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Burden of disease in parents and caregivers of children and adolescents diagnosed with disability-related disorders

Carga de la enfermedad en padres y cuidadores de niños y adolescentes diagnosticados con trastornos relacionados con la discapacidad

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SUMMARY

A disability diagnosis will always impact in the family and not only financially in terms of access to health services, but also at the emotional, mental and psychological level. So it is worth asking What has been the contribution of research on the burden of the disease in parents and caregivers of children and adolescents diagnosed with disability-related disorders? This systematic review article will seek to answer this question, emphasizing the need to study this concept from Clinical Psychology based on a qualitative methodology. Taking into account the consultation, 3 main ideas are proposed to consider for the study of the burden of the disease in parents of children and adolescents diagnosed with disabilities.

Keywords: *Burden of disease, clinic psychology, child and adolescents with a disability, dysfunction.*

RESUMEN

Un diagnóstico de discapacidad siempre impactará en la familia y no solo económicamente en cuanto al acceso a los servicios de salud, sino también a nivel emocional, mental y psicológico. Por tanto, cabe preguntarse ¿Cuál ha sido la contribución de la investigación sobre la carga de la enfermedad en los padres y cuidadores de niños y adolescentes diagnosticados con trastornos relacionados con la discapacidad? Este artículo de revisión sistemática buscará dar respuesta a esta pregunta, enfatizando la necesidad de estudiar este concepto desde la Psicología Clínica con base en una metodología cualitativa. Teniendo en cuenta la consulta, se proponen 3 ideas principales a considerar para el estudio de la carga de la enfermedad en padres de niños y adolescentes diagnosticados con discapacidad.

Palabras clave: *Carga de enfermedad, psicología clínica, niño y adolescente con discapacidad, disfunción.*

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INTRODUCTION

According to the definition of the World Health Organization (WHO) (01), disability is "any restriction or absence (due to a deficiency) of the ability to perform an activity in the form or within the margin that is considered normal for any human. It is characterized by inadequacies or excesses in performance and behavior in a routine activity, which can be temporary or permanent, reversible or irreversible, and progressive or regressive. It classifies them into nine groups: behavior, communication, personal care, locomotion, body disposition, dexterity, situation, a certain aptitude and other restrictions of activity".

In its attempt to generate a new understanding of functioning, disability, and health, WHO created the International Performance Classification (IPC) (02), which is part of the family of classification manuals created and/or promoted by WHO for knowledge of the various nosological entities related to health problems and quality of life in general.

The IPC (02) is the reference manual that uses standard language to describe and understand health as well as the dimensions related to it and therefore this classification understands functioning and disability in the individual, physical, social and contextual spheres. Therefore, the understanding of disability according to WHO (2001), cited in Giaconi, Pedrero, and San Martin (3) specifies that this is a term that includes deficiencies, activity limitations, and restrictions on participation.

Since its publication it has had great acceptance and impact due to the common language it uses throughout the life cycle since at any time in life a person can experience a disease that could generate some degree of disability, therefore the term or condition of disability is not characteristic of only a small group in a given society. The need to use the IPC (02) as a manual for the classification of functioning and disability arises due to the increasing trend in the increasing prevalence of disability in the different censuses held in each country. At this point, it is necessary to clarify that these estimates vary within the same country and between countries.

After the publication of the IPC (02), it was possible to structure more adapted concepts related to functionality and disability, which are known not to be mutually exclusive. On the different ways of understanding the concept of disability, a historical process of this definition can be related, which includes different models set out below (3).

Table 1

Models and definitions about disabilities

MODEL	DEFINITION
Prescindence	Disability is a condition generated by religious reasons, indicating that in subjects who had different and disabling physical or physiological characteristics there were diabolical messages, their illness being a punishment of the gods. For this reason, the term, implying that society could do without these people
Rehabilitator/Medic	The causes of disability are biomedical, society could no longer do without affected individuals because they could be useful if they were rehabilitated and thus reduce their functional deficit
Social	Disability is caused by society's limitations in providing services and assistance to the needs of subjects with these deficits, therefore disability is generated by social causes
Biopsychosocial	This model underlies biological and social origins, where disability is the result of the interaction between the health conditions of individuals and the characteristics of the social and physical context where it unfolds.

Source: self-made

It is noteworthy that the models that try to explain the origins of disability are several and that address it from different perspectives, as the model exposed by Bronfenbrenner referenced in the text of Amaincaña (4) in its ecological approach where in the different systems (microsystem – mesosystem – exosystem – macrosystem) the family would become the primary unit on which it is involved and subsequently the subject will be able to function in ever wider family scenarios, obtaining reciprocity with your environment. In this regard, the author states that this responds to the principle of inclusion in society.

Continuing the conceptual approach of disability should also refer to the model of diversity. Amaicaña (4) makes an argument that the criteria of "normality" on which society is based must be extended to consider what does not conform to the rule to take into account both deficiency and difference.

To end with the approach of the concept of disability considers what is stipulated by WHO (2011), cited in Barrios et al. (5), which explains that "disability is a complex phenomenon that reflects an interaction between the characteristics of the human organism and those of the society in which it lives, so interventions to overcome the disadvantages associated with it are multiple, systemic and varied according to the context".

Taking into account the above models that serve to understand the concept of disability can be initiated by raising the problem that interests this article and is the understanding of the emotional, physical, and psychological burden for families in their care for child and adolescents with disabilities, specifically for family. Caregivers may be the parents, uncles, grandparents, or any family member who assumes, either voluntarily or through a formal or informal agreement, the task of assisting and addressing all the requirements needed by the family member who is in a disability situation. Care ranges from aiding the person's postural changes when they are at rest or awake, surveillance at night, feeding, clothing, grooming or simply providing the company (01).

The caregiver's life changes depending on the care the person needs because he or she provides this care to his or her physical or emotional needs for a large portion of the day for weeks, months, or years without receiving financial retribution or prior training (6). All that involves the care of a family member in disability condition are understood to face a whole series of situations that can negatively affect not only the quality of life of them but also the same family dynamics and that is why reference is made to the "burden of the caregive" or "burden of disease" (7).

This burden of the caregiver or burden of the disease, caused by providing almost relentless care and meeting the needs of a person in a disability condition (7) includes the different feelings that can range from guilt to satisfaction with the effectiveness of care. This spectrum highlights negative feelings such as loneliness, sadness, feeling abandoned, nervousness, lack of leisure and rest, problems with sleep, and deterioration of the economic situation that cause impediments in the caregiver that allow him to be happy and achieve a minimum of well-being (8), therefore it can be understood that in the analysis of the burden of the disease involves not only the psychological aspects, emotional or physical, but also economic and labor factors.

This burden increases when access to the necessary health services that are indispensable for the person with this disability/dysfunctional condition is scarce. In Colombia, the use of legal mechanisms against Health Promoter Entities (EPS, by its acronym in Spanish) to provide timely rehabilitation therapies, medicines, and formalized professional caregivers (nurses, psychologists, physiotherapists, etc.) is common. For example, according to the Ombudsman's Office (9) for 2015 every 3.5 minutes a legal action was filed to access health services, being the year of 2015 in which the record of the use of this mechanism was broken with a total of 151 213 petitions, with Saludcoop receiving the most actions against (18 642), NUEVA EPS was the second (16 976) and Coomeva the third (13 441) according to the Colombian Ministry of National Health (10).

It is alarming that the parents and caregivers of children and adolescents between the age of 6-14 (18.4 %) with nervous system-related ailments such as childhood cerebral palsy and epilepsy are who most turn to these legal actions to ensure access to their children's health services. Following this group are children between the ages of 1-5 with diseases associated with congenital malformations, deformities, and chromosomal abnormalities representing 14.9 % of guardianship, with Down syndrome being the most common pathology (10).

However, this is a process that can take months or even years, and bureaucratic barriers to the health system represents very important limitations for the families of the person in disability status, so negativism in people is frequent in the face of the provision of the health care services they need. To address the problem, WHO (11) explains that this disabled population is a group with the worst health and academic outcomes, lower economic participation, higher rates of poverty, and greater dependence and limitation for participation in society (3).

Despite the problem that this represents in up-to-date studies on disability worldwide, difficulties such as biases in using appropriate assessment and registration methods, cultural changes, and difficulty in accessing the population can be encountered, so studies are outdated and those carried out by, by way of example, WHO (11) can only be considered as approximate to the actual problem; but even in the case of approximate data, it can be shown that there are a growing and worrying problem at the global level and, above all, in Colombia because of the historical debt to this population and their families in terms of adequate care on the part of health agencies.

If Colombia continues to be referred to, more clarity can be made from current data on disability, where through the Ministry of Health with the "situational room of persons with disabilities" (12) they offer identifications on the various disabling diseases, as well as the most affected age and population groups. The National Administrative Department of Statistics (DANE, by its acronym in Spanish) (13) identified 2, 624 898 million people who refer to a disability, however, through the Registry of Location and Characterization of Persons with Disabilities (RLCPD, by its acronym in Spanish) (12) there was identified 1'200,0000 people with some type of disability. Of these people, 15 % (161 543) are minors.

These figures are most relevant when social, cultural, and environmental conditions are considered because of the duty for these people to care for a disabled person in the family nucleus that generates a greater physical, economic, social, and emotional burden. These conditions correspond to Colombia according to the RLCPD (12):

- 9 % of the registered population (155,766) with disabilities in the RLCPD belong to an ethnic group
- Of these, 71 % (110,502) are Afro-Colombian, 26 % (40 789) are indigenous, 2 % (2 354) are rooted, 1 % (1,121) are palanquera and 1 % (910) are gypsy.
- 83 % (1, 159 658) is stratum 1, there are 464 931 registered persons of stratum 2 and 205 023 registered persons of stratum 3.
- It can also be seen that the disability that prevails are those related to the movement of the body, hands, arms, and legs and that affects 34 % of registered people (496 522) followed by the nervous system affecting 13 % of the registered population (379 835).

These figures reveal that there is currently an important problem to be taken into account in the Colombian population, especially in minors who responsible for all medical and home care are parents who must guarantee a minimum quality of life for their child. In this sense, according to Huerta and Rivera (6):

> *"The arrival of a child with a disability becomes an extraordinary, unexpected, and incomprehensible event for the family, restructuring family life, altering its dynamics and daily life (Guevara and González, 2012). It has an impact at different levels of the family, both relationally and economically and emotionally and socially, which requires reorganization and adaptation to context (González and Leppe, 2010)"*

It is then valid to say that the presence of a child with disabilities demands extra expenses from the family budget and that it will be reduced due to the degree of disability involvement and as this grows will also increase the tension and family stress (14) and the problem is aggravated when this family is Afro-Colombian, indigenous, living in rural settings or is stratum 0.1 or 2; 256 696 people with disabilities do not attend rehabilitation services for lack of money (12).

For this reason, this article will conduct a systematic review on addressing the burden of the disease on parents and caregivers of children and adolescents diagnosed with disability-related disorders. This to characterize them, identifying the particular characteristics that they possess and that allows concluding this concept which has been little addressed since Psychology, and abundantly addressed from Nursing, and thus be able to identify the true research needs that exist around the subject.

METHODS

Through Letelier's postulates (15) the Systematic Review or RS is one that reliably synthesizes all available quality scientific evidence that the researcher exhaustively compiles and analyzes, regarding a specific topic in a structured way. The author mentions two types of RS, among which are: a. RS. Qualitative or b. RS. Quantitative or meta-analysis. It will be important to mention that the typology methodology of systematic review used for the preparation of this work will be carried out from a qualitative court, in which the evidence will be descriptively presented in detail without the use of statistical analysis for the formulation of the same.

Using this methodology can be highlighted various researches and their contributions on addressing the burden of the disease in parents and/or caregivers of children and adolescents with disability disorders, which proposes to find specific qualities in terms of functionality and the revision from the science of the psychology of the affectations or consequences associated with this type of diagnoses or disorders. This, with the main advantage of clarifying an answer to the specific clinical question in ¿What are the contributions of researchs in regard of burden of disease in parents and caregivers of children and adolescents diagnosed with disability-related disorders? And to start answering this question a search was made for information that corresponds to scientific articles, undergraduate and doctoral thesis in the google search engine, as well as in journals such as Scielo, Redalyc Dialnet, PubMed, and the Digitals Repositories of Universities like the Magdalena University where the following keywords were used: disease burden, clinical psychology, caregivers, disability and dysfunctionality, children and adolescents, caregiver overload and stress and anxiety in parents and caregivers.

The following inclusion criteria for eligibility in this investigation were used for the found documentation:

- The material used must be from 2015 to 2020.
- The material must come from the medical sciences (nursing, medicine, physiotherapy, psychology) or social sciences.
- It should focus, or refer to, the type of patients or population under studies such as children and adolescents.
- It must give therapeutic responses, or at least mentions some recommendations about the psychological intervention that dispels the problem load studied.
- It should be based on what the IPC (02) describes as a disability or refer to diseases considered disabling or affecting the functionality of the child or adolescent.
- It should explain, as results of the research, the physical, emotional, psychological, economic, or work implications of having a child or adolescent diagnosed with a disability in the family nucleus.

Taking up what Letelier (15) "RS's are retrospective studies so they are subject to bias at various stages of the process: search, selection, analysis and synthesis of information. This is why the authors of an RS must take all necessary precautions to prevent this from happening". Since interpretive synthesis will be made in which it seeks to generate a higher level of interpretation to go beyond the findings and there will be no manipulation of a variable as population approaches or subjects the greatest investigative search for a correct interpretation will be aimed at critically analyzing the studies and information used to reach a quality result with previously selected material.

RESULTS

Considering the above-mentioned inclusion criteria for the literature search in the Scielo, Redalyc, Dialnet, PubMed databases and the digital repositories, 50 articles containing the keywords were found, after reading the title and summary of the articles 17 were discarded because they were not directly related to the subject of this SR, 14 articles were used to design the introduction and that is relevant for use in the discussion (in this section were included additional material from 2 bibliographic sources). For the methodology 1 article was used, as far as the results section was found relevant 2 research were found to establish contributions regarding the concept of disability, and 14 research to analyze the contributions to the concept of disease burden. These last 16 articles were published between 2015-2020.

Based on the identification of the refered categories "disability" and "disease burden", the corresponding investigative findings were organized. In the case of the first category, the assessments of 2 authors based on the concept of disability that can be obtained from the results of their research are highlighted.

Hernandez (16) in his research entitled "The Concept of Disability: From Disease to The Right Approach" was found to be an explanation from the medical model on that category. The author (16) states that the person with disabilities requires clinical care provided in the form of individual treatment, aimed at obtaining the cure or improvement of the subject, or a change in it, and explains the relevance of the paternalistic and charitable role with people with disabilities.

The relevant contribution made by the author is based on the emphasis that the limitations of persons with disabilities should not only be taken into account from a medical conception but by the physical and social barriers that the environment imposes on her because of her special condition, and that they prevent her from properly integrating and functioning skillfully in society and how they can generate that present relationship between the medical and the social from a biopsychosocial model that currently gives importance to equal opportunities.

The second research contribution to be referred to by the importance and relevance of its study comes from the United Nations Children's Fund (UNICEF) (17). Based on this global organization's 2019 study of "Children and Adolescents with Disabilities" emphasizes the exclusion and marginalization of both the child and his or her family in terms of human rights violations and lack of social inclusion, UNICEF (17) then stops at making a comparison between the usual development of NNA in their stage of development and how those under the disability status should suffer from general violations, they state: "Compared to their peers without disabilities, they are more likely to experience the consequences of social, economic, and cultural inequity. Every day they face negative attitudes, stereotypes, stigma, violence, abuse, and isolation".

More specifically, it is important to note that for UNICEF (17) disability in children and adolescents has a social effect that burdens and disturbs those in these physical conditions, since even the lack of guarantees on the part of the state in terms of the implementation of appropriate laws and policies hinder and limit the exercise of social inclusion, this correlates with the burden of the disease on parents, UNICEF (17) states that "Unfortunately, in many countries, the response to the situation of children and adolescents with disabilities is mainly limited to neglect, neglect or detention in institutions". Couple. 3. This same children's organization states in recent statistical data from 2019 that 8 million children under the age of 14 with disabilities live in Latin America and the Caribbean and that 7 out of 10 child and adolescents do not attend school and only 50 000 are institutionalized.

From this moment it can proceed to summarize the most relevant findings regarding the second important category for this RS which, for convenience and ease, were organized in the following table:

Some consensuses can be identified from Table 2 on what the term disease burden or caregiver

Table 2

Related contributions on understanding the burden of illness or caregiver

Title of the studied material	**Authors**	**About the burden of disease or burden of the caregiver**	**Investigative Contribution**
The burden of disease from Chronic Noncommunicable Diseases and Disability in Colombia	NATIONAL HEALTH Observatory ONS	The report on disease burden in Colombia published by the ONS (15) shows a conception from the experience of interviewees at the national level, one of the statements that came to close-in-family involvement was access to the benefits offered to special populations limited to people with disabilities.	The report on disease burden in Colombia published by the ONS in 2015 allows us to know the experience of people and this condition at the national level and how this perceptual contributes to better management by the Ministry of Health and Social Protection that gives in principle the possible guarantee of their fundamental rights, but more than this regulatory structure, one of the affectations of family development that causes the burden of disability-related illness is that as stated by the ONS (15).
Subjective burden and health-related quality of life in caregivers of children with disabilities and children with multi-disability	Milagros Cahuana Cuentas 2016 (19)	Research conducted by Cahuana (17) finds factors associated with quality of life weakened by the burden of disease in caregivers with children with some form of disability	Cahuana (16) talks about these negative consequences, this commitment to care often involves several consequences on their mental health — depression, anxiety, psychosomatic diseases, etc. — and physical, as well as repercussions on their family and social relationships, on their free time, their economy and their work. The author states that in his results he obtained "a significant negative correlation between the levels of overload and the mental and physical health components of health-related quality of life" p. 13
Overload, quality of life, well-being in caregivers of children with disabilities in two regions of Colombia	Reyes-Rojas et al. 2019 (20)	Reyes et al. (18) in their investigative formulation intend to "explore the field of disability in children and the traces left in the mental health of caregivers the daily work of taking care of children under these conditions" p. 135.	As for the overload category of the caregiver can be considered a variety of components that sharpen it, such as medical procedures or with EPS, actually diagnoses feedback to caregivers where the advances or the zero progress that these patients will already have medically speaking, the transfer or transport to different places, the economic difficulties, the lack

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…continuation Table 2.

Title of the studied material	**Authors**	**About the burden of disease or burden of the caregiver**	**Investigative Contribution**
			of family support. Findings regarding the quality of life and subjective well-being of caregivers who are close relatives who assume the role results in negative affection, poor health, and a high risk of overcharging are recorded
The overload of the main caregiver, analysis of the circumstances involved in its production	Revilla-Ahumada, De los Rios-Alvarez, Abril-Garrido, 2019 (21)	Overloading of primary caregivers (CPs) to this person's perception of the impact he or she suffers on the different aspects of his or her life is understood by having a patient with varying degrees of disability in his or her care. Subjective overload can also be understood as another element within the set of stressful events that can affect the caregiver.	Overload is related to the highest degree of patient dependence, disability, and immobility. In terms of caregiver profile, female gender, and age increase, the increased number of hours devoted to care and rehabilitation activities increase perceived overhead.
Care skill and level of over face in informal caregivers of dependents	Eterovic, Mendozza, Saez, 2015 (22)	It is common for the informal caregiver to take on the role in a short time, which does not allow her to reflect or question what she knows, what she does not know or the cost it will have for her life, and even if she wants to assume that role, because in the face of this reality, often, there is no alternative.	Skilled caregivers have developed balanced and functional ways to cope with the adverse conditions of home care, which would result in the acquisition of appropriate skills for the fulfillment of the role of caregiver and allow them less exposure and involvement to feel the work of caring for another person, such as a burden. The reflection on the part of the caregiver arises over time, as the demands of the role of care appear, demands that she must face few or sometimes no ability to care for, but that force her to assume more and more duties and, without realizing it, to gradually lose the right to take care of her health.
Level of overload and family functioning of child caregivers with Down syndrome, who attend the Center of Integral	Collazos Vidales, D. Fernandez Rivera, N. 2019 (23)	It is a "psychological state that results from the combination of physical work, emotional pressure, social constraints, as well as the economic demands that arise from caring for	Families who perform their functions properly and receive support for comprehensive and quality care are positively adapted to the presence of a child with SD, making the qualities of these people visible and

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Title of the studied material	Authors	About the burden of disease or burden of the caregiver	Investigative Contribution
Health Specialists Rebirth of the City of Popayán, 2019		a chronically ill or disabled person”	transforming their beliefs and expectations towards the opportunity to learn another way of living with dignity and solidarity. On the other hand, families that do not present optimal conditions and do not adequately perform functions of protection and adaptation prevail feelings such as denial, hidden rejection, frustration, misfits in having a person in the family with disabilities originating habits and customs that end in inequities such as overburdening in women's roles, making them solely responsible for the care of children, which could lead in these people to what is called “caregiver overload”
Family overload and functioning in families with children with disabilities	Anderson S. 2016 (24)	Overloading is defined as the set of repercussions or impacts, physically and mentally, involved in having a primary caregiver role in children with disabilities. These caregivers can experience high levels of stress and burden, until they discontinue their well-being, including employment and other activities. They have the worst levels of subjective well-being and pose an increased risk of psychological and physical health problems, including premature death, compared to non-caregivers.	Throughout the analysis of the data, some factors associated with overload have been identified, such as the age of the parent, the age of the child, the pathology of the child (in this case Autism Spectrum Disorder is linked to more overload), such as the economic level. In relation to overload and family functioning, it can be said that there is no relationship between them. So both overload and family function are independent variables that have no impact on each other. Therefore, a particular family operation does not have to incur overload levels, or overloading leads to adopting one type of family or other operation.
Overload of care and morbidity felt in caregivers of children with disabilities	Gomez et al. 2019 (25)	They studied the care of children with disabilities and found impacts in different areas such as social relationships, family relationships, affectation of the emotional state of	Most caregivers have factors associated with the development of subjective overload, including the socioeconomic level, since a large percentage is located in the lower strata one and two,

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Title of the studied material	**Authors**	**About the burden of disease or burden of the caregiver**	**Investigative Contribution**
		caregivers, related to the development of stress, depression, distress, sadness, non-acceptance, pain, and, in other cases, allergy. Related to physical conditions, they reported having acute lower back pain or chronically having it, which they associate by having to mobilize raised children from one place to another. Many talks about "physical fatigue", which is higher in the evenings after the day with their children.	and with educational training in primary and secondary grades. As for the perception of subjective overload in the sample studied, a significant report is evident in the care of children and young people with disabilities, which can be related to other predisponderant factors such as performance time and hours spent a day.
Brief report: burden of care on mothers of children with an autism spectrum disorder or intellectual disability	Faithorne, De Klerk, Leonard (26).	They estimated the maternal burden of care by comparing the duration of hospitalizations for psychiatric disorders and the rates of treatment of post-birth psychiatric disorders in mothers of children with Autism Spectrum Disorder (ASD) and Intellectual isability who had no psychiatric history.	Mothers of children with known intellectual disabilities, as well as mothers of children with ASD without intellectual disabilities, were found to belong to a particularly vulnerable group to develop psychiatric disorders in the future, compared to mothers of children with Down syndrome who were "resistant"
Labour and economic burden of families with preschoolers diagnosed autism spectrum disorders in urban areas of China: results of a descriptive study.	Jian-Jun et al. (27)	Few studies have been conducted in China on the burden of disease and the social phenomenon involved even though autism spectrum disorder (ASD) is known to affect many aspects of family life considering the social and economic burden that this diagnosis entails on the family.	58% of families with children with ASD and 19% of families with children with other with disabilities reported that childcare issues had greatly affected their work decisions compared to families with children with typical development.
Predictors of caregiver load among mothers of children with chronic conditions	Warnink-Kavelaars et al. (29)	Marfan Syndrome (MFS) is an inherited connective tissue disease. Diagnosis involves cardiovascular, musculoskeletal, ophthalmic, pulmonary, and facial features. The authors note that studies on perceptions and impact of this disease are limited and therefore explored the	Considering that children with MFS could not keep up with their peers from fatigue, pain, and physical deficiencies, as well as the same perceptions of children who experience restrictions on their participation in school, sports, play, and other leisure activities, the origin of the burden of the disease on parents was identified, those experiencing

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Title of the studied material	**Authors**	**About the burden of disease or burden of the caregiver**	**Investigative Contribution**
		perspectives of parents on the impact of THE MFS on the daily functioning of children from 4 to 12 years of age, including perceptions about themselves and the family regarding functional performance, participation in activities, personal and environmental factors.	great care needs, lack of support, limited social life and concerns about the child's development. The authors emphasize that professionals are needed who can address these support needs, either in the form of personalized interventions or psychotherapeutic programs
The role of patient and parent resilience in adolescents with chronic skeletal musculoskeletal pain	Gmuca et al. (30)	According to all resilience measures, patients and parents had low to moderate resilience levels. These levels were lower than previously reported among healthy populations, as well as among people with chronic medical conditions.	Increased patient resilience correlated with lower severity of the disease among adolescents with chronic musculoskeletal pain. Future research should explore whether building resilience in adolescents with chronic musculoskeletal pain by applying resilience training interventions mitigates the disease burden in this vulnerable patient population.
Impacts for children living with genetic muscle disorders and their parents: results of a population study	Jones et al. (31).	Because genetic muscle disorders, including diseases such as muscular dystrophies, congenital myopathies, and ion channel diseases, may be associated with significant disability for both children and their caretaker families, the authors set out to explore the children's and parents' perspectives on the impact of living with a diagnosis of this kind.	64% of families have a lower annual combined income than the national median income, so a diagnosis of genetic muscle disorder for a child implies more support than they are currently receiving. The necessary support can range from household chores and transportation. It highlights the impacts on quality of life, whose risk of deterioration for parents was 71%. The findings are relevant to those involved in the care and support of children and their families, who are affected by genetic muscle disorders. Specific guidelines are required to inform service delivery, along with promoting existing community services to improve access to financial support and assistance with day-to-day operations.

Source: self-made

burden entails, highlighting the following main ideas:

- The relationship between the disability of the child or adolescent with the subjective feeling of tiredness is evident as a product of the constant care that the child needs.
- Women are the most who take care of the needs of these children and adolescents.
- More balanced families will quickly find an adequate level of functionality upon the arrival of this family member with a disability.
- The more support the family receives, the lower the level of subjective burden experienced.
- The feeling of subjective burden is influenced by the age of the child or adolescent and the diagnosis and characteristics of the disability that the child possesses.
- The time care of the child and adolescent in disability condition varies depending on the differential characteristics, however, the time can vary from 8 to 24 hours while other activities are performed.
- Many studies establish the need to implement effective burden-care strategies for children and adolescents with disability-related diagnoses or diseases that may be considered disabling.

DISCUSSION

The development of this article and the tracking of related documents allowed to know the broad perspective on the current context of people with physical limitations, contemplating the disparity not only from the biomedical model but also from the psychosocial component that although less visible is evident in a marked way in the little social inclusion to this population. Disability is not just a limitation for the patient or subject but conforms to something systemically as it is in the family in general. When caring for a child or adolescent with a disability, evidence shows that it is saved in terms of resources for the health system, increasing the debt this sector has to families with children and adolescents with disabilities (22).

And it is here where Amaicaña (4) explains the relation with the ecological approach where it can see the Bronfenbrenner's systems where this, directly or indirectly, affects the person in their development, from the smallest and most immediate social circle: microsystem (home, school, immediate community) and mesosystem (relationships between school, home, and community); even the broadest: exosystem (circle of friends, parents' working media) and macrosystem (cultural values, laws) social, health and economic barriers to access to a decent quality of life for the child or adolescent in disability and his/her family are experienced in different ways.

These are positions that must be analyzed not only from the public agenda but also from the negative consequences that can consolidate a problematic situation for the unequal urgency that disabled people live to continue to consider the individual isolated from the perspective of the dysfunctional families that revolve in this health implication. Here we adopt what Anderson (24) raises that the birth of a child with a disability causes an imbalance in this microsystem and that it affects and is being influenced by the broader systems of society.

This shares the assertion that if a family is functional then it can react, adapt appropriately, and overcome crises. It will also have the ability to establish roles, have adequate channels of communication which will improve emotional expression and family cohesion. However, in many cases, it is family members who acquire a duty to meet the needs that a child or adolescent may have as a disability (23) without having time to think about it as they respond to the urgency with little chance of being delegated and the complexity increases as time progresses (22) and therefore establishes the relationship between what Cahuana expresses (19) about the state mental careers of these informal primary caregivers.

Cahuana (19) refers moods of depression, anxiety, or emotional stress reactions when viewed without the free time and no options to delegate this responsibility, often affecting the household economy and job performance, among other areas. This study found psychological or emotional problems in primary caregivers (near family) that have a major impact on the caregiver, high indicators of stress related to the care of these patients, and even a negative self-perception on themselves associated with the comprehensive and totalitarian occupation of their lives in pursuit of care and permanence to these that shorten the quality of life and health of them.

Reyes (20) states that the emotions experienced by relatives engaged in the care of these children and adolescents with disabilities are contradictory, for sometimes they feel happy for the small achievements of their children, but also frustrated and even anxious; and this is where the "burden of the caregiver" is evident because this implies that experienced feelings can range from guilt to satisfaction with the effectiveness of care (8). So, it's no surprise that this characteristics can be seen language and behavior of these parents because of their long time providing care. About the care time factor are authors who claim that the minimum daily care time can be at least 8 hours daily every day without rest, constituting a greater overload (21), however are other authors (25) specified that when it comes to a child in disability status the average care varies between 18-24 hours while other activities are being carried out.

It is also emphasized that as a child or adolescent in disability status, his primary caregivers – parents and other family members most manifest health problems, within which headache, lumbalgia, sleep disturbances (25) can be highlighted and that the set of characteristics, both positive and negative, that involves the care of this family member with disabilities, in turn, affects the economy, employment situation and social relations of the family.

To conclude this part of the present study, we wants to highlights the Faithorne et al (26), Jian-Jun et al. (27), Javalkar et al. (28), Warnink-Kavelaars et al. (29), Gmuca, et al. (30), and Jones et al. (31) recommendations about the importance that in the face of this wear and tear of parents and/or caregivers of children in disability, psychological care programs should be implemented so the afected caregivers can receive the guidance, help, counseling or, if applicable, initiate the psychoterapeutic process to face more adaptative this new reality were they are immersed from the birth of the child (14) or from the moment of diagnosis.

At more general view we also wantsto criticized that this topic has been very little studied from Psychology, specially in Colombia, in comparison of other important fields as Medicine, Nursing and Physiotherapy. For example, from the quantitative approach, valuable instruments such as the Zarit Caregiver Overload Scale (32) or SF-36 (33) can also be applied, as well as it is possible to study the problem using a qualitative approach that addresses the perceptions or beliefs of parents or caregivers around the diagnosis of a disability of children or adolescents in their care. This would be the first step in starting to give the importance that has been owed for years to this population group worldwide and more necessary in Colombia. The Lack of state guarantees for people with disabilities will always be a counter factor in ensuring these people, especially children and adolescents with this condition, reach an optimal level of development to overcome their condition.

CONCLUSIONS

Settling this investigation three main ideas are raised from what has been found. First, the need for further research on this concept is urgent and how it relates to families in their care for children and adolescents in disability status. In doing so, it was possible to understand more about what this situation entails beyond the economic since as was evident in Colombia the highest percentage of families with a member in disability corresponds to strata 1, 2, and 3. It is then necessary to understand this problem from all perspectives, which leads to the #2 approach and is the need to contextualize this issue from Clinic and Health Psychology because a relationship must be established between the medical and the biopsychosocial to balance equal opportunities to achieve an optimal quality of life for this population group and its families.

To support the above statement are the researchs used for this paper who comes from the Medical and Social Sciences as a whole, however, where it has been studied most is in the Nursing area. It is these and these professionals who have researched the burden of the disease on cancer, terminal, and palliative care patient (just to mention a few examples) however, although the concepts of caregiver burden, disease burden, and caregiver overload have elements involving psychological science such as stress, anxiety, depression, including alterations that are studied in Clinical Psychology such as insomnia, exhaustion, and loss of appetite, has not been properly studied from this field of application of Psychology.

Finally, and to continue with the common thread that leads to the #3 approach, more attention must be paid to these families, especially parents or persons in charge, and watch over the safety of this child or adolescent with disability. Strategies should be employed to alleviate this emotional discomfort they experience and grows daily by experiencing the many barriers that society imposes on the population as a disability where, due to their fisics, cognitive and/or emotional deficits, children and adolescents are the ones who will always be most affected.

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