PSYCHOLOGICAL ASPECTS OF THE QUALITY OF LIFE OF CAREGIVERS OF THE ELDERLY: AN INTEGRATIVE REVIEW

Aspectos psicológicos da qualidade de vida de cuidadores de idosos: uma revisão integrativa

Letícia Decimo Flesch, Samila Sathler Tavares Batistoni\textsuperscript{ab}, Anita Liberalesso Neri\textsuperscript{a}, Meire Cachioni\textsuperscript{ab}

OBJECTIVE: This article reviewed studies that relate aspects of double vulnerability (caregivers’ physical health, caregivers’ self-perceived health, care recipients’ dependency and perceived burden) with psychological aspects of caregivers’ quality of life. METHODS: The search was conducted in the PubMed, Capes, LILACS, SciELO and AgeLine indexes using keywords in English and their corresponding words in Portuguese. RESULTS: Twenty-three papers were analyzed. With regards to the methods, most articles were made up of transversal studies and included various outcomes. There was a wide age range for the caregivers in the studies’ samples, and many of them presented incomplete information about age. CONCLUSION: The results showed that a caregiver’s quality of life is affected by several simultaneous variables such as the degree and type of dependency of the elderly person receiving care, the caregiver’s health, perceived burden, and positive and negative affects.

KEYWORDS: caregivers; aging; quality of life; psychological stress; elderly health.

RESUMO

OBJETIVO: Este artigo revisou estudos que relacionam os aspectos da dupla vulnerabilidade (saúde física do cuidador, autopercepção de saúde do cuidador, dependência do alvo de cuidados e sobrecarga percebida) com aspectos psicológicos da qualidade de vida do cuidador. MÉTODOS: A busca foi realizada nos indexadores PubMed, Periódicos Capes, LILACS, SciELO e AgeLine com palavras-chave e seus correlatos em português. RESULTADOS: Foram analisados 23 artigos. Com relação ao método, a maioria deles era composta por estudos transversais que contavam com desfechos variados. Há uma grande variação na idade dos cuidadores nas amostras dos estudos e muitos deles apresentaram informações incompletas sobre isso. CONCLUSÃO: Os resultados mostraram que a qualidade de vida do cuidador é afetada por diversas variáveis simultâneas, como o grau e o tipo de dependência do idoso alvo de cuidados, sua saúde, a sobrecarga percebida e afetos positivos e negativos.

PALAVRAS-CHAVE: cuidadores; envelhecimento; qualidade de vida; estresse psicológico; saúde do idoso.

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INTRODUCTION

Most elderly people who need instrumental, social, affective, informational and/or material assistance are cared for by family members. Relatives, friends or acquaintances that are responsible for the care of dependent elderly without receiving remuneration are called informal caregivers.1

Studies have shown negative outcomes for caregivers of dependent elderly people, such as low rates of subjective well-being,2 depressive symptoms,3 and the impairment of physical health.4 Informal caregivers of the elderly tend to have reduced time for themselves, and suffer from a shortage of financial resources and a limited social life, which generates physical and psychological burden and compromises their quality of life.5

The last point mentioned is related to the positive characteristics of human life, which include physical and cognitive functionality, activity, productivity, emotional regulation, well-being, and economic, ecological and social resources. These conditions evaluated objectively and subjectively reflect quality of life.6

Some models have been adapted to assess quality of life, including Maslow’s theory of basic human needs.7 According to this theory, human beings share common needs. These needs are ordered hierarchically. As the most basic ones are satisfied (ex., food and safety), people seek to satisfy the highest, such as self-fulfillment and pleasure.8

Another model that is adapted for quality of life, but has a focus on the caregiver, is Pearlin et al.’s caregiver’s stress model,9 which has been used in most studies that investigate this topic.10,11 This model consists of identifying the context of the care, primary stressors (ex.: degree of dependence of the care recipient, perceived burden), secondary stressors (ex.: financial problems, low self-esteem), mediators (ex. coping strategies) and the results (ex.: depression, anxiety, physical symptoms).

Considering the diversity found among caregivers, researchers have verified the relationship between the stressors described in Pearlin et al.’s model9 with different outcomes. The demands for care have been studied as important predictors for caregivers of the elderly. Depression, for example, has been cited in the literature as an important outcome in relation to the demands of care. Association among caregivers was verified between greater care time, correspondence,12 controlling and manipulative behavior of the care recipient, and the restriction of activities among caregivers with depressive symptoms.13

The burden perceived by the caregiver regarding such demands has also been shown to be a relevant predictor of his or her health. Burden was associated with poorer quality of life of the caregiver,14 anxiety and depressive symptoms.15 High strain with regard to their role was also connected to higher mortality.16

The physical health of caregivers has been an important variable in studies with informal caregivers. Poor physical health is associated with more depressive symptoms and good physical health is associated with well-being.17 Longitudinally, the increase in physical symptoms was associated with an increase in depressive symptoms in the period of one year.18

How the caregiver evaluates their health is also a relevant aspect in studies with caregivers of the elderly. Those who evaluated their health in a negative way presented a greater risk for coronary disease19 and higher mortality20.

One aspect that is still rarely considered in the literature is the large variation in age among caregivers and an increase in older caregivers. There is evidence that shows that they have poorer health than younger caregivers,19 and that concern for one’s own health may have mental health disadvantages when compared to younger caregivers.4

The caregiver’s commitment to health is an aspect that needs to be considered in the assessment of caregivers. This, added to the stressors related to the demands of care, constitutes a double vulnerability for the caregiver.

Thus, the family caregiver is considered to be vulnerable due to the burden generated by the care activities that he or she performs. In addition, his or her physical health is often also compromised due to the little attention spent on him or herself and/or his or her own aging process. Thus, the caregiver is sometimes doubly vulnerable, because of the care burden and a physical impairment.

The main objective of this article was to review publications in periodicals of studies that related aspects of the double vulnerability (physical health of the caregiver, self-perception of the caregiver’s health, the care receiver’s dependence and perceived burden) with aspects related to the psychological dimensions of quality of life of the caregiver, such as well-being, pleasure, happiness and self-realization. Secondly, it aimed to analyze how these studies consider the age of the caregiver and how they use it in their analyses.

METHODS

In order to achieve the objective of this study, we used the integrative literature review model, which combines findings from several empirical studies.20,21 A search was done in the following indexes: PubMed, Periódicos Capes, LILACS, SciELO and AgeLine with the following keywords: caregiver, elderly and “subjective well-being”; caregiver, elderly and “psychological well-being”; caregiver, elderly and happiness; caregiver, elderly and self-realization; caregiver, elderly and pleasure, and the equivalent terms in Portuguese.
Empirical articles with elderly caregivers, published in periodicals from January 2005 to May 2017, in the English, Portuguese and Spanish languages were included. They had to relate well-being with some variable that represents the double vulnerability (dependence from the care receiver, burden, physical health, self-perceived health). We excluded studies carried out with formal caregivers or those that only had the research protocol.

An initial analysis of titles and abstracts was done so that repeated articles and those that do not meet the inclusion criteria were eliminated. In this stage, 18 articles were selected. In a second stage, the bibliographic references of these selected articles were analyzed. Five additional articles were included in this stage. The number of publications excluded by each criterion is shown in Figure 1.

In order to organize the data obtained in the previous stage, a table was made, in which variables related to the selected articles were identified: name of the first author; year of publication; methods used in the articles; objective(s) of the article; variables/instruments used in the article; main results found in the article.

The data were examined through descriptive analysis and the relationship between the variables is presented in Table 1.

An analysis of the results, which is presented in the discussion section, revealed five categories, which were constructed based on the objective of this review, that is, with aspects of double vulnerability, which were:

- physical health of the caregiver;
- health conditions of the care recipients;
- self-perceived health;
- caregiver burden.

## RESULTS

Initially, 788 articles were found. After removing the repeated articles and the articles that did not meet the inclusion criteria, 18 studies remained. In addition, five other studies were analyzed from the references of the selected articles, totaling 23 studies included in the review. In the Periódicos Capes portal, 518 articles were found; in PubMed, 234; in the AgeLine database, 19; in SciELO, 4; and in LILACS, only 3.

Regarding the populations of the studies, 14 of them investigated informal caregivers of elderly people with any type of dependency, 6 analyzed caregivers of elderly people with dementia, 1 looked at caregivers of elderly people with mild cognitive impairment (MCI), 1 evaluated caregivers of elderly people with musculoskeletal diseases and 1 compared caregivers of elderly people with physical and mental dependencies.

There was great heterogeneity regarding sample age. Of the 23 studies, only 10 presented the minimum and maximum age values, 16 showed the mean age and only 3 studies highlighted age as an inclusion criterion. This resulted in studies showing very large age ranges (ex: 21 to 88, 20 to 89).

Articles were identified that used the following study methods: a diary study, an intervention study, an instrument validation study, a prospective cohort study, a longitudinal study and other cross-sectional studies.

Most of the studies aimed to evaluate the caregivers of elderly people with regard to variables related to dual vulnerability and psychological aspects of quality of life. Two studies aimed to compare caregivers with non-caregivers. Two intended to validate an instrument for caregivers. Another aimed to evaluate an intervention for caregivers and one sought to document a psychological evaluation of caregivers who have spouses with MCI.

The presented articles had the following outcome variables:

- psychological well-being,
- physical well-being,
- general well-being,
- subjective well-being,
- positive and negative affects,
- quality of life,
- stress of the role,
- helplessness,
- health risk behaviors,
- state of health,
- self-perceived

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### Table 1: Presentation of the Variables Related to Double Vulnerability

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<tr>
<th>Year of Publication</th>
<th>Methods Used</th>
<th>Objectives</th>
<th>Variables/Instruments</th>
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![Figure 1 Selecting the articles.](image-url)
Table 1 Description of the selected articles.

<table>
<thead>
<tr>
<th>Study</th>
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<th>Main results</th>
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<tr>
<td>Savla et al., (2011)²²</td>
<td>Diary method (7 days) n = 30 caregiver spouses Age: 59 to 85 years old M = 72.60; DP = 6.91 Age in the analysis: age entered into the model as an independent variable</td>
<td>Document the spouse’s assessment of the daily frequency and intensity of early symptoms of memory loss and the behavior of their husbands or wives with mild cognitive impairment</td>
<td>- demographic characteristics - mini-mental state examination - instrumental activities of daily living - 16-item deficit awareness scale - CES-D scale; - chronic health conditions - Environmental Mastery Subscale of the Ryff Scales of Psychological Well-being - daily - reduction of activities - time spent on leisure activities - Daily Inventory of Stressful Events - spousal interactions; - sleep disorder Symptoms - positive and negative affects - cortisol</td>
<td>The physical and cognitive conditions of the caregiver were not predictive of negative or positive affect. Depressive symptoms and poor health condition reported less positive affect overall. Age was not a predictor of negative or positive affect.</td>
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<td>Mcconaghy and Caltabiano (2005)²⁷</td>
<td>Survey n = 42 Age: 21 to 88 years old M = 62; SD = 13.25 Age in the analysis: the sample was divided among young caregivers (21 to 63) and older caregivers (64 to 88 years old)</td>
<td>Identify the impact of variables such as gender, time of care, coping style, depression, and burden on the physical and psychological well-being of caregivers of people with dementia.</td>
<td>– information about the caregiver - Satisfaction With Life Scale; - CES-D scale; - COPE; - Short Form (SF)-12v2; - Caregiver Burden Scale.</td>
<td>The perceived burden was responsible for 41.7% of the variation in life satisfaction. A significant negative correlation was found between burden and health. There was no statistically significant difference in life satisfaction scores for older and younger caregivers.</td>
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<td>Séoud et al. (2007)²⁸</td>
<td>Exploratory correlational study n = 319 Age = 30 to 49 years old M = 46.1; SD = 14.5 Age in the analysis: Age was not assessed</td>
<td>To identify the dimensions of the health care context of caregivers of elderly relatives in Lebanese families.</td>
<td>– welfare: GWB - tension and helplessness: Zarit Burden Interview - loss of functional autonomy: SMAF - problematic behaviors: Revised Memory and Behavior Problems Checklist - memory loss - care tasks: two scales based on the Quebec Health and Social Survey - formal or informal support: The Inventory of Socially Supportive Behaviors - sociodemographic variables</td>
<td>The degree of functional impairment, frequency of depression, and disruptive behaviors are linked to at least one of three caregiver health indicators. The greater the loss of autonomy and the greater the frequency of disruptive behaviors, the lower the levels of well-being as reported by caregivers.</td>
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| Yang et al. (2012)    | Cross-sectional study n = 1144 | To describe the health-related quality of life among Chinese caregivers of the elderly in the community and to explore the predictors of the caregiver’s quality of life | - quality of life: SF-36
- demographic characteristics of the caregiver
- characteristics of the elderly
- objective burden: care tasks, level of care, amount of time spent on daily care
- subjective burden: ZBI
- Confrontation: SOC scale | Demographic characteristics of the caregivers, patient characteristics and subjective burden accounted for most of the total variance for all aspects of quality of life. Subjective burden was the strongest predictor of physical and mental QOL. Caregivers who had chronic diseases, with lower income, spouses that care for elderly people with more chronic diseases and with higher levels of dependence tended to report worse physical and mental QOL. Age was not a predictor of QOL. |
| Won et al. (2008)     | Six-week psycho-educational intervention study (PTC) N = 118 | To analyze the impact of participation in a community-based program in building self-care skills and increasing self-efficacy on caregivers. | - demographic characteristics of the caregiver
- assisting with the patient’s personal care
- number of chronic conditions that the patient has and the conditions affecting physical functioning and care
- health risk behaviors
- time spent on exercise, relaxation or stress management techniques
- psychological well-being: MHI-5 | Health, risk behaviors, self-care and psychological well-being improved for both the general group and each age stratum. Caregivers aged ≥ 65 years old had a lower reduction in health risk behavior than those aged <65 years, and had less improvement in psychological well-being than the younger subgroup. |
| Dulin and Dominy (2008) | Survey N = 158 | To examine the contribution of positive attitudes with regard to helping others predict emotional functioning among a sample of caregivers of people with dementia. | - beliefs, feelings and behaviors related to helping: HAS
- coping: RWCCl
- positive and negative affect: PANAS
- demographic questionnaire | Helping attitudes predicted a positive affect with other demographic and coping variables. The higher the age, the lower the positive affect of the caregivers of the sample. The only final predictors of negative affect were the number of hours of daily care and magical thinking. |
| Hoefman et al. (2011) | Survey N = 230 | To investigate the validity of the construction of the CarerQol instrument, which measures and evaluates effects on the caregiver in a new population of informal caregivers. | - burden (CarerQol-7D) and happiness (CarerQol-VAS)
- objective burden: duration and intensity of care, type of tasks, constant surveillance of the care receiver, use of home care and respite care
- subjective burden: SRB; PU | Scores from the happiness scale were higher when the caregiver’s health was better, when he or she felt less overwhelmed, and when the PU was positive. Age was not a predictor of happiness. |
Table 1 (Continuation).

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<td>Sequeira (2013)</td>
<td>Quantitative, analytical and correlational study N = 184 Age: 87.4% &gt; 40 years old and 40.2% &gt; 60 years old Age in the analysis: age was not analyzed</td>
<td>To characterize the main difficulties, coping strategies, sources of satisfaction and levels of burden of caregivers, and to compare the impact among caregivers of elderly people with physical dependence and caregivers of elderly people with mental dependance</td>
<td>- ADL dependency: Barthel Index and Lawton Index &lt;br&gt; - Cognitive Function: Mini Mental State Examination &lt;br&gt; - stage of dementia: Clinical Dementia Rating:  &lt;br&gt;- caregiver difficulties: CADI  &lt;br&gt;- coping strategies: CAMI &lt;br&gt;- Burden: Scale of Caregiver Burden.</td>
<td>Caregivers of elderly people who were dependent due to physical conditions reported higher levels of satisfaction for all dimensions of CASI than caregivers of people who were dependent due to mental conditions. The instruments of difficulties and burden (CADI and the Scale of Caregiver Burden) showed a negative correlation with CAMI and CASI.</td>
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<td>Tomomitsu et al. (2014)</td>
<td>Survey - data from the FiBRA Study N = 338 caregivers and 338 non-caregivers Age = 65 years and over Age in the analysis: age entered into the univariate logistic regression analysis</td>
<td>To investigate the associations between life satisfaction and sociodemographic variables, health conditions, functionality, social involvement and social support for elderly caregivers and non caregivers, and between satisfaction and intensity of stress in the caregiver group</td>
<td>satisfaction with life &lt;br&gt;- age, gender and family income &lt;br&gt;- intensity of stress associated with care &lt;br&gt;- number of diseases &lt;br&gt;- fatigue: two items from CES-D &lt;br&gt;- depressive symptoms: GDS &lt;br&gt;- insomnia &lt;br&gt;- IADLs &lt;br&gt;- Involvement in AADL &lt;br&gt;- perceived social support</td>
<td>Caregivers with less satisfaction and greater stress had more chronic diseases, fatigue and partial dependence for IADLs than caregivers with less satisfaction and less stress. The elderly with greater satisfaction reported having fewer diseases. There were associations between low satisfaction and insomnia, six or more depressive symptoms and fatigue. Age was not associated with lower satisfaction with life.</td>
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<td>Egbert et al. (2008)</td>
<td>Telephone survey N = 77 Age: ≥ 55 (70%) Age in the analysis: age entered into the hierarchical multiple regression analysis</td>
<td>To explore whether the difficulties of the caregivers were related to their psychological well-being, after controlling for variables related to care and demographics</td>
<td>- Psychological well-being: PGWB Positive Well-Being subscale &lt;br&gt;- quality of care &lt;br&gt;- perception of the difficulty in providing care &lt;br&gt;- weekly hours of care &lt;br&gt;- perception of the care offered &lt;br&gt;- demographic data</td>
<td>Lower psychological well-being was directly related to health, but inversely associated with age and the difficulty in providing care. Psychological well-being was lower when the caregiver experienced greater difficulty in providing emotional support, was in a poorer health situation, or was older.</td>
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<td>Lu et al. (2015)</td>
<td>Survey N = 494 Age: M = 62.6; SD = 11.9 Age in the analysis: younger caregivers had lower levels of physical and developmental burden. Older caregivers had greater social burden</td>
<td>To examine the correlations of each dimension of burden experienced by family caregivers of frail elderly with musculoskeletal disorders in China, and to examine the role of caregiver burden in stressors and subjective well-being</td>
<td>- subjective well-being: depressive symptoms (CES-D) and satisfaction with life (Satisfaction with Life Scale) &lt;br&gt;- Burden: Chinese Caregiver Burden Inventory &lt;br&gt;- the elderly care recipient’s dependence on ADL: Barthel Index &lt;br&gt;- cognitive state of the elderly care recipient: SPMSQ &lt;br&gt;- behavioral problems of elderly caregivers</td>
<td>The elderly person’s dependence on ADL was associated with the caregiver’s satisfaction with life. The association between ADL dependency and life satisfaction was measured by time dependence and burden. The overall indirect effect of cognitive status on life satisfaction was statistically significant.</td>
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| Domínguez-Guedea and Garcia (2015)²⁴ | Cross-sectional study with a non-probabilistic sample N = 386 Age = 19 to 87 years old (M = 49.05, SD = 12.41) Age in the analysis: stratified to characterize the sample | To analyze the influence of burden on the welfare of caregivers, exploring the mediating role of sociocultural and family factors                                                                                   | - help to carry out basic activities and IADLs  
- well-being: Subjective Well-Being Scale for Family Caregivers of Elder Persons  
- abnegation: Abnegation Scale for Family Caregivers of Elder Persons  
- burden: Burden Scale for Family Caregivers of Elder Persons  
- social support: Social Support Scale for Family Caregivers of Elder Persons  
- family involvement | The perception of burden had a direct negative effect on subjective well-being and in the family environment. Socio-cultural and familial resources had a direct positive effect on subjective well-being and, at the same time, mediated the effect of burden on subjective well-being. |
| Alvira et al. (2015)²⁵       | Cross-sectional study N = 2,014 Age = M of each country varied between 80.9 and 84.7 Age in the analysis: the M and SD of age in each country were described | To describe the associations between positive and negative reactions of informal caregivers of people with dementia, and to describe health outcomes in eight European countries | - positive and negative reactions: CRA  
- care and caregiver health data  
- burden: ZBI  
- quality of life: EQ-5D  
- psychological well-being  
- neuropsychiatric symptoms of the elderly with dementia: NPI  
- comorbidities: Charlson Comorbidity Index  
- the care receiver’s dependence on activities of daily living: Katz Index | Variability was observed between countries. In general, self-esteem and lack of family support were correlated with caregiver burden and psychological well-being. Burden, QOL, psychological well-being and interruptions in routine were strongly correlated with the degree of health problems in all of the countries. |
| Chow and Ho (2015)²⁶         | Cross-sectional study N = 112 Age = 56 to 90 years old (M = 74.80, SD = 6.88) Age in the analysis: a comparison was made between younger and older caregivers | To examine the differences in the multiple dimensions of psychological well-being among spouse caregivers of elderly with low and high strain. And investigate the differences in the multiple dimensions of psychological well-being among younger and older caregivers | - caregiver strain: CSI  
- distress: RSS  
- psychiatric disorders: GHQ  
- depressive symptoms: GDS  
- subjective well-being: PWI  
- satisfaction: LSS  
- purpose in life: PIL  
- demographic data | Caregivers with high strain had greater emotional and social distress, negative feelings and depression, as well as lower mental health, subjective well-being, life satisfaction and purpose in life compared to caregivers with low strain. Older caregivers scored lower on emotional and social distress, negative feelings and depression. Additionally, they had greater subjective well-being. |
| Lutomski et al. (2013)²⁷     | Instrument validation study N = 3,269 Age = M = 62, SD = 12 Age not assessed | Validate the CarerQol                                                                                                                                  | - sociodemographic variables  
- self-perceived health  
- average number of hours of care  
- care-related burden: CarerQol-7D and SRB  
- happiness: CarerQol-VAS  
- Process utility: CarerQol-VAS and transfer of care (Transfer)  
- vulnerability of the elderly care recipient: 45-item Frailty Index | Poor self-perceived health and fragility of the care recipient were negatively associated with the caregiver’s happiness and positively associated with increased burden. The results support the validity and applicability of the CarerQol instrument in several contexts. |
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<td>Ho et al. (2009)</td>
<td>Cross-sectional study &lt;br&gt; N = 294 caregivers and 492 non-caregivers &lt;br&gt; Age: 54.1% were 35-49 years old; 34.6% were aged 50-64 years old; 11.4% were 65 or older &lt;br&gt; Age in the analysis: stratified to characterize the sample</td>
<td>To investigate the impact of caregiving on the health state and quality of life of primary caregivers of elderly in Hong Kong</td>
<td>- health: list of 14 diseases suffered in the last year &lt;br&gt; - list of eight physical and psychological symptoms experienced in the last four weeks &lt;br&gt; - self-perceived health: health compared to a year ago &lt;br&gt; - depression: CES-D &lt;br&gt; - physical, psychological and social domains of quality of life: SF-36 &lt;br&gt; - burden: Zarit Burden Scale</td>
<td>Caregivers were at greater risk for reporting poorer health, more doctor visits, anxiety, depression and weight loss compared to non-caregivers. Increased burden on caregivers was associated with worse outcomes in all domains of QOL, and worse physical and psychological health.</td>
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<td>Takai et al. (2011)</td>
<td>Cross-sectional study &lt;br&gt; N = 118 &lt;br&gt; Age: M = 60.9; SD = 14.0 &lt;br&gt; Age in the analysis: Age not assessed</td>
<td>To investigate the predictive factors of QOL in caregivers of patients with dementia</td>
<td>- QOL: WHO / QOL-26 &lt;br&gt; - burden: BM &lt;br&gt; - Depressive symptoms: BDI-II &lt;br&gt; - Care recipient &lt;br&gt; - cognitive screening: MMSE &lt;br&gt; - neuropsychiatric symptoms: NPI &lt;br&gt; - cognitive functioning: CDR</td>
<td>Every dimension of the caregivers QOL was correlated with depressive symptoms and burden. The neuropsychiatric symptoms of the patients were correlated with total and physical QOL. The depressive symptoms in caregivers were the strongest predictor of QOL and QOL was best predicted by the combination of depressive symptoms, burden and cognitive impairment of the patients.</td>
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<td>Zarit et al. (2010)</td>
<td>Cross-sectional study &lt;br&gt; N = 67 &lt;br&gt; Age = 41 to 85 years old (M = 62.5, SD = 11.6) &lt;br&gt; Age in the analysis: Age not assessed</td>
<td>To examine the associations between risk factors and outcomes commonly used in caregiver literature</td>
<td>- ADL limitation: Lawton &amp; Brody Scale &lt;br&gt; - hours of care &lt;br&gt; - psychological and behavioral symptoms related to dementia: WRB &lt;br&gt; - strain of the dyad &lt;br&gt; - frequency and dissatisfaction with formal and informal help &lt;br&gt; - recreation &lt;br&gt; - depressive symptoms: PHQ-9 &lt;br&gt; - irritation: HSC &lt;br&gt; - positive affect: DQoL &lt;br&gt; - subjective health: MOS &lt;br&gt; - burden</td>
<td>Caregivers varied in number and type of risk factors and outcomes, in which they had elevated scores. Positive affect was positively correlated with subjective health and negatively correlated with burden from the role. In a bivariate analysis and in the multivariate analyses, different combinations of predictor risk factors were found for each outcome.</td>
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<td>Borg and Hallberg (2006)</td>
<td>Cross-sectional population-based study &lt;br&gt; N = 151 frequent caregivers; 392 non-frequent caregivers; 1,258 non-caregivers &lt;br&gt; Age = 50 to 89 years old &lt;br&gt; Age in the analysis: age assessed in non-parametric analyses</td>
<td>To investigate informal caregivers’ satisfaction with life</td>
<td>- satisfaction with life: LSIZ &lt;br&gt; - age, gender, education, social support, economic resources, mental health and physical health: OARS part A, OMFAQ</td>
<td>Frequent caregivers had lower satisfaction with life than less-frequent caregivers and non-caregivers. The most important factors explaining lower satisfaction with life among frequent caregivers were lack of social resources and poor health. Satisfaction declined as age increased.</td>
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| Colin Reid et al. (2010) | Cross-sectional study N = 243 Age: M = 54.1 | To examine the relationship between work interferences and caregiver burden, well-being and self-esteem | - burden: Zarit Caregiver Burden Inventory  
- well-being: Life Satisfaction Scale  
- self-esteem: Rosenberg Self-Esteem Scale  
- care time in months  
- limitations of the care recipients’ ADL: scale of 15 items  
- Care recipients’ behavior problems: scale of 10 items  
- perceived social support: Pearlin, Lieberman, Menaghan and Mullan scale  
- use of social and health services: 12 items scale | Well-being is positively affected by perceived social support and self-esteem, and negatively affected by burden.  
Work was not related to the outcomes in the total sample.  
In the sub-sample of employed caregivers, only the item “work performance was affected by care activities” was associated with all outcomes (self-esteem, burden and well-being). |
| Lethin et al. (2017)   | Prospective cohort study N = 1,223 Age: 54 to 77 years old Age was assessed in the bivariate analysis | Investigate the psychological well-being of informal caregivers of people with dementia, and review the increase in psychological well-being | - psychological well-being: GHQ-12  
- experience of care: CRA  
- burden: ZBI  
- need for care: RUD  
- QOL: EQ-5D-3L  
- self-perceived health: EQ-VAS  
- comorbidity of the care recipient: CCI  
- QOL of the person with dementia: QoL-AD proxy rated  
- ADL: Katz-ADL  
- neuropsychiatric symptoms: NPI-Q  
- depression in dementia: CSDD | At the baseline, positive experience with care, less burden, higher QOL, higher self-perceived health, and care of male subjects with higher QOL, few neuropsychiatric symptoms and few depressive symptoms were associated with greater psychological well-being.  
Increased psychological well-being was associated with less burden, positive experience with care, higher QOL, higher self-perceived health, less need for care from the recipient, male care recipient with a higher QOL, and fewer neuropsychiatric symptoms. |
| Niimi (2016)           | Cross-sectional study N = 2,840 Age: 20 to 69 years old | To examine the impact of informal care on parents with regard to the subjective well-being of caregivers | - subjective well-being: visual scale of happiness  
- filial obligation  
- health of the care recipient  
- conditions of care  
- sociodemographic data  
- work status  
- perception of standard of living | Care has a greater negative impact on single caregivers than on married couples. The care recipient's poor health was related to lower happiness and to single caregivers.  
The relationship between age and happiness was U-shaped, showing a decline in middle age. |
| van Dam et al. (2016)  | Longitudinal study N = 350 Age: M = 63 (SD = 13.3) | To describe the QOL related to care of informal caregivers after geriatric rehabilitation, and to identify associated determinants | - burden: CarerQol-7D  
- happiness: CarerQol-VAS  
- self-perceived health: 2 items from the RAND 36-item Health Survey  
- functionality of the care recipient: The Barthel Index  
- the cognition of the care recipient: CPS  
- depression of the care recipient: DRS | Happiness was inversely associated with burden. The association between age and self-perceived health with happiness was not investigated. |

n: number of participants; M: mean; SD: Standard Deviation; MCI: mild cognitive impairment; CES-D: Center for Epidemiological Studies Depression; COPE: coping, practical forms of coping; GWB: General Well-being Schedule; SF-36: 36-item Short-Form Health Survey; ZBI: Zarit Caregiver Burden Inventory; MHI-5: Mental Health Index-5; HAS: Helping Attitudes Scale; PWI: Personal Well-being Index; RUD: Relative Stress Scale; ADL: activities of daily living; CADI: Caregiver Assessment of Difficulties Index; CAMI: Caregiver Assessment of Managing Index; CASI: Caregiver Assessment of Satisfactions Index; FIBRA: Fragility in Elderly Brazilians; GDS: Geriatric Depression Scale; IADLS: instrumental activities of daily living; AADL: advanced activities of daily living; PGWB: Psychological General Well Being; SPMSQ: Short Portable Mental Status Questionnaire; CRA: Caregiver Reaction Assessment; ZBI: Zarit Burden Interview; EQ-SD: Quality of Life Scale; NPI: Neuropsychiatric Inventory; CSI: Caregiver Strain Index; RSS: Relative Stress Scale; GHQ: General Health Questionnaire; PNL: Personal Well-being Index – Adult; LSS: Life Satisfaction Scale – Chinese; PIL: Purpose in Life Test; CarerQol: Care-Related Quality of Life Instrument; WHO/QOL-26: World Health Organization Quality of Life 26; BM: Pines Burnout Measure; BDI-II: Beck Depression Inventory; MMSE: Mini-Mental State Examination; CDR: Clinical Dementia Rating; WRB: Weekly Record of Behavior; PHQ-9: Patient Health Questionnaire; HSC: Hopkins Symptoms Checklist; DQoL: Dementia Quality of Life Instrument; MOS: Medical Outcome Studies; LSIZ: Life Satisfaction Index Z; OARS: Older Americans’ Resources Schedule; OMFAQ: Multidimensional Functional Assessment Questionnaire; CCI: Charlson Comorbidity Index; DRS: Depression Rating Scale
The following independent variables were used: sociodemographic characteristics, the care recipient's impairment, the caregiver's perception about the patient's cognitive decline, the patient's behavioral problems, depressive symptoms, the physical health of the caregiver, reduction of activities, leisure time, stressful events, conjugal interactions, perceived burden, support received, self-denial, family involvement, self-perceived health, health risk behaviors, help attitudes, caregiver difficulties, sleep and exercise problems or relaxation techniques. Information on the studies is available in Table 1.

**DISCUSSION**

**The caregiver's physical health**

In the reviewed studies, the physical health of the caregiver was related to psychological variables associated with quality of life. The better the physical health of the caregiver, the higher their scores on the happiness scale and the greater the satisfaction. Likewise, poor physical health of the caregiver was related to lower psychological well-being, poorer physical and mental quality of life, less positive affect and lower satisfaction.

In the study by Tomomitsu et al., a relationship between stress and the caregiver's physical health was perceived, since when comparing two groups of caregivers who reported low satisfaction, the one who had higher stress also had more chronic illnesses, fatigue and partial dependence for instrumental activities of daily living (IADLs).

Another interesting fact found in the review was the study by Borg and Hallberg, which identified that the most frequent caregivers (who provide care for at least four days a week) had significantly poorer health than less frequent caregivers. These results show that there is an association between physical health and well-being of caregivers. Considering the caregiver stress model of Pearlin et al., which emphasizes the appearance or worsening of physical symptoms as a possible outcome of the stress from care, another outcome seems to be also correlated with the health of the caregiver: psychological well-being. That is, the studies presented previously indicate that the well-being of the caregiver is just as at risk as their physical health.

**Health conditions of the care recipient**

Research has shown that the health conditions of the elderly care recipient and the type of impairment they suffer affect the well-being of the family caregiver. Poor quality of life of the caregiver was associated with poor health and greater cognitive impairment of the care recipient. Poor health of the care recipient was also associated with a lower level of caregiver happiness.

Regarding the association between psychological aspects of the quality of life of caregivers and dependence on activities of daily living (ADL), Lethin et al. identified that caregivers with greater psychological well-being cared for older people with more comorbidities, less cognitive impairment, and less dependency on ADL. Lu et al. found that the elderly person's dependence on ADL was also associated with the caregiver's satisfaction with life. The overall indirect effect of ADL dependency on life satisfaction was not statistically significant. However, the association between ADL dependency and life satisfaction was mediated by time dependence and developmental burden. The overall indirect effect of cognitive status on life satisfaction was statistically significant. However, in the study by Zarit et al., the dependence on ADL was not associated with positive affect nor with the caregiver's self-perceived health assessment.

Regarding the care receiver's impairment, one study found that caregivers of patients with memory loss had a lower mean for well-being and a higher mean for role strain than caregivers of patients without memory loss. In another study, caregivers of elderly individuals with a physical impairment reported a higher level of satisfaction than those caring for elderly people with a mental impairment.

The greater the impairment, the greater the demands for care. It has long been argued in the literature that most dependent elderly are cared for by a primary caregiver and care tasks are rarely shared with other caregivers, whether formal or informal. The studies in this review reinforce the need for services that may reduce the workload of caregivers.

**Caregiver Burden**

Studies also showed that high levels of burden were associated with low levels of well-being and positive affect. And the lower levels of burden were associated with greater happiness. Burden was also negatively associated with the psychological aspect of quality of life.

The studies corroborate the importance of evaluating and intervening in perceived burden. In addition, other potentially stressful non-care situations need to be considered. Often there is an accumulation of roles, i.e., the caregiver is already burdened with other stressors, such as work problems, child care, personal illness, among others. This makes the perception of care-related burden even greater for the caregiver.
Self-perceived health

Only three studies analyzed self-perceived health. Lutomski et al. found that poor health self-perceived health was negatively associated with caregiver happiness and positively associated with increased burden. In the study by Zarit et al., positive affect was positively correlated with subjective health; and Lethin et al. identified that health self-perceived health is associated with psychological well-being.

Self-perceived health is increasingly being researched in health and aging studies. However, it has been poorly explored in research with caregivers, although an association has already been found between negative self-perceived health and burden in caregivers of the elderly. Therefore, the fact that this variable is not frequently found in recent studies concerning the welfare of caregivers seems to be an important gap to be filled in the literature.

Age of the caregiver

It is possible to notice a great variation in age in the studies’ samples. Furthermore, the information provided was not always complete (it did not present mean or minimum and maximum age, for example). In most studies, age was not a significant variable. However, four studies pointed to increased risks for older caregivers. In the article by Dulin and Dominy, being older was correlated with lower positive affect. In the study by Borg and Halberg, satisfaction with life decreased as age increased.

The age differences among caregivers of the elderly present divergences, which are little studied. This finding raises questions about how empirical and interventional studies on caregivers are being conducted. Pruchno and Gitlin argue that care affects people differently according to the type of care provided, an evaluation of existing resources and the stage of development that the person becomes a caregiver. Some studies of this review have pointed to differences in the responses of caregivers of different ages with regard to the demands of care, however, they need to be further investigated. For example, we need to know how and why they occur.

CONCLUSION

It can be observed from the results and discussion of this review that the psychological variables that make up the quality of life of caregivers of the elderly are the result of multiple factors. The results of the studies also showed that these variables are affected by several simultaneous factors, such as the degree and type of dependence of the elderly care recipient, the caregiver’s own health, and the perceived burden. These data are important because they help illustrate the factors that interfere in the quality of life of the caregiver and provide assistance for the implementation of interventions involving caregivers of the elderly. It is interesting to note that self-perceived health was rarely analyzed, as it appeared in only two studies. Because this measure is related to physical and psychological health, using it in future studies to verify its association with the well-being of elderly caregivers would help understand the phenomenon.

Another notable aspect in the investigated studies is the heterogeneous nature of the samples. Most studies evaluated caregivers of very different ages and cohorts, and such variation could be further examined in other studies. The same goes for the various types of care provided. Within the research methods employed, only one longitudinal study was found. This type of study could help answer more questions, as it would specify how the relationship between risks and outcomes changes over time and also what risks most impact caregivers of different ages and cohorts. More longitudinal, population-based and multi-center studies may also help understand the nuances that may affect caregivers’ well-being.

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CONFLICTS OF INTEREST

The authors declare that there were no conflicts of interest.

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