

# Overload And Depression In The Informal Primary Caregiver Of Patients With Disabling Diseases: Theoretical Review

Pérez Padilla Elsy Arlene<sup>1</sup>, Góngora Alfaro José Luis<sup>2</sup>, Salgado Humberto<sup>2</sup>

<sup>1</sup>(Psychopedagogical Department/ Faculty Of Medicine / Autonomous University Of Yucatán, México)

<sup>2</sup>(Regional Research Center "Dr. Hideyo Noguchi" / Autonomous University Of Yucatán, México)

---

## Abstract:

There is great interest in studying the role of the informal primary caregiver due to the relationship between care, caregiver overload, and the psycho-emotional problems that arise. In this context, various epidemiological studies in the last two decades showed that the effect of caring for a patient with a chronic disease and with limitations in activity can affect the emotional and psychological health of the caregiver. Notably, caring for a patient with a disabling illness (dementia, cancer, vascular stroke, neuromusculoskeletal diseases, among others) can produce a series of discomforts in the informal primary caregiver, such as overload or burnout, affecting performance and satisfaction in care tasks and, even more so, affect the emotional health of the caregiver by increasing stress and anxiety, which, in turn, can trigger the symptoms of major depressive disorder. Therefore, it is essential to study and prevent primary caregivers of patients with activity limitations from affecting their emotional and psychological health. This review focuses on the importance of caring for a family member with a disabling illness and the repercussions of care work on primary caregivers' activities and emotional health.

**Key Word:** Overload; Primary Caregiver; Disabling Diseases; Emotional Health.

---

Date of Submission: 16-12-2023

Date of acceptance: 26-12-2023

---

## I. Introduction

The World Health Organization and the Global Burden of Disease reported in 2018 that nearly 1.3 billion people worldwide have a significant disability.<sup>1,2</sup> The WHO defines *disability* as the state in which people suffer a loss of physical, mental, intellectual, or cognitive autonomy and who need assistance or help to manage the daily activities of life.<sup>1</sup> This means that due to their patients characteristics, they need another person, called a caregiver, who helps them carry out the activities they cannot do; said informal caregiver generally belongs to the family circle. The Informal Primary Family Caregiver is "that person who assumes total responsibility for the patient, helping him or her to carry out all the activities that he or she cannot."<sup>3,4</sup> The literature mentions that there are common risk factors found in caregivers. Primary factors include sex, family relationship with the patient, marital status, educational level, employment status, a greater number of hours dedicated to care, and economic level.<sup>5-8</sup> Caring for a person with activity limitations is one of the most stressful and challenging events for families.<sup>3</sup> Notably, the performance of the caregiver role entails symptoms such as discomfort, stress, and deterioration linked to providing assistance for an indeterminate period and without probable rest; this symptomatology is known as "overload or burnout." When this overload occurs in a prolonged or intense manner, it produces physical, psychological, and social imbalances that impact the caregiver's social activities, leisure, intimacy, and lost emotional balance, developing the "Caregiver Burden Syndrome." The latter has been associated with sleep problems, irritability, high levels of anxiety, and resentment towards the person who cares. On many occasions, it has been associated with the appearance of depressive symptoms in the caregiver. Therefore, it is essential to identify and treat this condition in time to improve the quality of life of caregivers and the patients in their care.

## II. Disability in the world

It is estimated that, in the world, more than one billion people live with some disability, that is, about 15% of the world's population, of which, according to the World Health Survey, about 200 million have difficulties with very significant functioning (severe disability).<sup>2</sup> In the last three decades it has been observed that disability is increasing because the population ages and, more and more people suffer from chronic diseases such as diabetes, cardiovascular diseases, cancer, dementia, Parkinson's, and different psychiatric disorders.<sup>5, 9-13</sup>

---

Among the main problems generated by disability is that its presence often generates deficiencies from mild to severe, with symptoms, signs, or consequences that make it impossible for people to carry out Activities of Daily Living (ADL), which requires It implies the need for care from another person, a relationship known as "dependency." Given these conditions, patients with these diseases are considered dependent individuals who require special and long-term care from a family member and health system services because they have significant limitations in their activities of daily living, such as moving, walking, taking care of themselves in terms of daily hygiene, dressing, feeding, medicating, and on many occasions socializing.<sup>6,9,10,14</sup>

### **III. The informal primary caregiver**

Mcmullan et al., 2022 define the Informal Caregiver as "that person who provides support to the patient, this being a family member or friend who assumes absolute responsibility in everything regarding their basic care, or as that person who, in a voluntary and determined way, he takes the option of becoming a caregiver for that other who is limited in his resources to face the demands of the world."<sup>15</sup> It must be emphasized that this person (the caregiver) is not trained or part of the professional caregivers that make up your health team, such as nurses, doctors, social workers, and therapists. Instead, he provides social, functional, economic, material, emotional, and assistance support in various forms to the person in his charge. For this reason, the family caregiver constitutes a social unit vulnerable to the conditions and pressures present in their cultural, economic, and social environment at a given time.<sup>16,17</sup> In this context, caregivers may experience a wide range of feelings and emotions such as anger, guilt, frustration, exhaustion, anxiety, fear, pain, sadness, and a decrease in self-esteem and satisfaction with the work performed, depending on the situations and in the way in which he assumes his role.<sup>17,18</sup>

The above predisposes the quality of life of the informal caregiver to be affected, given the work overload due to the tasks of caring for a patient with activity limitations.<sup>17,18</sup> In this sense, the biggest problem that informal caregivers present lies in psychological and social repercussions; among them, we can highlight major.<sup>19-21</sup> It is important to mention that, despite scientific advances and new strategies implemented for health care, they focus solely on patient care. However, what happens with the deterioration of the informal caregiver's quality of life and health? Then, who takes care of the caregiver? Therefore, it is important to characterize the informal primary caregiver and describe the degree of affectation that he or she may present when performing his or her important role.

Various studies report a predominance of the female sex in the performance of the role of informal primary caregiver; for example, in a study carried out in the United States of North America, it was found that 69.6% of the caregivers were female<sup>22</sup>, a similar situation was found in studies carried out in Spain, Ghana and China where the proportion of women ranged from 50 to 91%.<sup>23-25</sup> This fact makes visible gender inequality in informal care, where it is women who carry out this activity of caring for patients with disabling diseases.<sup>25</sup> This differential burden in the distribution of the roles of informal primary caregivers between women and men in patient care is a fact.<sup>26</sup> However, this does not mean it is an activity exclusively by women. However, there is a connotation of feminization in the role of the caregiver, where the unemployed woman, generally with a lower educational level, is the one who is responsible for domestic tasks, care, and support of a family member with limitations in the activity.<sup>26-28</sup> In this sense, it has been observed that women assume the role of the caregiver as a moral and natural commitment framed by emotional issues. The fact is that informal care work constitutes a scenario of gender inequality in which a woman simultaneously plays several roles: mother, wife, worker, and the role of caregiver. This significantly affects her social and personal life and, why not say it, her health<sup>28</sup> (see Table 1).

**Table no1. Profile of the informal primary caregiver of patients with activity limitations.**

Patient's illness	Age of informal primary caregiver	Sex	Education	Country	Reference
Patients with impaired consciousness	53.4 +/- 12.7 years	F 64.4% M 35.6%	Basic studies 52.8%	Italy	Covelli et al., 2016 <sup>7</sup>
Patients with mental problems	52.08 +/- 14.42 years	F 60% M 40%	Professional Studies 79%	USA	Shaffer et al., 2016 <sup>8</sup>
Stroke patients	47.6 +/- 10.4 years	F 80% M 20%	Mid education	China	Wang et al., 2021 <sup>40</sup>
Patients with Prader Willi Syndrome	49.9 +/- 14.8 years	F 64% M 36%	ND	Argentina	González-Ruiz et al., 2023 <sup>38</sup>
Elder people	47.41±16.8 years	F 84.5% M 15.5%	Primary studies 44.9%	Brazil	Dos Anjos et al., 2014 <sup>41</sup>
Patients with neuromusculoskeletal disease	46.6 ± 13.4 years	F 83.3% M 16.7%	Professional Studies 50%	México	Hijuelos-García et al., 2018 <sup>6</sup>
Elder people	61.5 ±13.1 years	F 66.2% M 33.8%	Mid (32.5%) or primary (26.45%) education	Spain	Perpiñá-Galvañ et al., 2019 <sup>39</sup>

ND= no determined\*(10)

#### **IV. Burnout in the informal primary caregiver**

The term “overload” or Burnout syndrome refers to the discomfort and stress that informal primary caregivers experience when facing immediate stressors typical of the performance of care and the deterioration that this presents when assisting the patient with limitation in activity during an indeterminate period without rest.<sup>29,30</sup> In general, caregivers are in charge of patients from diagnosis. From this point on, they carry out pertinent actions to ensure the well-being of the person in their care, dedicating much of their time to this role. This leads to the development of a perception of poor health, deterioration in the quality of life, and various physical, psychological, and social problems over time, causing care to become a stressor that negatively impacts the caregiver—increasing the probability of causing overload.<sup>30,31</sup> Informal primary caregiver overload syndrome is characterized by a state of emotional exhaustion, stress, and tiredness.<sup>32</sup> It has also been reported that caregivers lack sleep and time for themselves, have financial difficulties (lower income and higher expenses), and experience decreased social and leisure activities. In such a way, with those above, the informal primary caregiver is subjected to physical, psychological, social, and economic stress that can impact their quality of life and health.<sup>31,32</sup>

Caring for a family member with activity limitations exceeds the caregiver's own physical and emotional capacity, which leads to a chronic stressful state that generates overload and burnout. It is a state that threatens the physical and mental health of the caregiver due to the persistent difficulty of caring and the physical, psychological, and emotional problems that he or she may experience. It has been reported that many informal primary caregivers have dedicated between 5 and 10 years to caring for a family member; this care occurs during the day and night.<sup>33-35</sup> Due to the large time dedicate to care, they are considered vulnerable because, as mentioned above, caring for a family member represents important material, economic, social, and health costs, producing overload or burnout syndrome.<sup>34-36</sup> Table 2 shows the time of care and the level of overload or burnout experienced by informal primary caregivers.

**Table no2. Patient care time and informal primary caregiver overload**

Reference	Years of care	Hours of daily care	Primary caregiver overload
Figueiredo et al., 2022 <sup>34</sup>	> 3 years	>12 hours day	45% of caregivers presented overload

Dos Anjos et al., 2014 <sup>41</sup>	6-10 years	9-18 hours day	47% of caregivers presented overload
Wang et al., 2021 <sup>40</sup>	>5 years	>12 hours day	48.2% of caregivers presented overload

It has also been reported that inflexible work schedules and interruptions due to caregiving responsibilities correlated with feelings of burden or burnout. Caregiving wives were more likely than sons to present with depressive symptoms and loss of general health. These results may be due to advancing age and declining physical health, as well as the likelihood that a spouse will live in the same household as the person with a disability and assume a more significant burden of caregiving responsibilities than a spouse would typically assume.

### V. Depression in the informal primary caregiver

Caregivers constitute a population at high risk of suffering emotional disturbances, given the constant demands of caring for a family member with activity limitations. The mental health of informal primary caregivers has been reported to be affected.<sup>37</sup> One of the negative consequences of caregiving is depressive and anxious symptoms.<sup>23</sup> However, not all caregivers present depressive symptoms. Some studies have found associations between the variables overload, fatigue, stress, anxiety, and depression.<sup>23,38</sup> Additionally, caregiver burnout was associated with worse health.

Other studies report that the main alterations that the caregiver presents are depression, anxiety, and insomnia as a manifestation of their emotional stress. Of them, the most common is depression. For example, a study reported that 61% of informal primary caregivers of people with Prader-Willi syndrome presented overload, 32% anxiety, and 40% depression.<sup>38</sup> Notably, another study found that 41.6% of informal primary caregivers of patients with cancer or neurodegenerative diseases presented burnout, 48.1% anxiety, and 18.2% depression.<sup>39</sup> Also, a study carried out on informal primary caregivers of stroke patients showed overload in 21% of them. While 20% of caregivers suffer from anxiety and depression.<sup>40</sup> The consequences of the caregiver's psychological problems greatly influence the individual and family level and, most importantly, the care of the patient with activity limitations. The existence of a high correlation between overload and the depression index in the informal primary caregiver is consistent in the literature, regardless of the variability in the type of studies, since they were carried out in patients with autism, chronic pain, and neurological disorders, neuromusculoskeletal diseases, or a disability due to adulthood. These results indicate that having a close relationship with a patient who has a disability contributes to the informal primary caregiver's feelings of overload and contributes as a risk factor for him or her to develop depressive symptoms. In these studies, associations have been identified between depressive symptoms and the caregiver's life factors, including the quality of the caregiver's sleep, the duration of caregiving, the type of activity limitation, financial problems, and the overload experienced by the caregiver. For example, Koyanagui et al. in 2018, in a meta-analysis study, they found that the caregiver's problems falling asleep increased the risk of depressive symptoms.<sup>42</sup> López et al. in 2016, found a correlation between the limitation in the patient's activity and the depression index in the informal primary caregiver ( $r=0.63$ ,  $p=0.0048$ ).<sup>28</sup> Navarro-Sandoval et al. in 2017, they reported that more than 50% of caregivers presented overload (mild and intense); of these, 32.9% presented mild depressive indices and 11.8 moderate indices.<sup>43</sup> In this context, the analysis of correlations reveals that intense caregiver overload is significantly associated with the depression index (Table 3).

**Table no3. Association of overload experienced by the caregiver and depressive symptoms**

Type of limitation on activity	Correlation Overload and depression	reference
Patients with cancer and neurodegenerative diseases	$R^2=0.524$ (linear regression)	Perpiñá-Galvañ et al., 2019 <sup>39</sup>
Patients with neuromusculoskeletal disease	$r= 0.72$ ; $p=0.0007$	Dzul-Gala et al., 2018 <sup>27</sup>
Alzheimer's patients	$r= 0.59$ ; $p=0.001$	Coffman et al., 2017 <sup>44</sup>
Elderly patients	$r= 0.417$ ; $p<0.001$	Wang et al., 2016 <sup>45</sup>

### VI. Future perspectives

Although it has been reported that the presence of a limitation in patients' activity is a source of overload and depression in the informal primary caregiver, several factors can influence the presence of these

symptoms. Among them, the duration of care and the social and economic aspects of the caregiver have been reported.

Identifying each of the factors that affect the physical and psychological health of the caregiver can not only reduce caregiver stress but can also help patients recover. For this reason, appropriate interventions aimed at their psychosocial, physical, and health needs are required to reduce the risks that can be caused by caring for a family member with activity limitations. Several associations have been identified between depressive symptomatology and life factors, including caregiver sleep quality, overload, duration of caregiving, unemployed caregiver, financial problems, and female sex. In this context, the health of caregivers can be improved by strengthening the psychological and psychosocial environment, as subjective burden and lack of positive aspects of caregiving have been found to lead to poorer health. However, a better understanding of each factor affecting caregivers' long-term health status is required before a helpful intervention strategy can be devised.

On the other hand, some studies have suggested that psychosocial interventions for primary caregivers can help improve overall quality of life.<sup>47,48</sup> In this review, some factors involved in overload and their relationship with depressive symptoms of the informal primary caregiver were identified. Due to the emotional and physical impact that occurs on the informal primary caregiver, psychological support is essential. Some studies have carried out interventions to support informal primary caregivers. However, the participation of caregivers is low.<sup>49,50</sup> This is because many of them have difficulties leaving home. Therefore, internet-based interventions can be an excellent option to support each caregiver. In this sense, some studies suggest that Internet interventions for informal primary caregivers of patients with activity limitations improve depressive symptoms, overload, and stress.<sup>23,51,52</sup>

On the other hand, it is essential to mention that from the moment the treatment of a patient with a chronic illness or with limitation in activity begins, the support of his family or informal primary caregiver is essential, where information must be provided. To the latter about their family member's illness so that they become aware of the illness and can begin with management and coping strategies since this will favor the work of care and reduce overload and depressive symptoms. In addition, it is crucial to make the caregiver aware that caring for another person should not affect or interfere with the performance of their activities or neglect their health. The caregiver must attend to their physical, social, leisure, and productivity needs, balancing them and their satisfaction with care performance. The quality of care you provide to your family members will depend mainly on their excellent physical, mental, and emotional health. Finally, we consider that work should be done to make the primary caregiver aware of how important it is to share the care tasks with other family members and not fall into the mistake that the caregiver is the only one who can or should attend to the child's needs. In this way, we will contribute to caring for the caregiver and the same person with illness and activity limitations.

## References

- [1]. World Health Organization. World Bank . World Report On Disability. WHO; Geneva, Switzerland: 2011. <https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/world-report-on-disability>
- [2]. GBD 2017 Disease And Injury Incidence And Prevalence Collaborators. Global, Regional, And National Incidence, Prevalence, And Years Lived With Disability For 354 Diseases And Injuries For 195 Countries And Territories, 1990-2017: A Systematic Analysis For The Global Burden Of Disease Study 2017. *Lancet*. 2018 Nov 10;392(10159):1789-1858. Doi: 10.1016/S0140-6736(18)32279-7. Epub 2018 Nov 8. Erratum In: *Lancet*. 2019 Jun 22;393(10190):E44. PMID: 30496104; PMCID: PMC6227754.
- [3]. Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver Burden: A Clinical Review. *JAMA*, 311(10), 1052–1060. <https://doi.org/10.1001/jama.2014.304>
- [4]. Cheng S. T. (2017). Dementia Caregiver Burden: A Research Update And Critical Analysis. *Current Psychiatry Reports*, 19(9), 64. <https://doi.org/10.1007/s11920-017-0818-2>
- [5]. Sun V, Raz DJ, Kim JY. Caring For The Informal Cancer Caregiver. *Curr Opin Support Palliat Care*. 2019 Sep;13(3):238-242. Doi: 10.1097/SPC.0000000000000438. PMID: 31157656; PMCID: PMC6669089.
- [6]. Hijuelos García NA, Ortiz Campos A, Bolaños C, Tun Colonia JA, Salgado Burgos H, Arcila Novelo RR, Pérez Padilla EA. Desempeño Ocupacional Y Satisfacción De Los Cuidadores Primarios Informales De Pacientes Con Limitación En La Actividad. *Revista Iberoamericana De Las Ciencias De La Salud* 2018;7(13):1-32.
- [7]. Covelli V, Sattin D, Giovannetti AM, Scaratti C, Willems M, Leonardi M. Caregiver's Burden In Disorders Of Consciousness: A Longitudinal Study. *Acta Neurol Scand*. 2016 Nov;134(5):352-359. Doi: 10.1111/Ane.12550. Epub 2016 Jan 8. PMID: 26748540.
- [8]. Kelly M. Shaffer, Youngmee Kim & Charles S. Carver (2016) Physical And Mental Health Trajectories Of Cancer Patients And Caregivers Across The Year Post-Diagnosis: A Dyadic Investigation, *Psychology & Health*, 31:6, 655-674, DOI: 10.1080/08870446.2015.1131826
- [9]. Garcia-Ptacek S, Dahlrup B, Edlund AK, Wijk H, Eriksdotter M. The Caregiving Phenomenon And Caregiver Participation In Dementia. *Scand J Caring Sci*. 2019 Jun;33(2):255-265. Doi: 10.1111/Scs.12627. Epub 2018 Nov 29. PMID: 30488971; PMCID: PMC7432177.
- [10]. Sun, Y., Ji, M., Leng, M., Li, X., Zhang, X., & Wang, Z. (2022). Comparative Efficacy Of 11 Non-Pharmacological Interventions On Depression, Anxiety, Quality Of Life, And Caregiver Burden For Informal Caregivers Of People With Dementia: A Systematic Review And Network Meta-Analysis. *International Journal Of Nursing Studies*, 129, 104204. <https://doi.org/10.1016/j.ijnurstu.2022.104204>
- [11]. Bidwell JT, Lyons KS, Lee CS. Caregiver Well-Being And Patient Outcomes In Heart Failure: A Meta-Analysis. *J Cardiovasc Nurs*. 2017 Jul/Aug;32(4):372-382. Doi: 10.1097/JCN.0000000000000350. PMID: 27617564; PMCID: PMC5346066.

- [12]. Smith, E. R., Perrin, P. B., Tyler, C. M., Lageman, S. K., & Villaseñor, T. (2019). Parkinson's Symptoms And Caregiver Burden And Mental Health: A Cross-Cultural Mediation Model. *Behavioural Neurology*, 2019, 1396572. <https://doi.org/10.1155/2019/1396572>
- [13]. Treanor, C. J., Santin, O., Prue, G., Coleman, H., Cardwell, C. R., O'Halloran, P., & Donnelly, M. (2019). Psychosocial Interventions For Informal Caregivers Of People Living With Cancer. *The Cochrane Database Of Systematic Reviews*, 6(6), CD009912. <https://doi.org/10.1002/14651858.CD009912.pub2>
- [14]. Pindus, D. M., Mullis, R., Lim, L., Wellwood, I., Rundell, A. V., Abd Aziz, N. A., & Mant, J. (2018). Stroke Survivors' And Informal Caregivers' Experiences Of Primary Care And Community Healthcare Services - A Systematic Review And Meta-Ethnography. *Plos One*, 13(2), E0192533. <https://doi.org/10.1371/journal.pone.0192533>
- [15]. McMullan J, Lohfeld L, Mcknight AJ. Needs Of Informal Caregivers Of People With A Rare Disease: A Rapid Review Of The Literature. *BMJ Open*. 2022 Dec 12;12(12):E063263. Doi: 10.1136/bmjopen-2022-063263. PMID: 36523233; PMCID: PMC9748923.
- [16]. Mulroy, S., Robertson, L., Aiberti, K., Leonard, H., & Bower, C. (2008). The Impact Of Having A Sibling With An Intellectual Disability: Parental Perspectives In Two Disorders. *Journal Of Intellectual Disability Research : JIDR*, 52(Pt 3), 216–229. <https://doi.org/10.1111/j.1365-2788.2007.01005.x>
- [17]. Hogan, U., Bingley, A., Morbey, H., & Walshe, C. (2022). The Experience Of Informal Caregivers In Providing Patient Care In Hospitals In Low- And Middle-Income Countries: A Qualitative Meta-Synthesis. *Journal Of Health Services Research & Policy*, 27(4), 321–329. <https://doi.org/10.1177/13558196221101968>
- [18]. Papadakos, J., Samoilo, D., Umakanthan, B., Charow, R., Jones, J. M., Matthew, A., Nissim, R., Sayal, A., & Giuliani, M. E. (2022). What Are We Doing To Support Informal Caregivers? A Scoping Review Of Caregiver Education Programs In Cancer Care. *Patient Education And Counseling*, 105(7), 1722–1730. <https://doi.org/10.1016/j.pec.2021.10.012>
- [19]. Smith, G. C., Egbert, N., Dellman-Jenkins, M., Nanna, K., & Palmieri, P. A. (2012). Reducing Depression In Stroke Survivors And Their Informal Caregivers: A Randomized Clinical Trial Of A Web-Based Intervention. *Rehabilitation Psychology*, 57(3), 196–206. <https://doi.org/10.1037/A0029587>
- [20]. Boyd, R. C., Gerdes, M., Rothman, B., Dougherty, S. L., Localio, R., & Guevara, J. P. (2017). A Toddler Parenting Intervention In Primary Care For Caregivers With Depression Symptoms. *The Journal Of Primary Prevention*, 38(5), 465–480. <https://doi.org/10.1007/S10935-017-0481-8>
- [21]. Araújo, O., Lage, I., Cabrita, J., & Teixeira, L. (2015). Intervention In Informal Caregivers Who Take Care Of Older People After A Stroke (Incare): Study Protocol For A Randomised Trial. *Journal Of Advanced Nursing*, 71(10), 2435–2443. <https://doi.org/10.1111/Jan.12697>
- [22]. El-Jawhri A, Greer JA, Pirl WF, Park ER, Jackson VA, Back AL, Kamdar M, Jacobsen J, Chittenden EH, Rinaldi SP, Gallagher ER, Eusebio JR, Fishman S, Vandusen H, Li Z, Muzikansky A, Temel JS. Effects Of Early Integrated Palliative Care On Caregivers Of Patients With Lung And Gastrointestinal Cancer: A Randomized Clinical Trial. *Oncologist*. 2017 Dec;22(12):1528-1534. Doi: 10.1634/theoncologist.2017-0227. Epub 2017 Sep 11. PMID: 28894017; PMCID: PMC5728034.
- [23]. Lopez L, Vázquez FL, Torres AJ, Otero P, Blanco V, Díaz O, Páramo M. Long-Term Effects Of A Cognitive Behavioral Conference Call Intervention On Depression In Non-Professional Caregivers. *Int J Environ Res Public Health*. 2020 Nov 11;17(22):8329. Doi: 10.3390/ijerph17228329. PMID: 33187116; PMCID: PMC7696761.
- [24]. Wang Y, Hou D, Wu X, Qiu L, Chen H, Xin J, Yan Z, Sun M. An Intensive Education Program For Caregivers Ameliorates Anxiety, Depression, And Quality Of Life In Patients With Drug-Resistant Temporal Lobe Epilepsy And Mesial Temporal Sclerosis Who Underwent Cortico-Amygdalohippocampectomy. *Braz J Med Biol Res*. 2020;53(9):E9000. Doi: 10.1590/1414-431x20209000. Epub 2020 Jul 17. PMID: 32696820; PMCID: PMC7372948.
- [25]. Radcliffe C, Sam A, Matos Q, Antwi S, Amisshah K, Alhassan A, Ofori IP, Xu Y, Deng Y, Reynolds NR, Paintsil E; Sankofa Team. Sankofa Pediatric HIV Disclosure Intervention Did Not Worsen Depression Scores In Children Living With HIV And Their Caregivers In Ghana. *BMC Public Health*. 2020 Oct 20;20(1):1578. Doi: 10.1186/S12889-020-09678-2. PMID: 33081739; PMCID: PMC7576749.
- [26]. Possin KL, Merrilees JJ, Dulaney S, Bonasera SJ, Chiong W, Lee K, Hooper SM, Allen IE, Braley T, Bernstein A, Rosa TD, Harrison K, Begert-Hellings H, Kornak J, Kahn JG, Naasan G, Lanata S, Clark AM, Chodos A, Gearhart R, Ritchie C, Miller BL. Effect Of Collaborative Dementia Care Via Telephone And Internet On Quality Of Life, Caregiver Well-Being, And Health Care Use: The Care Ecosystem Randomized Clinical Trial. *JAMA Intern Med*. 2019 Dec 1;179(12):1658-1667. Doi: 10.1001/jamainternmed.2019.4101. PMID: 31566651; PMCID: PMC6777227.
- [27]. Dzul-Gala F, Tun-Colonia JA, Arankowsky-Sandoval G, Et Al. Relación Entre La Sobrecarga Y El Índice Depresivo De Cuidadores Primarios De Pacientes Con Enfermedades Neuromusculares. *Rev Biomed*. 2018;29(3):61-69.
- [28]. Buenfil Díaz, B. K., Hijuelos García, N. A., Hijuelos García, N. A., Carlos Pineda, J., Carlos Pineda, J., Salgado Burgos, H., Salgado Burgos, H., Pérez Padilla, E. A., & Pérez Padilla, E. A. (2016). Depresión En Cuidadores Primarios Informales De Pacientes Con Limitación En La Actividad / Depression In Primary Informal Caregivers Of Patients With Activity Limitations. *RICS Revista Iberoamericana De Las Ciencias De La Salud*, 5(10), 148 - 173. Recuperado A Partir De <https://www.rics.org.mx/index.php/RICS/Article/View/42>
- [29]. Van Den Wijngaert, M. A., Vernooij-Dassen, M. J., & Felling, A. J. (2007). The Influence Of Stressors, Appraisal And Personal Conditions On The Burden Of Spousal Caregivers Of Persons With Dementia. *Aging & Mental Health*, 11(6), 626–636. <https://doi.org/10.1080/13607860701368463>
- [30]. Lapid, M. I., Atherton, P. J., Kung, S., Sloan, J. A., Shahi, V., Clark, M. M., & Rummans, T. A. (2016). Cancer Caregiver Quality Of Life: Need For Targeted Intervention. *Psycho-Oncology*, 25(12), 1400–1407. <https://doi.org/10.1002/Pon.3960>
- [31]. Ricou B, Gigon F, Durand-Steiner E, Liesenberg M, Chemin-Renais C, Merlani P, Delaloye S. Initiative For Burnout Of ICU Caregivers: Feasibility And Preliminary Results Of A Psychological Support. *J Intensive Care Med*. 2020 Jun;35(6):562-569. Doi: 10.1177/0885066618768223. Epub 2018 Apr 11. PMID: 29642743.
- [32]. Wilz, G., & Barskova, T. (2007). Evaluation Of A Cognitive Behavioral Group Intervention Program For Spouses Of Stroke Patients. *Behaviour Research And Therapy*, 45(10), 2508–2517. <https://doi.org/10.1016/j.brat.2007.04.010>
- [33]. Liu, Y., Dokos, M., Fauth, E. B., Lee, Y. G., & Zarit, S. H. (2019). Financial Strain, Employment, And Role Captivity And Overload Over Time Among Dementia Family Caregivers. *The Gerontologist*, 59(5), E512–E520. <https://doi.org/10.1093/geront/gnz099>
- [34]. Figueiredo, L. C., Barbosa, G. C., Monteiro, D. Q., Martins, G., Silva, A. F. O. E., Ruy, L. F. T., Sato, T. O., & Gratao, A. C. M. (2022). Factors Associated With Symptoms Of Physical And Emotional Burden In Informal Caregivers Of The Elderly. *Revista Brasileira De Enfermagem*, 75(Suppl 4(Suppl4)), E20210927. <https://doi.org/10.1590/0034-7167-2021-0927>
- [35]. Terassi, Marielli, Et Al. "Influence Of Burden, Stress And Depressive Symptoms On The Health Of Older Adult Caregivers: A Longitudinal Study." *Escola Anna Nery* 27 (2023): E20220437.

- [36]. Santos-Orlandi, A. A. D., Brigola, A. G., Ottaviani, A. C., Luchesi, B. M., Souza, É. N., Moura, F. G., Zacarin, J. F., Terassi, M., Oliveira, N. A., &Pavarini, S. C. I. (2019). Elderly Caregivers Of The Elderly: Frailty, Loneliness And Depressive Symptoms. *Revista Brasileira De Enfermagem*, 72(Suppl 2), 88–96. <https://doi.org/10.1590/0034-7167-2018-0137>
- [37]. De Vugt, M. E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I., Jolles, J., &Verhey, F. R. (2004). Do Caregiver Management Strategies Influence Patient Behaviour In Dementia?. *International Journal Of Geriatric Psychiatry*, 19(1), 85–92. <https://doi.org/10.1002/Gps.1044>
- [38]. González Ruiz Y, Gerk A, Stegmann J. Mental Health Impact On Primary And Secondary Prader-Willi Syndrome Caregivers. *Child Care Health Dev*. 2023 Aug 23. Doi: 10.1111/Cch.13162. EpubAhead Of Print. PMID: 37614065.
- [39]. Perpiñá-Galvañ J, Orts-Beneito N, Fernández-Alcántara M, García-Sanjuán S, García-Caro MP, Cabañero-Martínez MJ. Level Of Burden AndHealth-Related Quality Of Life In Caregivers Of Palliative Care Patients. *Int J Environ Res Public Health*. 2019 Nov 29;16(23):4806. Doi: 10.3390/Ijerp16234806. PMID: 31795461; PMCID: PMC6926780.
- [40]. Wang J, Liu J, Li L, Man J, Yue S, Liu Z. Effect Of Education And Muscle Relaxation Program On Anxiety, Depression And Care Burden In Caregivers Of Acute Stroke Survivors: A Randomized, Controlled Study. *Medicine (Baltimore)*. 2021 Jan 29;100(4):E24154. Doi: 10.1097/MD.00000000000024154. PMID: 33530205; PMCID: PMC7850736.
- [41]. Dos Anjos AC, Zago MM. RessignificaçãoDa Vida Do Cuidador Do PacienteIdoso Com Câncer [RessignificationOf Life Of Caregivers Of Elderly Patients With Cancer]. *Rev Bras Enferm*. 2014 Sep-Oct;67(5):752-8. Portuguese. Doi: 10.1590/0034-7167.2014670512. PMID: 25517669.
- [42]. Koyanagi A, DeVylderJE, Stubbs B, Carvalho AF, Veronese N, Haro JM, Santini ZI. Depression, Sleep Problems, And Perceived Stress Among Informal Caregivers In 58 Low-, Middle-, And High-Income Countries: A Cross-Sectional Analysis Of Community-Based Surveys. *J Psychiatr Res*. 2018 Jan;96:115-123. Doi: 10.1016/J.Jpsychires.2017.10.001. Epub2017 Oct 5. PMID: 29031131.
- [43]. Navarro-Sandoval, Cristina, Et Al. "Depresión Y Sobrecarga En Cuidadores Primarios De Pacientes Geriátricos Con Dependencia Física De La UMF 171." *RevistaMédica Del Instituto Mexicano Del Seguro Social* 55.1 (2017): 25-31.
- [44]. Coffman I, Resnick HE, Lathan CE. Behavioral Health Characteristics Of A Technology-Enabled Sample Of Alzheimer's Caregivers With High Caregiver Burden. *Mhealth*. 2017 Aug 29;3:36. Doi: 10.21037/Mhealth.2017.08.01. PMID: 28894746; PMCID: PMC5583040.
- [45]. Wang, Jing, Et Al. "Mobile And Wearable Technology Needs For Aging In Place: Perspectives From Older Adults And Their Caregivers And Providers." *Nursing Informatics* 2016. IOS Press, 2016. 486-490.
- [46]. Khare S, Rohatgi J, Bhatia MS, Dhaliwal U. Burden And Depression In Primary Caregivers Of Persons With Visual Impairment. *Indian J Ophthalmol*. 2016 Aug;64(8):572-7. Doi: 10.4103/0301-4738.191493. PMID: 27688278; PMCID: PMC5056544.
- [47]. Treanor CJ, Santin O, Prue G, Coleman H, Cardwell CR, O'Halloran P, Donnelly M. Psychosocial Interventions For Informal Caregivers Of People Living With Cancer. *Cochrane Database Syst Rev*. 2019 Jun 17;6(6):CD009912. Doi: 10.1002/14651858.CD009912.Pub2. PMID: 31204791; PMCID: PMC6573123.
- [48]. Qiu D, Hu M, Yu Y, Tang B, Xiao S. Acceptability Of Psychosocial Interventions For Dementia Caregivers: A Systematic Review. *BMC Psychiatry*. 2019 Jan 14;19(1):23. Doi: 10.1186/S12888-018-1976-4. PMID: 30642300; PMCID: PMC6332684.
- [49]. Borrescio-Higa F, Valdés N. The Psychosocial Burden Offamilies With Childhood Blood Cancer. *Int J Environ Res Public Health*. 2022 Jan 5;19(1):599. Doi: 10.3390/Ijerp19010599. PMID: 35010854; PMCID: PMC8744617.
- [50]. Orrell M, Yates L, Leung P, Kang S, Hoare Z, Whitaker C, Burns A, Knapp M, Leroi I, Moniz-Cook E, Pearson S, Simpson S, Spector A, Roberts S, Russell I, De Waal H, Woods RT, Orgeta V. The Impact Of Individual Cognitive Stimulation Therapy (Icst) On Cognition, Quality Of Life, Caregiver Health, And Family Relationships In Dementia: A Randomised Controlled Trial. *PlosMed*. 2017 Mar 28;14(3):E1002269. Doi: 10.1371/Journal.Pmed.1002269. PMID: 28350796; PMCID: PMC5369684.
- [51]. Cristancho-Lacroix V, Wrobel J, Cantegreil-Kallen I, Dub T, Rouquette A, Rigaud AS. A Web-Based Psychoeducational Program For Informal Caregivers Of Patients With Alzheimer's Disease: A Pilot Randomized Controlled Trial. *J Med Internet Res*. 2015 May 12;17(5):E117. Doi: 10.2196/Jmir.3717. PMID: 25967983; PMCID: PMC4468784.
- [52]. Lai C, Holyoke P, Plourde KV, Décary S, Légaré F. What Older Adults And Their Caregivers Need For Making Better Health-Related Decisions At Home: A Participatory Mixed Methods Protocol. *BMJ Open*. 2020 Nov 9;10(11):E039102. Doi: 10.1136/Bmjopen-2020-039102. PMID: 33168556; PMCID: PMC7654109.