Psychol	Promoting personal resources and reducing exhaustion through positive work reflection among caregivers	2018	Germany	Clinical trial	1B
Lok N <sup>(22)</sup> Arch Gerontol Geriatr	Pilot testing of the "First You Should Get Stronger" program among caregivers of older adults with dementia	2017	Turkey	Clinical trial	1B
Kaufman AV <sup>(23)</sup> J Gerontol Soc Work	Social support, caregiver burden, and life satisfaction in a sample of rural African American and White caregivers of older persons with dementia	2010	USA	Cross-sectional	2C
Lewis SL <sup>(24)</sup> Rehabil Nurs	A stress-busting program for family caregivers	2009	Spain	Clinical trial	1B
Lee CJ <sup>(25)</sup> J Gerontol Nurs	A comparison of health promotion behaviors in rural and urban community-dwelling spousal caregivers	2009	Portugal	Observational	2C
Torp S <sup>(26)</sup> Health Soc Care Community	A pilot study of how information and communication technology may contribute to health promotion among elderly spousal carers in Norway	2008	Norway	Intervention	1B
Furlong KE <sup>(27)</sup> Qual Health Res	Self-Care behaviors of spouses caring for significant others with alzheimer's disease: The emergence of self-care worthiness as a salient condition	2008	Canada	Observational Grounded theory	2C
Mittelman MS <sup>(28)</sup> Am J Geriatr Psychiatry	Preserving health of alzheimer caregivers: Impact of a spouse caregiver intervention	2007	USA	RCT	1B
O'Connell B <sup>(29)</sup> Aust Health Ver	Promoting the health and well being of older carers: a proactive strategy	2003	Australia	Descriptive	2C
Farran CJ <sup>(30)</sup> J Gerontol Nurs	Caring for self while caring for others: the two-track life of coping with Alzheimer's disease	2004	USA	Intervention	1B

evidence 1B, aimed at assessing the impact of interventions on the development and compliance with self-care and behaviors that promote health and quality of life. Chart 2 presents the characterization of the included results (n=12) according to the main author and journal, study title, year of publication, country where the article was developed, methodological design and LoE.

Health promoting behaviors adopted by informal caregivers of older adults represented a significant reality in this study, in which the search for information and family counseling, as well as for support and social support, directly contributed to coping with stressful events related to demands of care, favoring health maintenance, quality of life, and well-being. Still, reflections on routine care, strengthening of beliefs, compliance with community programs aimed at psychoeducation, physical activities, use of communication technologies, emotional assistance and valuing self-care were highlighted as strategies associated with better role of caregiver and minimal satisfaction physical, mental and social repercussions arising from care. Chart 3 presents the healthy behaviors identified during informal care.

## Discussion

Despite the predominance of clinical trials capable of supporting self-care and health promoting behaviors with safety, efficacy and quality, other relevant designs for clinical nursing practice were found, such as observational studies that demand less time and cost, being constantly used for indicate prognoses and assess risk exposure results.

In this review, informal care represented a frequent practice in the face of increased life expectancy, physical, mental and social limitations and the states of dependency imposed by the aging process, configuring itself as a complex and multidimensional phenomenon, capable of impacting the state health, personal functioning and quality of life of caregivers.<sup>(19-30)</sup>

In this context, being in the condition of informal caregiver of older adults was associated with their greater perception of burden, showing compromises in skills and abilities for self-care, as well as causing difficulties in prioritizing their own needs and lack of support to manage their physical and mental limitations.<sup>(22-24,26)</sup>

Compared to the general population, informal caregivers are vulnerable to greater impairments in



**Chart 3.** Health promoting behaviors by caregivers (n=12)

Health promoting behaviors	Main results and conclusions
Participation in education activities about the health status of older adults and group meetings, as well as family counseling. <sup>(19)</sup>	Improved perception of health status, mental well-being and quality of life. Furthermore, there was a better relationship between caregiver and recipient.
Participation in psychoeducational community intervention. <sup>(20)</sup>	Improved mental health, increased satisfaction with care, and decreased tension and stress. These results were associated with the existence of a secondary caregiver, the number of hours of care and the level of dependence of older adults.
Daily reflection of care activities. <sup>(21)</sup>	Reduction of emotional exhaustion and fatigue indicators as well as promoting well-being.
Search for psychoeducational activities "First you must get stronger." <sup>(22)</sup>	Reducing the burden of care and developing healthy lifestyle behaviors, such as the pursuit of physical activity, better eating habits, weight control, interpersonal communication, moral development and stress management.
Strengthening of support networks and social support. <sup>(23)</sup>	Dimensions of social support aimed at socialization and receiving positive feelings, respect and self-esteem were predictors of satisfaction with life and with the demand for care, directly resulting in a reduction in burden levels.
Compliance with a stress-reduction program based on education, stress management, problem solving, and support. <sup>(24)</sup>	Demonstrated improvements in the ability to deal with care stressors effectively, resulting in self-control, greater ability to manage patients' needs and better quality of personal life.
Strengthening of interpersonal relationships, spiritual growth and stress control and physical activity. <sup>(25)</sup>	Appreciation of interpersonal relationships (talking and sharing experiences) and spiritual growth (reflection and prayer) positively influenced the maintenance of physical health and the control of stressful events
Use of information and communication technology (ICT) to seek informal support. <sup>(26)</sup>	Despite revealing a significant reduction in stress or mental health problems, health promoting effects were found, allowing greater control of perceived health due to the possibilities of support and contact with other caregivers who experience similar experiences.
Search for relational (emotional assistance) and instrumental (physical assistance) support, as well as for valuing and showing interest in self-care (physical activity, specialized consultations, participation in support group meetings). <sup>(27)</sup>	Improvement in well-being.
Support and advice on caregivers' health condition. <sup>(28)</sup>	Benefits were evidenced related to the reduction of stress and depressive symptoms, better satisfaction with the role of caregiver and social support.
Participation in social and health activities, compliance with physical activity (Walking) and eating with friends were the most mentioned activities. <sup>(29)</sup>	Well-being and quality of life promotion. Factors related to dependence on care, the inability to leave older adults alone, physical and mental exhaustion made it difficult to comply with health promoting behaviors.
Development of mental health maintenance skills. <sup>(30)</sup>	Reduction of depressive symptoms

health conditions, less satisfaction with life and a feeling of overload. This results from prioritizing the needs of older adults, resulting, in most cases, in the abandonment of personal, work, financial, social and affective activities as well as double or triple work shifts.<sup>(21,23)</sup>

Amidst this, most of the included studies focused on the development and assessment of interventions as favorable resources for coping with the impacts arising from informal care for older adults, as well as to ensure the preservation of the different dimensions that make up caregivers' health.

In this context, the identified health promoting behaviors comprised systematized actions developed by caregivers and presented positive and lasting outcomes for the maintenance of physical functioning, quality of life and well-being.<sup>(19,27,29)</sup>

Among the practices and strategies evidenced, the search for the formation and strengthening of social support networks stood out as the main strategy associated with the reduction of clinical manifestations and the negative repercussions of care, as it allows for the appreciation of their sense

of belonging, contact and rapprochement between people who have lived the same experiences, as well as specialized services for counseling, information about the clinical conditions of older adults and mobilization of other family members for active participation in the care plan.<sup>(22-25,27,28)</sup>

Other interventions involving psychoeducational strategies had direct effects on reducing the burden of care, managing stressful events and self-control. In nursing, the incorporation of educational programs and strategies has grown in recent years, aiming at assessing the contributions of biological, cognitive, affective and behavioral factors in coping with painful experiences.<sup>(19,20,22)</sup>

In this study, psychoeducational activities included healthy lifestyle behaviors such as performing relaxation techniques, practicing physical activity, modifying eating habits, weight management, interpersonal communication, moral development and stress management.<sup>(22,24,29)</sup>

Evidence related to spiritual growth was also associated with maintaining health and controlling stressful events. Adopting religious practices can contribute to coping with the new de-

mands for care, leading to social reintegration, lesser burden of symptoms and negative feelings, strengthening of bonds, relief of suffering and preservation of physical, psychological and social dimensions.<sup>(25)</sup>

A study that assessed the use of information and communication technologies by informal caregivers of older adults showed that, despite not directly reflecting on the reduction of indicators and levels of stress, compliance with these resources represents an important health promoting behavior by favoring training support networks and social support as well as the exchange of experiences and the search for changes in lifestyle habits.<sup>(26)</sup>

Therefore, it is considered that the results found are promising in showing the development and compliance with health promoting behaviors during informal care, as well as the constant positive effects for reducing the levels of overload, anxiety and depression and for maintaining caregivers' health, quality of life, and well-being. However, the relationship between older adults' clinical conditions and the state of dependence with the impacts on self-care is still incipient, representing a gap in knowledge.

Studies of this nature allow us to measure the physical, emotional, social and financial impacts suffered by family caregivers of older dependent adults, as well as demonstrate to managers, professionals, especially nurses and society in general, the important role of these caregivers. It also makes it possible to identify the need for public policies and comprehensive lines of care aimed at quality of life, risk management and health promotion for informal caregivers.

The absence of national studies in the sample surveyed proved to be a limitation to highlight the Brazilian reality of informal caregivers, making it difficult to compare international findings on this modality of care for older adults and family members who work in Brazil. Thus, the evidence raised in the international scenario may not be adequate to guide policies to support informal caregivers of older adults in the country. Furthermore, socio-demographic and cultural differences between countries must be taken into account.

## Conclusion

This study showed that the action of caring for an older adult was configured as a condition that generates morbidity and negatively impacts informal caregivers' physical, mental and social health. Even so, it was possible to survey the development and adoption of health promoting behaviors, in which the search for information and social support constituted valid and effective mechanisms for coping with stressful events related to care demands, favoring the maintenance of quality of life and well-being. Other practices associated with self-care and greater satisfaction with the role of caregiver involved strengthening beliefs, using communication technologies, performing physical activities and complying with community programs aimed at psychoeducation and emotional assistance.

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