Journal of Positive Psychology & Wellbeing
2022, Vol. 6, No. 2, 1884 – 1900

http://journalppw.com
ISSN 2587-0130

The experience of informal caregivers of children with disabilities: objective and subjective burden - a systematic review

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Abstract:

Objective: Describe the experience of informal caregivers of children with disabilities to understand the burden of caregiving. **Methods:** This article uses the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), we defined study inclusion criteria using a PICOS scheme. Essentially, we included only studies that reported data on documents related to caregivers: fathers and mothers of children, adolescents, and adults (P = Population) who diagnosed with any type of disability (I = Intervention), compared to formal caregivers (C = Comparison), and that these parents had the experience of being a caregiver (O = Outcome). In terms of study design, studies with any type of design were included to get a broader view of how existing research has addressed the issue, and a full understanding of the implications of informal caregiving (S = Study Design). The thematic research was carried out in the thesauri of MeSH, my NCBI, PubMed and Scopus. The MeSH terms were used in databases the search was guided by the terms suggested in their Thesaurus tool**. Results:** The initial search retrieved 136 records. After duplicates were removed (n = 86), the remaining 50 records (titles and abstracts) were screened against our study inclusion criteria, resulting in the exclusion of another 30. Titles not relevant or unrelated to the topic; titles mentioning disability, but not parents; those alluding to formal care; those describing formal medical or nursing care; and those describing nursing caregivers were excluded. **Conclusion:** A promising avenue for addressing informal caregiving emerges by delving into the need to propose interventions that improve the physical and mental health of caregivers. These interventions should urgently focus on the mental health of mothers, who present greater psychological distress than fathers. It is necessary to propose programs that reveal the need to care for the caregiver, according to the subjective burden (stress); and programs that promote the care of children with disabilities (objective burden), who may be affected by the mental health of their caregiver.

Keywords: informal caregivers, caregivers burden, stress, disabilities, experiences.

1. INTRODUCTION

Informal caregivers (López, 2016; Cantillo Monjo et al., 2018), also called primary (Ruiz Ríos et al., 2012), family (Arias-Rojas et al., 2021) or principal (Encuesta de Calidad de vida -ECV, 2021), occupy an essential place in the care of persons with disabilities, assuming the main, but not professional, responsibility for caregiving. The experience of an informal caregiver acquires great relevance for the person being cared for, so it is considered important to study caregiving, to the same extent that disability is studied (García-Cantillo et al., 2021). In addition, informal caregivers constitute a population that is neither remunerated nor made visible (Encuesta de Calidad de vida -ECV, 2021), since it is considered a voluntary work, lacking labor and legislative value (García Cantillo y Reyes-Ruiz, 2021;García-Cantillo et al., 2021). In this review, it is important to highlight that the concept of informal caregiver of López (2016) and Cantillo (Cantillo Monjo et al., 2018) is assumed to differentiate it from the formal caregiver of Cahuana (Cahuana, 2016) (specialized caregivers) and to identify mothers and fathers who in a non-professional way assume the work of caregiver of a diagnosed child. Thus, the informal caregiving experience produces a wear and tear on the physical and emotional health of the caregiver (Lambert et al., 2017). Therefore, informal caregivers have a responsibility, which leads them to establish a bond with their diagnosed child (López et al., 2019).

According to Mathias et al. (2019), informal caregiving is considered a woman's activity, recognizing the gender inequality in caring for a child with a disability, a situation that leads women to be the main historical support for the task of caregiving (Bathyány, 2021). However, there are differences in the caregiving experiences for male and female caregivers, where women tend to feel hopelessness, and men assume a positive attitude (Mathias et al., 2019).

In this sense, the diagnosis of disability in a child generates an impact on families, which implies the presence of a caregiver, "since there is always someone who is taking care (...) and that someone is the woman" (Montaño, 2021). However, according to Oñate and Calvete (Oñate y Calvete, 2017), within the family, although it is the woman who usually provides care, there are also men who dedicate themselves to this task. In this order of ideas, the appearance and increase of the informal male caregiver assumed by the fathers of children with disabilities is subject to the progressive incorporation of women into the labor market (Barreto et al., 2021), therefore, in everyday life, those who also assume the role of informal male caregiver are the husbands of working women.

Zamarripa et al. (2017), state that the role of an informal caregiver goes beyond physical effort; the caregiver is even involved in the emotional area, generating a bond between the caregiver and the person being cared for (López et al., 2019). In addition, given the lack of support received, the informal caregiving experience, according to Kumar and Gupta (2014) generates stress and poses changes in the adaptation to the new family scenario of the informal caregiver. Generating an impact that, according to Crespo and Ribas (2015), alters the caregiver's life and disrupts his or her relationships. This impact is also reflected in the economic and occupational spheres. Thus, caregiving disrupts the financial area (Zamarripa et al., 2017) due to the economic costs in the life of the informal caregiver, which may be direct (expenses arising from caregiving) or indirect (loss of income due to leaving the labor market).

Some authors (Sarris et al., 2020) consider that the study of informal caregiving has not been investigated in depth, since research focuses on disability, leaving aside the informal caregiver (García-Cantillo et al., 2021). However, the need to emphasize this population is recognized due to the burden that caregiving produces (Lambert et al., 2017); that is, a physical and mental wear and tear that can end up affecting both the person with disability and the caregiver. The studies found reflect the impact of informal caregiving from the perspective of the objective burden (in relation to the problems generated by the disability in the child) and the subjective burden (in relation to the anguish and stress resulting from long hours of caregiving) produced by the experience of caring for children with disabilities. Caregiver burden is important in the study of informal caregiving, because it refers to "the quantifiable cost, such as the costs of care and the loss of free time for caregivers" (Mathias et al., 2019), or, in other words, the wear and tear produced by the intensity of the hours, the days of care, the bond between caregiver and cared-for person, which disrupts the intimate and social life of a mother or father caregiver.

2. METHOD

This article uses the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) system of Moher, et al. and The PRISMA Group (2009) whose graphical reporting is specified in Figure 1.

2.1. Study Inclusion Criteria

We defined study inclusion criteria using a *PICOS* scheme, as adapted from Riva et al. (2012). Essentially, we included only studies that reported data on documents related to caregivers: fathers and mothers of children, adolescents, and adults **(P = Population)** who diagnosed with any type of disability **(I = Intervention),** compared to formal caregivers **(C = Comparison),** and that these parents had the experience of being a caregiver (**O = Outcome).** In terms of study design, studies with any type of design were included to get a broader view of how existing research has addressed the issue, and a full understanding of the implications of informal caregiving **(S = Study Design).**

2.2 Search Strategy and Study Selection

The thematic research was carried out in the thesauri of MeSH, my NCBI, PubMed and Scopus. The MeSH terms were used in databases the search was guided by the terms suggested in their Thesaurus tool. The following equations defined the search for articles on informal caregivers of children with disabilities:

(Caregivers experiences [MeSH terms] OR Caregiver burden [MeSH terms] AND Caregivers stress [MeSH terms] AND disability [MeSH terms] AND psychosocial adaptation). Moreover, we checked the reference lists of all included articles. Results (titles and abstracts) were screened independently by two reviewers (the first and second authors), and consensus was reached about eventual article inclusion, which were organized using the bibliographic reference software ®Mendely reference manager.

2.3 Data Synthesis To synthesize data from included articles, we provided a summary of each study. For each study, we described participant demographics and methodological details, followed by the main efficacy findings.

3. RESULTS

Fig. (1) presents the PRISMA diagram showing the steps followed from initial identification to the final inclusion of studies for review. The initial search retrieved 136 records. After duplicates were removed (n = 86), the remaining 50 records (titles and abstracts) were screened against our study inclusion criteria, resulting in the exclusion of another 30. Titles not relevant or unrelated to the topic; titles mentioning disability, but not parents; those alluding to formal care; those describing formal medical or nursing care; and those describing nursing caregivers were excluded.

Fig. (1). PRISMA flow diagram for reviewed studies.

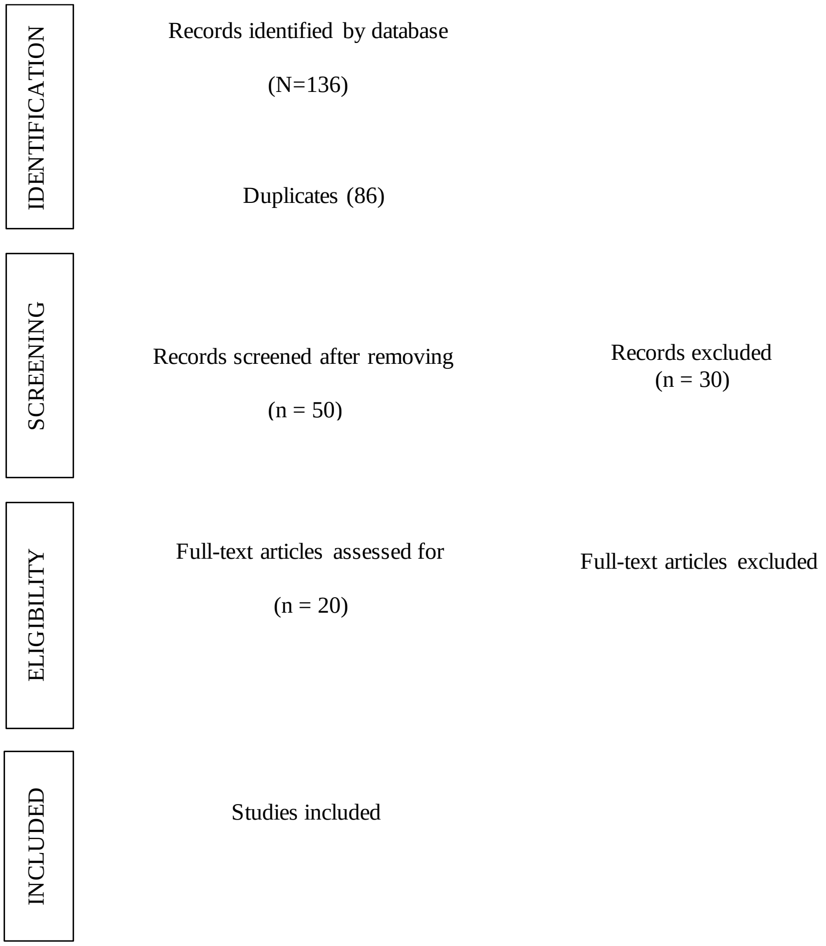

Table 1. Characteristics of studies included in the systematic review.

Table 1 Combinations of MeSH Terms and Eligible Results							
Year	***Country***	***Type of study***	***Sample***	***Measures***	***Results***	***Conclusions***	***References***
2018	North India	Phenomenological	18	In-depth interview.	**High stress, high tension, hostility**. Embodied experiences of **psychological and social distress** were consistently	Somatic symptoms of **stress** and **gender** findings.	[11]

					described by **women**, but not by **men.**		
2016	Holland	Longitudinal	126	Caregiver strain was assessed with the Caregiver Strain Index (CSI).	Passive coping style, increased **symptoms of anxiety** and feeling less supported affect the caregiver: **high tension.**	Symptoms of anxiety and perceived **quality of care for the caregiver.**	[35]
2014	India	Cross	80	Hamilton Depression Rating Scale, Multidimensional Scale for Perceived Social Support, and Zarit Burden Interview.	The **caregiver burden** is significantly **higher for women.**	The caregiver burden is low when social support is present. **Early psychosocial intervention** especially in the **vulnerable family caregivers.**	[17]
2014	Sri Lanka	Cross-sectional	375	Caregiver Difficulties Scale and multivariate linear regression was used to assess **stress, coping,** and **caregiver burden.**	Low income and rural residence **males** are related with a **caregiver burden**, while **spousal support is associated with a lower burden.**	**Psychosocial interventions** focused on assessing and improving social **support for caregivers** may help families at high risk for caregiver distress **to minimize negative outcomes.**	[32]
2012	Milan, Italy	Observational multi-centre study	477	Caregiver Needs Assessment, Family Strain Questionnaire, Short Form 12, Spielberger State Trait Anxiety Inventory-Y,	**High level of depressive** symptoms in caregivers and high **burden** related **to providing care.**	Issues with **social interactions** and **emotional burden.** **Coping strategies** most frequently used: **acceptance, return to religion, positive reinterpretation, and planning.**	[22]

				Beck Depression Inventory and Coping Orientations to Problem Experiences.			
2018	Cincinnati, USA	Descriptive correlational study	205	Interview and survey.	**The care facilitators generate a positive attitude,** the result of care.	**Caregivers can prioritize the concerns related to the child's** well-being. Importance of **psychological and social support for caregivers**.	[40]
2017	Ghana, India and the Russian Federation	Cross-sectional	903 Ghana (n=143) India (n=490) and Russia (n=270)	Then, quality of life (QOL), perceived stress, depression, self-rated health (SRH) and health risk factors were compared.	Caregivers with **moderate or high caregiver burden reported lower quality of life and higher perceived stress** than those with low **caregiver burden**.	**Initiatives and programs** are **needed to ensure that caregivers** in low- and middle-income countries **can fulfill their role** without **compromising their own health**	[9]
2010	Birmingam, UK	Cross	42	The Pittsburgh Sleep Quality Index, and measures of parental stress, child problem behaviors, and social support.	The strongest predictor of poor sleep quality was **parental stress.**	**Parental stress is associated with poor sleep quality** in parents of children with developmental disabilities.	[37]
2017	South Korea	Correlational	108	Caregiving-Related Stress.	**Caregiving stress** showed a significant	A variety of **intervention programs** need to be planned and	[39]

				Korean Depression Scale. Rosenberg's Self-Esteem Scale (1985).	**positive correlation** with **depression** and with **economic and psychological stress**, and it showed a significant **negative correlation** with **self-esteem.**	implemented **for family caregivers** at the national and municipal levels.	
2017	Brazil	Exploratory descriptive study, with a cross-sectional design	168	Questionnaires about the profile and burden of the caregivers (Zarit Burden Interview)	The caregivers presented a **moderate burden.**	Caregivers of children or adolescents with Down Syndrome showed a **moderate burden** compared with caregivers of children or adolescents **without disabilities**.	[41]
2016	New Delhi.	Cross-sectional	51	Caregiver Burden Scale and depression (Centre for Epidemiologic Studies Depression Scale).	**Burden correlated** with **degree of disability**. On multiple linear regression, **burden predicted depression.**	**Caregivers merit community support**, **financial benefit**, interventions to diagnose and treat depression, and **training in coping.**	[33]
2016	Peru	Cross-sectional	798,308	Washington Group on Disability Statistics.	**A family member**, usually **female**, was identified as	**Children develop dependence** with the **female caregiver**. **Informal care**, probably **female** and provided by relatives, is very common.	[23]

					a **caregiver** in 94.3%. **Higher the education level**, the lesser the overall **disability burden.**		
2010	Seattle, USA	Cross-sectional	1238	Johnson & Johnson Stress Profile. Kessler psychological distress scale. Zarit burden Interview. Brief Resilient, and Coping Scale.	**A high level of caregiving demands** reported by 50.4% of **women caring** for one or more relatives. **Stress level higher** than 90% of the general population.	**Caregivers present psychological distress**, and it is associated with **low self-esteem and a low sense of control** related to feelings of lack of control over life events.	[38]
2010	Quebec, Canada	Cross-sectional	9467	National Longitudinal Survey of Children and Youth in Canada (1994).	**Physical health problems.**	Caregivers exhibited a greater number of **health and psychosocial issues.**	[42]
2010	Virginia,	An exploratory cross-	112	Online questionnaire	**The well-being of the**	**Caregivers must readily adapt to**	[43]

	USA	sectional design.		s to assess demographic and psychosocial factors.	**caregiver** is related to the perceived vulnerability of the child's health, the satisfaction of the caregiver and the search for benefits. **Maternal caregivers who report high levels of anxiety**, but **do not seek counseling**.	**the ever-changing needs of the child.** Difficulties maintaining **their own level of well-being.**	
2020	Australia	Qualitative interview design with purposive sampling	12	Interview	Caregivers described **the best aspects of their experience:** helping their care recipient remain in their home. **The worst aspects:** referred to	There is a **need for public policies, programs, and health services to better respond to the living, financial and support needs of family caregivers.**	[19]

					the living and financial challenges of the caregiving work.		
2020	Pakistan	A Comparative cross-sectional survey	162	Caregiver Burden Inventory	**Parents** of **intellectually challenged children** need more respite and other services as compared to **hearing impaired children**	Parents of **intellectually challenged** children face more **burden and stress.**	[29]
2020	France, Germany, Spain, and the United Kingdom	Cross-sectional	4 European countries	The Zarit Burden Interview	The severity of the disease was associated with more **time of care** and a **higher burden on the caregivers**.	**The hours of informal care provided** could, therefore, reflect a **quantifiable burden.**	[30]
2020	China	A purposive sample	234	Caregiving Burden Inventory. Perceived Difficulty	Chinese informal caregivers experience **burden** due	**Poor mental health** among caregivers is associated with greater c**aregiving challenges and**	[31]

				Scale, and a modified Chinese Coping Scale.	to their **caregiving responsibilities.**	**burden**s. **Internal coping** helped to buffer but **external coping** worsened **the effect of burdens** on mental health outcomes.	
2020	India	Cross-sectional	101	The Kingston Caregiver Stress Scale.	64.3% of the caregivers had the **severe level of stress.**	**Caregiver's stress** is an important element to determine the **burden and the psychological pressure** a caregiver holds onto.	[36]

A total of 20 articles relevant to the search combinations were found, published between 2010-2020 written in English; Table 1 shows the characteristics of the studies found.

The topic has been investigated the most in India (n=4), and United States (n=3), Italy (n=1), Sri Lanka (n=1), Netherlands (n=1), United Kingdom (n=2), Russia (n=1), Canada (n=1), Korea (n=1), Brazil (n=1), Peru (n=1), Pakistan (n=1), China (n=1), Australia (n=1). Themes of interest were informal caregiving experiences related to stress (n=7); depressive symptoms (n=2); burden (n=7) and experiences about informal caregiving (n=4).

The instruments most used by the authors to measure the degree of burden in informal caregivers was the Zarit Scale. On the other hand, to describe the experiences of informal caregivers, the authors made use of the Interview; they also used the Beck Depression Inventory, because they found depression associated with burden, being this the most used. Likewise, they used the Korean Depression Scale of MS Lee and M. K. Lee. They applied the family stress questionnaire because of the multiple changes that occur in the family because of informal caregiving. The authors made use of the multidimensional scale for Perceived Social Support, taking into account that caregivers who presented less burden are those who had social support; they applied coping questionnaires, because they found stress as a main associated factor; they used the 1996 Johnson and Johnson Adapted Stress Profile and the Kessler Psychological Distress Scale; they also applied the 1985 Rosenberg Self-Esteem Scale and the Pittsburgh Sleep Quality Index, because they found that the strongest predictor of poor sleep quality was the stress of informal caregivers.

DISCUSSION

In response to the questions proposed for the achievement of the objective of this review, it was found that the experiences of male and female caregivers are different (Bernabe-Ortiz et al., 2015) according to: the hourly intensity and the affective commitment (Bernabe-Ortiz et al., 2015) that the mother dedicates to her child (Mathias et al., 2019), which is why they present greater psychological distress (Kumar, 2014). In addition, the authors mention that the aspects associated with the experience of caring for a diagnosed child are stress, support, and caregiving responsibilities (Lambert et al., 2017). Regarding caregiver burden, it is considered that the demanding work of caregiving is a threat to physical and mental health (Zarit et al., 1980; Arias-Rojas et al., 2021), due to the stress and tension it produces (Creemers et al., 2016).

Let's see:

The caregiving experiences

Sarris et al. (2020) considers that the most mentioned aspect in the experience of caregivers of children with disabilities is the bond they have with the person being cared for; however, caregivers report that the existing vital and economic needs cannot be covered by themselves, since this work is not remunerated.

Caregivers report needing support from the state and the health system, due to the time intensity of their work and the little economic and labor support they receive (Sarris et al., 2020).

There are differences in the experiences of male and female caregivers. According to Mathias et al. (2019), they affirm that informal caregiving falls on the shoulders of women, who tend to dedicate hours to caregiving with a greater affective commitment. This contrasts with male caregivers, who increase the strengthening of social ties while caring for their diagnosed child. Lambert et al. (2017) mention that the aspects associated with the experience of caring for a diagnosed child are: stress, support, and caregiving responsibilities. They state that it is a challenge to educate children in the role of caregiver, which produces stress. Likewise, Leonardi et al. (2012), point out the high level of burden of informal caregivers since their daily lives are characterized by limited social relationships. For their part, Bernabe-Ortiz et al. (2016) found that informal caregiving, probably female and provided by relatives, is very common, however, it is inequitable in relation to men, this refers to the emotional bond that is stronger in women.

The caregiver's burden: objective and subjective burden

Informal caregiving work that leads to greater stress is considered instrumental, according to Cascella and García-Orellán (2020), i.e., an informal caregiver tends to be considered as an object and not a subject that provides care for long hours. In this regard, the literature recognizes Zarit's concept of burden (2002), to indicate mental exhaustion in the face of caregiving (Zambrano and Ceballos, 2007), threatening the physical and mental health of the caregiver (Zarit et al., 1980; Arias-Rojas et al., 2021), to relate it to the stressors that the caregiver faces in his or her daily life, which generates difficulties in his or her health.

Kumar and Gupta (2014) also defined the concept of burden as the distress, physical health problems, and deterioration of the family because of caregiving. Objective burden relates to the disabled child, his or her symptoms, behaviors and sociodemographic characteristics, and changes in his or her routine. The subjective burden, on the other hand, is related to the distress and mental health of family members, which is highly affected. In female caregivers who maintain their employment, the caregiver burden is greater (Kumar and Gupta, 2014).

Caregiver burden is also defined as a multidimensional response to physical, psychological, emotional, social and financial stressors, usually associated with the caregiving experience and which may be objective or subjective (Syed et al., 2020), for their part, Aranda et al. (2020) consider that the type of disability is associated with a greater burden for caregivers, so that one of the reasons for caregiver burden is associated with the responsibility that caring for a child demands and with the time of being a caregiver (Sit et al., 2020).

Likewise, Wijesinghe et al. (2015) defined caregiver burden as the caregiver's response to various stressors associated with caregiving. This suggests that a high level of caregiver burden affects the physical and mental health of the caregiver and the person being cared for. In this regard, Khare et al. (2016) state that informal caregivers neglect their own needs, resulting is a burden. And that efforts to address disability rarely target caregivers, furthermore, they mention that caregiver burden is related to the type of disability they care for. On the other hand, with respect to subjective burden, García et al. (2016) report that feelings such as happiness, pride, love, and satisfaction are manifested in response to the behavior of the children towards the caregivers and are perceived as compensating for the caregiver's burden.

Stress in informal caregivers

The stress produced by the experience of caring for children with disabilities is considered high and, in turn, is a generator of tension (Creemers et al., 2016). The stress on caregivers negatively affects their emotional well-being by producing psychological distress and the need for social support (Creemers et al., 2016). According to Ramachandran et al. (2020) caregiver stress is an important element in determining the burden and psychological pressure on a caregiver.

On the other hand, Gallagher et al. (2010) found that parents of children with disabilities had poorer sleep quality and the predictor was stress. In other words, increased caregiver stress can affect sleep quality, which has an impact on their quality of life. Likewise, Kenneson and Bobo (2010), consider that distress and stress were predicted by low resilience and low income, due to lack of financial support. In addition, caregiving stress showed a significant positive correlation with depression and showed a significant negative correlation with self-esteem (Kim, 2017).

Finally, studies emphasize the experience of informal caregiving, recognizing the 7importance of caregiver health (Peay et al., 2018; Barros et al., 2017; Lach et al., 2010). Thus, it is necessary to promote efforts for early diagnosis and early detection of the diagnosis of disability to provide timely advice and support to the informal caregiver (Foster et al., 2010). Interventions focused on resilience and social support (Barros et al., 2017) are likely to improve the quality of life of informal caregivers, and perhaps also of caregivers of children with other disabilities or special health care needs.

CONCLUSION

Informal caregiving has an impact on the well-being of the caregiver. Therefore, it is necessary to work for the care of the caregiver. The studies underline the importance of providing health interventions to meet the precise needs of informal caregivers of children with disabilities and that, in turn, these interventions improve their health. This suggests the importance of giving greater visibility to the task of caregiving. A promising avenue for addressing informal caregiving also emerges by delving into the need to propose interventions that improve the physical and mental health of caregivers. These interventions should urgently focus on the mental health of mothers, who present greater psychological distress than fathers. It is necessary to propose programs that reveal the need to care for the caregiver, according to the subjective burden (stress); and programs that promote the care of children with disabilities (objective burden), who may be affected by the mental health of their caregiver. Also, emphasize social and family support and stress management; because informal caregivers need a better understanding of mental illness, an increase in their skills, better access to financial resources and social support services, all of which are deficient. The authors emphasize that caregivers deserve support from the state, the community, the health care system, financial benefit, interventions to diagnose and treat the burden of caregiving, and training to cope.

CONTRIBUTORS

All authors contributed to the conception and design of this project. The first and second authors conducted the initial literature searches, as well as subsequent screening and final selection of studies. The first author synthesized findings from reviewed studies and produced the initial draft of the manuscript. All authors contributed to the final version of the manuscript.

CONSENT FOR PUBLICATION

Not applicable.

STANDARD OF REPORTING PRISMA

Guidelines and methodology were followed.

FUNDING

This research was supported by grants from the Ministerio de Ciencia, Tecnología e Innovación – Minciencias, Gobernación del Atlántico, from the 809 call: Formación de Capital Humano de Alto Nivel para las Regiones – Atlántico 2018, COLFUTURO and Universidad Simón Bolívar in Barranquilla, Colombia.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise. The authors alone are solely responsible for the content and writing of the paper.

ACKNOWLEDGEMENTS

The authors wish to thank Emma Turner, BS, for her help with reformatting references.

REFERENCES

[1] Aranda-Reneo I, Peña-Longobardo LM, Oliva-Moreno J, et al. (2020) The Burden of Spinal Muscular Atrophy on Informal Caregivers. Int J Environ Res Public Health. 2020;17(23):8989. Published 2020 Dec 2. doi:10.3390/ijerph17238989

[2] Arias-Rojas M, Carreño Moreno S, Sepúlveda García A, Romero Ballesteros I. (2021) Sobrecarga y calidad de vida de cuidadores de personas con cáncer en cuidados paliativos. Rev Cuid [Internet]. 2021;12(2). Disponible en: http://dx.doi.org/10.15649/cuidarte.1248

[3] Arias-Rojas M, Carreño Moreno S, Sepúlveda García A, Romero Ballesteros I. (2021) Sobrecarga y calidad de vida de cuidadores de personas con cáncer en cuidados paliativos. Rev Cuid [Internet]. 2021;12(2). Disponible en: http://dx.doi.org/10.15649/cuidarte.1248

[4] Barreto R V, Coral R, Campos M, Gallardo K, Támara V. (2021) Cuidadores y cuidadoras familiares de personas con enfermedad crónica en Colombia: más similitudes que diferencias. Revista Científica Salud Uninorte. 2021;31(2) Disponible en: http://dx.doi.org/10.14482/sun.31.2.6988

[5] Barros ALO, Barros AO, Barros GLM, Santos MTBR. (2017) Burden of caregivers of children and adolescents with Down Syndrome. Sobrecarga dos cuidadores de crianças e adolescentes com Síndrome de Down. Cien Saude Colet. 2017;22(11):3625-3634. doi:10.1590/1413-812320172211.31102016

[6] Bathyány K. (2021) Políticas del cuidado. CLACSO; 2021.

[7] Bernabe-Ortiz A, Diez-Canseco F, Vásquez A, Miranda JJ. (2016) Disability, caregiver's dependency and patterns of access to rehabilitation care: results from a national representative study in Peru. Disabil Rehabil. 2016;38(6):582-588. doi:10.3109/09638288.2015.1051246

[8] Cahuana M. (2016) Carga subjetiva y calidad de vida relacionada con la salud en cuidadores de niños con discapacidad y niños con multidiscapacidad. Revista de Psicología [Internet]. 2016 [cited 9 September 2019];6(2):13-28. Available from: http://ucsp.edu.pe/investigacion/psicologia/wp-content/uploads/2017/04/Rev-psicolUCSP-2016-6-2.pdf

[9] Cantillo Monjo M, Lleopart Coll T, Ezquerra Samper S. (2018) El cuidado informal en tiempos de crisis. Análisis desde la perspectiva enfermera. Enferm glob. 2018;17(2):515–41.

[10] Cascella Carbó G, García-Orellán R. (2020) Burden and Gender inequalities around Informal Care. Investigación y Educación en Enfermería. 2020;38(1).

[11] Creemers H, de Morée S, Veldink JH, Nollet F, van den Berg LH, Beelen A. (2016) Factors related to caregiver strain in ALS: a longitudinal study. J Neurol Neurosurg Psychiatry. 2016;87(7):775-781. doi:10.1136/jnnp-2015-311651

[12] Crespo M, Rivas M. (2015) La evaluación de la carga del cuidador: una revisión más allá de la escala de Zarit. Clínica y Salud. 2015;26(1):9-16.

[13] Encuesta de Calidad de vida (ECV) [Internet]; 2019 [Consultado 2019 Sep 16] Disponible en: https://www.dane.gov.co/index.php/estadisticas-por-tema/salud/calidad-de-vidaecv/encuesta-nacional-de-calidad-de-vida-ecv-201

[14] Foster RH, Kozachek S, Stern M, Elsea SH. (2010) Caring for the caregivers: an investigation of factors related to well-being among parents caring for a child with Smith-Magenis syndrome. J Genet Couns. 2010;19(2):187-198. doi:10.1007/s10897-009-9273-5

[15] Gallagher S, Phillips AC, Carroll D. (2010) Parental stress is associated with poor sleep quality in parents caring for children with developmental disabilities. J Pediatr Psychol. 2010;35(7):728-737. doi:10.1093/jpepsy/jsp093

[16] García Á, Gómez L, Villa P. (2016) Carga del cuidador familiar de jóvenes dentro del TEA: estudio de dos casos. [Internet]. 2016. [citado: 2021, noviembre] Disponible en: http://hdl.handle.net/10554/21337

[17] García Cantillo, C. C. & Reyes-Ruiz, L. (2021). Aspectos que impactan la vida de las madres cuidadoras de hijos en situación de discapacidad. En Reyes-Ruiz, L., Carmona Alvarado, F. A. & Sánchez Villegas, M. (Eds.), Aproximaciones epistemológicas y teóricas de las acciones investigativas en el doctorado en Psicología (pp.179-214). Barranquilla, Colombia: Ediciones Universidad Simón Bolívar. (https://bonga.unisimon.edu.co/bitstream/handle/20.500.12442/9602/APROXIMACIONES%20EPISTEMOLOGICAS%20Y%20TEORICAS%20DE%20LAS%20ACCIONES%20-%20ELECTRONICO.pdf?sequence=1&isAllowed=y#page=237

[18] García-Cantillo C, Reyes-Ruiz L, Sánchez-Villegas M. (2021) Abordaje de los cuidadores informales de discapacidad: una mirada desde el análisis documental de la normatividad colombiana. Archivos Venezolanos de Farmacología y Terapéutica. 2021; 40(5).

[19] Kenneson A, Bobo JK. (2010) The effect of caregiving on women in families with Duchenne/Becker muscular dystrophy. Health Soc Care Community. 2010;18(5):520-528. doi:10.1111/j.1365-2524.2010.00930.x

[20] Khare S, Rohatgi J, Bhatia MS, Dhaliwal U. (2016) Burden and depression in primary caregivers of persons with visual impairment. Indian J Ophthalmol. 2016;64(8):572-577. doi:10.4103/0301-4738.191493

[21] Kim D. (2017) Relationships between Caregiving Stress, Depression, and Self-Esteem in Family Caregivers of Adults with a Disability. Occup Ther Int. 2017;2017:1686143. Published 2017 Oct 17. doi:10.1155/2017/1686143

[22] Kumar K, Gupta M. (2014) Clinical and socio-demographic determinants of psychological health and burden in family caregivers of patients with unipolar depression. Asian Journal of Psychiatry. 2014;9:51-56.

[23] Lach LM, Kohen DE, Garner RE, et al. (2010) The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders. Disabil Rehabil. 2010;31(8):607-618. doi:10.1080/09638280802242163

[24] Lambert SD, Bowe SJ, Livingston PM, Heckel L, Cook S, Kowal P, (2017) Impact of informal caregiving on older adults' physical and mental health in low-income and middle-income countries: a cross-sectional, secondary analysis based on the WHO's Study on global AGEing and adult health (SAGE). BMJ Open. 2017;7(11):e017236.

[25] Leonardi M, Giovannetti AM, Pagani M, Raggi A, Sattin D; (2012) National Consortium Functioning And Disability In Vegetative And In Minimal Conscious State Patients. Burden and needs of 487 caregivers of patients in vegetative state and in minimally conscious state: results from a national study. Brain Inj. 2012;26(10):1201-1210. doi:10.3109/02699052.2012.667589

[26] López E. (2016) Puesta al día: cuidador informal. Revista de enfermería CyL [Internet]. 2016 [cited 4 August 2019];8(12):71-77. Available from: http://www.revistaenfermeriacyl.com/index.php/revistaenfermeriacyl/article/viewFile/164/144

[27] López M, Montoya V, Rodríguez L, Foronda L. (2019) "Experiencias y formación de cuidadores informales de pacientes en el municipio de Envigado" [Internet]. [Medellín]: Universidad CES; 2019. Disponible en: https://repository.ces.edu.co/bitstream/10946/4856/5/1010030559_2020.pdf

[28] Mathias K, Kermode M, San Sebastian M, Davar B, Goicolea I. (2019) An asymmetric burden: Experiences of men and women as caregivers of people with psycho-social disabilities in rural North India. Transcult Psychiatry. 2019;56(1):76–102.

[29] Moher D, Liberati A, Tetzlaff J, Altman DG; PRISMA Group. (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med. 2009;6(7):e1000097. doi:10.1371/journal.pmed.1000097

[30] Montaño S. (2021) Las mujeres mayores y el envejecimiento con dignidad en América Latina [Internet]. Repositorio.cepal.org. 2021 [cited 9 November 2021]. Available from: https://repositorio.cepal.org/handle/11362/1484

[31] Oñate L, y Calvete E. (2017) Una aproximación cualitativa a los factores de resiliencia en familiares de personas con discapacidad intelectual en España. Psychosocial Intervention [Internet]. 2017 [cited 10 August 2019];26(2):93-101. Available from: https://www.redalyc.org/articulo.oa?id=1798/179851770003

[32] Peay HL, Meiser B, Kinnett K, Tibben A. (2018) Psychosocial Needs and Facilitators of Mothers Caring for Children with Duchenne/Becker Muscular Dystrophy. J Genet Couns. 2018;27(1):197-203. doi:10.1007/s10897-017-0141-4

[33] Proyecto de Ley 041 de 2020 [Internet]; 2021 [Consultado 2021 julio 26] Disponible en: http://leyes.senado.gov.co/proyectos/index.php/textos-radicados-senado/p-ley-2020-2021/1822-proyecto-de-ley-041-de-2020

[34] Ramachandran A, Vyas N, Pothiyil D. (2020) Stress among the caregivers of mentally disabled children visiting a rehabilitation centre in Chennai, Tamil Nadu – A cross-sectional study. Clinical Epidemiology and Global Health. 2020;8(4):1155-1157.

[35] REFERENCES

[36] Riva JJ, Malik KM, Burnie SJ, Endicott AR, Busse JW. (2012) What is your research question? An introduction to the PICOT format for clinicians. J Can Chiropr Assoc. 2012;56(3):167-171.

[37] Ruiz Ríos A, Nava Galán M (2012) Cuidadores: responsabilidades-obligaciones. Revista de Enfermería Neurológica. 2012;11(3):163-169.

[38] Sarris A, Augoustinos M, Williams N, Ferguson B. (2020) Caregiving work: The experiences and needs of caregivers in Australia. Health Soc Care Community. 2020;28(5):1764-1771. doi:10.1111/hsc.13001

[39] Sit HF, Huang L, Chang K, Chau WI, Hall BJ. (2020) Caregiving burden among informal caregivers of people with disability. Br J Health Psychol. 2020;25(3):790-813. doi:10.1111/bjhp.12434

[40] Syed IH, Awan WA, Syeda UB. (2020) Caregiver Burden among Parents of Hearing Impaired and Intellectually Disabled Children in Pakistan. Iran J Public Health. 2020;49(2):249-256.

[41] Wijesinghe CJ, Cunningham N, Fonseka P, Hewage CG, Østbye T. (2015) Factors associated with caregiver burden among caregivers of children with cerebral palsy in Sri Lanka. Asia Pac J Public Health. 2015;27(1):85-95. doi:10.1177/1010539514548756

[42] Zamarripa E, Tamez B, Ribeiro M. (2017) Repercusiones del cuidado informal en la vida laboral y personal de las mujeres cuidadoras. Revista Internacional De Trabajo Social Y Bienestar. 2017;0(6): 47-56. Disponible en: https://revistas.um.es/azarbe/article/view/273401

[43] Zambrano R, y Ceballos P. (2007) Síndrome de carga del cuidador. Rev Colomb Psiquiat [Internet]. 2007 [cited 9 August 2019];XXXVI(1):26-39. Available from: http://www.scielo.org.co/pdf/rcp/v36s1/v36s1a05.pdf

[44] Zarit SH, Reever KE, Bach-Peterson J. (1980) Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist. 1980;20(6):649-655. doi:10.1093/geront/20.6.649

[45] Zarit SH. Caregiver's Burden. (2002) En S. Andrieu y J.P. Aquino: Family and professional carers: findings lead to action. Serdi Edition y Fondation Médéric Alzheimer; 2002.