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IMPACT OF DISABILITY ON THE FAMILY

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Abstract— This paper investigates "Impact of disability on the family", which aimed to determine the impact of care of a disabled patient on the family, a systematic review of 38 articles that were the result of the search in databases such as SCOPUS, EBSCO HOST and GOOGLE SCHOOL. The information obtained was ordered and synthesized into double-entry tables to then be selected or discarded. Subsequently, extracts of the method, results, discussion, conclusions and limitations of 12 relevant investigations were placed in the study case. As a result it was found that the majority are Inferential descriptive studies, where 50% have studied the impact of various diagnoses, also 59% have considered in the sample parents the rest represents 61%, being in the studies stress and the lack of quality of life in the mother and father, the support they receive is not enough, there are expectations from parents about availability of the service. As a conclusion, the search for the greatest amount of information on the study topic was completed, finding that 25% are Inferential Descriptive Research, 17% Econometric Method, 18% (9% Inductive, 9% Qualitative Descriptive) and 8% respectively for Narrative, Qualitative, Case Study, Theoretical and Descriptive Debate. It has also been possible to determine that stress in the mother and father affects their quality of life, the representative samples selected have been mother and father. As limitations in studies, parental volunteering to participate in studies prevails and it is recommended to deepen research on family expectations towards providers, further development in terms of policy, improvements in FQOL and resilience

Index Terms— Repercussions, disability, family, caregiver

1 INTRODUCTION

The objective of this research is to determine the repercussions of caring for a patient with a disability in the family, which is why a search has been carried out for the greatest number of information about the families or the caregiver as the main role of caring for the patient

This study is structured as follows:

First, the theoretical foundation is carried out as a result of applying the systematic review of 38 investigations. The general and specific objectives were then established. The information obtained in the procedure; they were arranged in a double entry box; as a process to analyze by author, title, the criteria for its selection and the reason for not selecting it. Subsequently, the extracts of each paragraph of the selected investigations have been placed in a matrix where the method, results, discussion, conclusions and limitations of each investigation are detailed.

Como resultado de sintetizar una vez finalizada las lecturas se elabora la discusión donde se ha comparado el logro del presente estudio respecto a identificar las necesidades, experiencias e inquietudes de las familias; con otras investigaciones incluidas en los cuadros de doble entrada para finalizar con las conclusiones obtenidas, las limitaciones y las futuras líneas de investigación posibles a desarrollar

The article is organized in 5 sections. In section 2, we review the methods of processing the impact of disability on the family. In section 3, the proposed method is explained. Section 4 explains the results obtained after applying the method; finally, the conclusions follow in the section

2 METHODS Y MATERIALS

Here are some background information related to the impact of disability on the family

2.1 Impacts on quality of life

The quality of life represents an agent of change based on the support, the community, the organizations and the practice for the provision of the service, the study considers that the quality of life is important where the disability is not only a biological characteristic but is related to context. The presence of a child with a disability generates fatigue that varies the family's lifestyle, as it requires more time willpower and can cause loss of care to other family members. As a solution, it is recommended to provide assistance and training to families [2].

The types of patient care tasks that men and women perform are completely different. While women perform more at home in time-consuming activities (cleaning), men, on average, perform activities that require more strength physical activity. This same analysis is applied in families where the impact is stronger for daughters or young female members, which would imply a greater time commitment and young men are less likely to collaborate. It recognizes the secondary effects on health and can help to design more efficient policies, it is essential to determine the causes of differences between men and women [30]

Stress related to raising a child with a disability negatively influences the quality of life of parents. Stress management with the aim of preventing and reducing it may be an important aspect of the intervention to improve the quality of life of caregivers [7]

The family is involved to a greater or lesser extent, although over time the siblings leave home and the responsibility continues on the

aging parents. This commitment is often from birth and in most cases lasts a lifetime. Concerns increased due to the lack of provision of services. Planning for the future is promoted internationally as a means of mitigating concerns that are not being heard; also as a stimulant to develop services [6]

Parents of a child with ID are not relegated to a poor quality of life. It considers that informal non-family relationships contribute in a unique way to FQOL for emotional well-being, this means that relationships matter in the configuration of perceptions, family, friend, professional. You can add specificity to design parenting practices and policies. You can also add religiosity, general spirituality. However Along with accurate information, effective interventions and appropriate referrals, professionals should reinforce messages of hope and encouragement to parents about the quality of their family life in the future [4]

Although parents of a school-age child with a disability are happy to adopt the role of caregiver and appreciate the positive aspects of having a child with a disability, lack of support within the education system and long-term caregiving has an effect. harmful that impacts on the occupations of parents, their health and well-being and, consequently, on the quality of life of their family [3]

Families caring for a child with DS experience considerable social and economic impact. The greater burden of care is on the mother than the father. Interrupted work life is mostly for mothers. Care activities are related to: Seizure surveillance, medical care, daily tasks due to intellectual disability, behavior, communication, sleeping and eating disorders [23]

Parents' perceptions of family support, stress and Quality of Life (ASD) have been considered dynamically, especially in the Chinese context. Several conclusions can be drawn: A systematic family support network should be provided for both mothers and fathers to improve ASD. The study indicates that family support can significantly predict ASDL for Chinese families by providing professional support, respite care to prepare families to respond to stress and develop resilience. Psychological support, mental health services, and informational support can also be provided [38].

Researchers analyze the impact of disability on the quality of life of families due to the lack of professional care services, the distribution of activities between men and women is not the same, women always have a greater workload , also mostly work is interrupted for women from the birth of the child. The siblings eventually leave home, but the parents continue to care for the patient even as they age. Causing effects of stress and poor quality of life in families. They recommend providing psychological support and developing resilience.

2.2 Impact on mental health

Reports on the mental health of parents of children with disabilities in Australia. The findings highlight that some parents of children with ID are at increased risk of experiencing mental health difficulties, underscoring the importance of providing information and interventions to promote their mental health. Severe and extremely severe depression are shown in the results. The demands associated with caring for the disability can exceed the resources of

some parents and contribute to increased stress and other mental health difficulties [15].

Parents are emotionally affected by the diagnosis of the illness of a child with an intellectual disability. Therefore, health professionals must be aware of the emotional disturbance that such a diagnosis can cause in parents and be sensitive to their needs to support them in this process [23]

Service providers can improve patient care; focused and collaborative with parents; explicitly discussing parental expectations at the beginning and during therapy. Parental satisfaction and participation in therapy can be improved if parents and service providers negotiate and agree on service expectations [30].

Several studies highlighted health issues that arose for parents of a child with ID and identified challenges that parents experienced around adjustment, coping responses, and acceptance. They have experienced poor physical and mental health that they attributed to parenting a young child with ID. There were more positive gains, less stress, and fewer symptoms of anxiety and depression experienced by the children's parents when acceptance was present [20].

Researchers highlight that some parents suffer from greater mental health difficulties when the child is young and show severe and extremely severe depression. Therefore, health professionals must give the diagnosis taking into account the causes that can be generated in the parents and be more sensitive with them. Regarding the services that caregivers provide, it may be better if they negotiate and agree on the expectations of the parents regarding the service provided. When acceptance of the symptoms of anxiety and depression is present, there is greater gain for families.

3. PROPOSED PROCEDURE

In order to develop the research, a systematic review had to be carried out to identify the points of view and experiences of families when they are caring for a relative with disabilities. The search began by previously making a list of keywords referring to the subject of study, in Table No. 01 each of the categories that were used are listed.

Categories

- Disability repercussions
- Disability in the family
- Children with disabilities
- Relatives with disabilities
- Disability family
- Consequences of disability
- Effects of disability on the family
- Effects of disability
- Parents' experiences with disability
- Raising children with disabilities
- Perceptions of disability
- Significance of disability
- Sequel to disability

The method consists of determining the impact of caring for a disabled patient on the family. In order to do this, the greatest amount of information must first be sought on families that have a relative with a disability. Second, to find the theory or the construct that may

be useful to carry out standardized measurements on the functioning of families that have a relative with a disability. Third, determine the variable (s) that is affecting the theory that has been commented previously on the functioning of families that have a relative with a disability.

In the search, the databases used were: SCOPUS, EBSCO HOST, GOOGLE SCHOOL; When entering the elements, the selection process is focused, and it is important to define detailed criteria in the selection protocol that specify the study design, method, discussion, limitations, results, conclusion and proposal.

The search is oriented towards obtaining recent publications between 2005 and 2020, the search was broadened to increase the range between the years 2004 and 2014. As well as the language.

The time used for the search was four days. As expected, many entries appeared, so it was necessary to further narrow the search field using and, or, of, the. As a result, once a quantity of literature was detected, the availability of the material was verified, at this stage the evaluation criteria were established for their relevance to the question posed and a total of 38 studies were included.

Each study was carefully read and then analyzed. Relative information such as author (s), title, selection criteria was extracted from each study; Four themes were identified in the review: emotional impact, mental health and parental coping, support systems, hope, and fears.

More research is needed on the needs of parents regarding how to acquire support to play a fuller role in the lives of their children, since there is currently little work on the perception of the quality of families with school-age children and to a lesser extent on minors and special educational needs. [2]

3.1 Data analysis

For the data analysis, a double entry table is prepared where the information is ordered as; the title, author (s), the selection criteria and the reason for the article that was not selected, in total 38 studies were found.

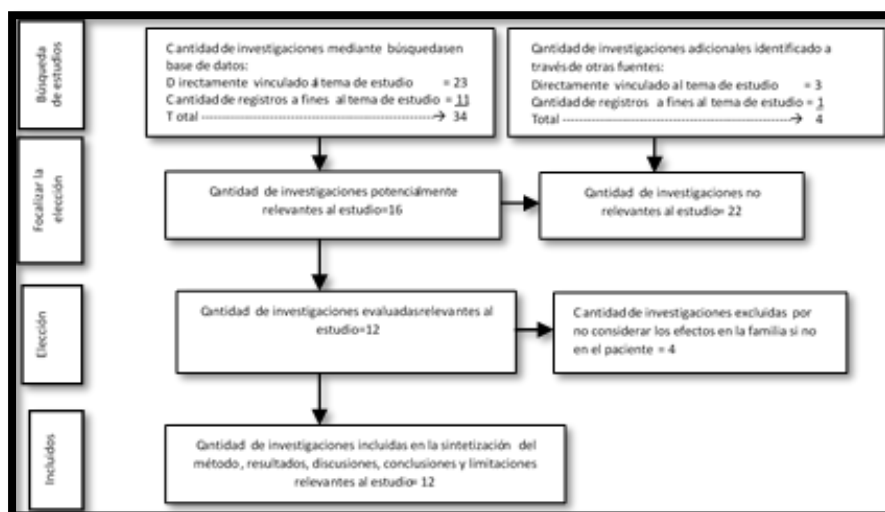


Figure.1 Proposed method

Once the search in databases and other sources has been completed, the choice should be focused on the subject of study. As a result, potentially relevant studies will be obtained. Investigations data is evaluated if complete to choose. Once the choice is finalized, the total number of studies are included in a double entry table to synthesize the method, results, discussions, conclusions and limitations of the relevant research.

4 RESULTS

The 38 investigations were exhaustively read as a result of the database searches, of which 34 were found and from other sources 4. Of the total, it was necessary to focus considering selection criteria regarding the subject of study as a result there were 16 relevant studies. Of which 4 had to be discarded because it did not consider the effects on the family but on the patient. Therefore, the number of investigations considered for the synthesis was 12.

Nº	Author (s) (year)	Title	Selection criteria Reason	Item not selected Reason
1	Michelsen, S., Esben M Flachs, E.M., Madsen, M & Peter Uldall, P. (2015)	Parental social consequences of having a child with cerebral palsy in Denmark.		Repercussions on the parents in the economic situation of the families.
2	Save, J., Poncelin, D & Auvin, S. (2013)	Caregiver's burden and psychosocial issues in alternating hemiplegia of childhood.		Investigate parental perceptions and psychosocial issues of AHC.
3	Tøssebro, J & Wendelborg, C (2015)	Marriage, Separation and Beyond: A Longitudinal Study of Families of Children with Intellectual and Developmental Disabilities in a Norwegian Context.		Separation of marriages
4	Pacheco, D. (2018)	Spillover Effects of Long-Term Disabilities on Close Family Members.	It evaluates the effect of living with a relative dealing with a long-term disability, they evaluate the health status of the relatives, resulting in the impact that depends on sex and role in the family. In general, women show more negative	

			effects. For children, the impact depends on the relationship with the disabled person	
5	Chakraborty, B., Rao, A., Shenoy, R., Davda, L &Suprabha, B. (2019)	Stress-mediated quality of life outcomes in parents of disabled children: A case-control study.	The purpose of the present study was to determine whether caring for a child with a disability influences the physical and mental health of caregivers and whether stress is related to the quality of life of caregivers of a child with a disability.	
6	Uematsu, M., Numata-Uematsu, Y., Aihara, Y., Kobayashi, T., Fujikawa, M., Togashi, N., Shiihara, T., Ohashi, K., Hattori, A., Saitoh, S & Kure, S. (2020)	Behavioral problems and family distress in tuberous sclerosis complex.		The objective of the investigation is the patient.
7	Gardiner, E., Millera, A &Lach, L. (2020)	Service adequacy and the relation between child behavior problems and negative family impact reported by primary caregivers of children with neurodevelopmental conditions.		They found it difficult to determine how the perceived inadequacy of services for children and families compares. I have made a correlational comparison. Children with more behavior problems were associated with perceptions of a greater number of dissatisfied children and the

				need for family service, as well as with a greater perceived negative family impact.
8	Nabbout, R., Dirani, M., Teng, T., Bianic, F., Martin, M., Holland, R., Chemaly, N & Coque N. (2020)	Impact of childhood Dravet syndrome on care givers of patients with DS. A major impact on mothers.	The study rated parents on their general health	
9	Manor, I., Benatov, J & Abu-Kaf, S. (2019)	Social support, depression, and somatization among Bedouin mothers of adolescents with or without developmental disabilities.		The objective of the research is towards the comparison between situations only of the mother
10	Matsuzawa, A., Shiroki, Y., Arai, J & Hirasawa A. (2020)	Care coordination for children with medical complexity in Japan: Caregivers' perspectives.		The objective of this study was to describe the provision of care coordination services to children with medical complexity, to explore the factors associated with the quality of the service.
11	Armijos, Y. & Sierra, J. (2019)	Fathers matter too! Lived experience of pedagogical hope in raising children with Down syndrome.		The experiences of parents with a child with special abilities are discussed, however the repercussions or impact of raising a child with a disability are not discussed.

12	Phoenix, M., Smart, E & King, G. (2019)	'I Didn't Know What to Expect': Describing Parents' Expectations in Children's Rehabilitation Services.	Describes the nature, training and impact of parents of children with disabilities	
13	Bhopti, A., Brown, T & Lentin, P. (2019)	Opportunities for participation, inclusion and recreation in school-aged children with disability influences parent occupations and family quality of life: A mixed-methods study.	Study the relationships between work, lifestyle and support provided, which affect the family circle of disabled children.	
14	Marsh, L., Brown, M & McCann, E. (2020)	The Views and Experiences of Fathers of Children with Intellectual Disabilities: A Systematic Review of the International Evidence.		This study talks about the experiences of parents of children with and without disabilities, however, there is little talk about the repercussions that children with disabilities generated on their parents
15	Marsha, L., Brown, M & McCann E. (2020)	The views and experiences of fathers regarding their young child's intellectual and developmental disability diagnosis: findings from a qualitative study.	They examine the views and experiences of parents after their child's diagnosis; with an intellectual disorder, a qualitative design was used to obtain the views and experiences of parents.	
16	Marsh, L., Warren, L & Savage, E. (2018)	"Something was wrong": A narrative inquiry of becoming a father of a child with an intellectual disability in Ireland.	Analyzes and presents the narratives of the parents, upon receiving the diagnosis of disability in their children, a qualitative narrative	

			research design was used.	
17	Hu, X. (2020)	Chinese fathers of children with intellectual disabilities: their perceptions of the child, family functioning, and their own needs for emotional support.		Parents perception of raising children with or without disabilities
18	Zeng, S., Zhao, H., Hu, X., Lee, J., Stone-MacDonald, A & Price, Z. (2020)	Are we on the Same Page: a Dyadic Analysis of Parental Stress, Support, and Family Quality of Life on Raising Children with Autism Spectrum Disorders.	Examines parenting, support and stress in families with children with autism disabilities in China, Employing the actor-couple interdependence mediation model.	
19	Boyd, M., Lacono, T & McDonald, R. (2019)	The Perceptions of Fathers About Parenting a Child With Developmental Disability: A Scoping Review.		Parents experiences are discussed about their role in raising a child with a disability, however, the data obtained was not sufficient for the subject investigated.
20	Chiang, F., Hsieh, J., Fan, S., Wang, Y & Wang, S. (2020)	Does the Experience of Caring for a Severely Disabled Relative Impact Advance Care Planning A Qualitative Study of Caregivers of Disabled Patients.		Study on the experience of caregivers influences decisions of advance planning of care.
21	Benito, E. & Carpio, C. (2016)	Families with a disabled member: impact and family education	Whether the quality of household lifestyles is depleted or progresses due to the presence of a member with a disability is debated, carrying out a	

			theoretical evaluation of the effect on the family..	
22	Dobson, B., Middleton, S & Beardsworth, A. (1998)	The impact of childhood disability on family life.		Explore the additional financial costs of raising a child with a disability
23	Carr, D., Cornman, J., Freedman, V. (2019)	Do Family Relationships Buffer the Impact of Disability on Older Adults' Daily Mood An Exploration of Gender and Marital Status Differences.	Assess whether family relationships ease the stress of raising a child with a disability..	
24	Shivers, C., & Resor, J. (2020)	Health and Life Satisfaction Among Parents of Children with Physical Disabilities.		The study considers mothers who do not have disabled children
25	Christensen, B., Björk, M., Almqvist, L & Huus, K. (2019)	Patterns of support to adolescents related to disability, family situation, harassment, and economy.		Patterns of support for adolescents with disabilities
26	Boehm, T & Carter, E. (2019)	Family Quality of Life and Its Correlates Among Parents of Children and Adults With Intellectual Disability.		Child behavior associated with family impact..
27	Gardiner, A., Miller, R & Lach, L. (2018)	Family impact of childhood neurodevelopmental disability: considering adaptive and maladaptive behavior.		Study on adaptive and problematic behavior and perceived family impact
28	Morris, C., Blake, S., Stimson, A., Borek, A & Maguire, K. (2020)	Resources for parents raising a disabled child in the UK.		Help resources for parents
29	Langley, V., Totsika & Hastings, R. (2019)	Psychological well-being of fathers with and without a child with intellectual disability: a		Study children with and without disabilities

		population-based study.		
30	Du Bocage, C., Marangoni., Ferrari, F., Araújo, M., Venancio, F., Silveira da Rosa, T &Falcão , F. (2020)	Health demands and care of children with congenital Zika syndrome and their mothers in a Brazilian state.		Health claim due to ZIKA syndrome
31	Grey, J.,Totsika, V., Hastings, R., Emerson, E., Hatton, C. (2019)	Early Years Parenting Mediates Early Adversity Effects on Problem Behaviors in Intellectual Disability.		The role of parenting in the first stage from adversity
32	Columna, L., Prieto, L., Revollo, G &Haegele, J. (2019)	The perspectives of parents of youth with disabilities toward physical activity: A systematic review.		Expectation of your children's physical activity
33	Senthanar, S., MacEachen, E &Lippel, K. (2019)	Return to Work and Ripple Effects on Family of Precariously Employed Injured Workers.		Explore work-related illnesses
34	Mongeau, S., Ba, M., lightfoot, N., Macewan, L., Dphil, R & Eger, T. (2019)	Mining-Related Lower Back Injuries and the Compensation Process.		It is adjusted to the assessment of the patient.
35	Grey, J., Totsika, V & Hastings, R. (2017)	Physical and psychological health of family carers co-residing with an adult relative with an intellectual disability.		It is more suited to patient care.
36	Gardiner, E., Miller, A &Lach, L. (2018)	Family impact of childhood neurodevelopmental disability: considering adaptive and maladaptive behavior.		Identify functional predictors of the perceived impact of disability.
37	McKenzie, J &McConkey, R. (2015)	Caring for Adults with Intellectual Disability: The Perspectives of Family Carers in South Africa.		Reviews and evaluates adult care.

38	Giallo, R., Seymour, M., Matthews, J., Gavidia-Payne, S., Hudson, A & Cameron, C. (2014)	Risk factors associated with the mental health of fathers of children with an intellectual disability in Australia.	Research has focused primarily on the mental health of mothers and our understanding of the effects on fathers..
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Figure.2 Investigations related to the study topic

The 26 studies that were not considered were due to the fact that when reading the investigations, it was found that the information did not influence the subject of study in [26] the impact was on the economic part. The one from [32] investigated perceptions in the AHC. [35] studied the effects of separation of marriages. [37] the study objective was patient effects. [13]

It was difficult for them to determine how the perceived inadequacy of services for children and families compares. [19] towards the comparison between situations only of the mother. [24] described the provision of care coordination services. [1] I talk about the lived experiences of parents. [20] talks about the experiences of parents of children with and without disabilities, [17] the perception of parents raising children with or without disabilities. [5] the data obtained were not sufficient for the subject investigated. [8] influences advance care planning decisions. [11] explores the additional financial costs of raising a child with a disability. [34] the study considers mothers who do not have disabled children. [9] patterns of support for adolescents with disabilities.

[4] child's behavior associated with family impact. [14] study on adaptive and problem behavior. [26] investigated help resources for parents. [18] studies children with and without disabilities. [12], Health claim for ZIKA syndrome. [36] the role of parenting in the first stage from adversity. [10] expectation about their children's physical activity. [33] explores work-related illnesses. [27] is adjusted to the assessment of the patient. [25] reviews and evaluates adult care. [35] identifies functional predictors of the perceived impact of disability. [16] is more suited to patient care. [37] the objective of the research is the patient.

Most of the 12 studies presented are of the Inferential Descriptive type that represents 25%, followed by the Econometric Method with 17%, 9% are Inductive, Qualitative Descriptive and 8% are respectively for Narrative, Qualitative, Case Studies , Theoretical and

Descriptive Discussion as shown in Figure 2

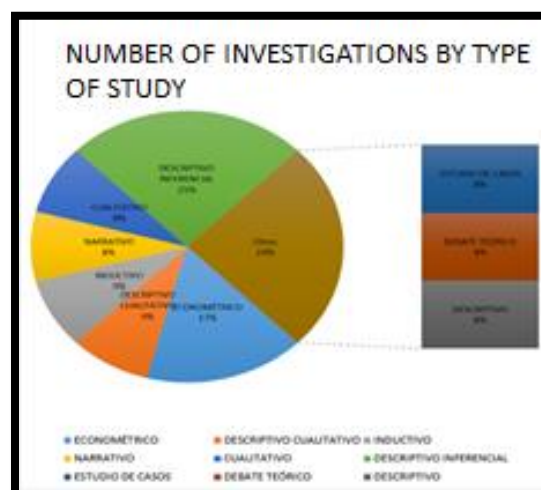


Figure 3. Number of investigations by type of design

In Figure 3., it can be seen that 50% of investigations have studied the repercussions of different diagnoses of disability in the family; followed by ID cases with 17%, DS 9%, 8% respectively for IDD and others 16% (ASD 8%, FQOL 8%).

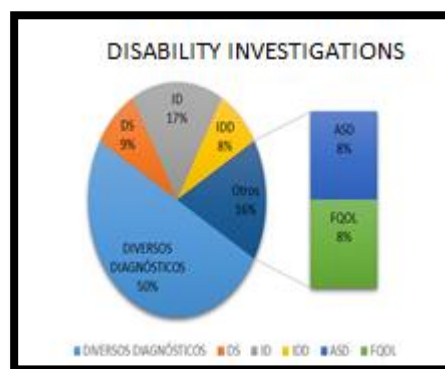


Figure 1 Investigaciones por discapacidad

In Figure 4., the data obtained from the 12 studies are presented, where 59% have considered fathers and mothers in the sampling; 9% to families and 8% correspond to caregivers, households, couples and theoretical and empirical literature; in other words, the patient who is not necessarily in the care of his parents if he cannot be someone else.

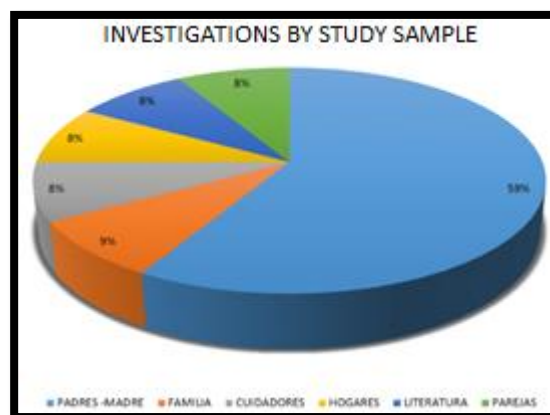


Figure 5. Investigations by study sample

In Figure 5., the repercussions found in the family in the care of the disability of the children are presented.

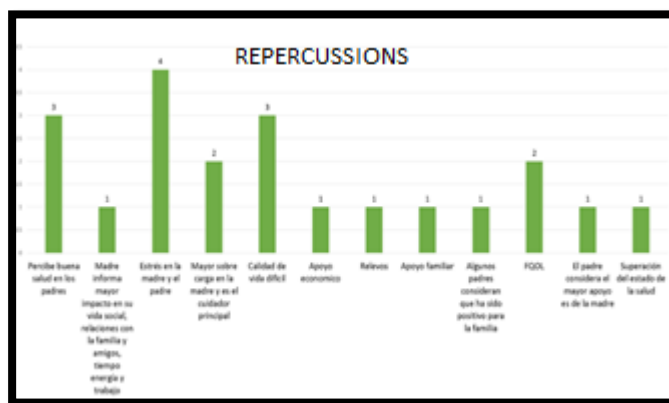


Figure 6. Repercussions

Although there are 3 studies of the twelve that perceive good health in parents; It can be observed that four studies have found greater stress on the mother and father, as well as 2 studies consider that she is the main caregiver and in 02 investigations it has been found that the mother has the greatest burden on patient care. Just as in an investigation the father considers that the greatest support is from the mother. There are 3 studies that have considered that the quality of life of the parents is very difficult. Families have economic support, in some countries there are relays but it is not enough, a lack of professionalism was also found on the part of the health personnel when reporting the diagnosis of disability, it is convenient to highlight what Benito, et al. (2016) on the pain that parents feel at the beginning when they learn that they lost a healthy child; but that as time passed, the pain disappeared, Pacheco, et al. (2018) also mention that over time people adapt and will gradually improve their health. Giallo, et al. (2014) explain that socioeconomic factors did not predict mental health difficulties. The strongest predictors of parental mental health difficulties were children's behavioral problems, daily stress arising from parents' own needs and childcare needs, and low parental satisfaction. For Zeng, et al. (2020) the perception of the quality of family life was statistically significant ($\beta = -0.440$, $p < 0.001$). Also the effect of the perceptions that parents have on family support; stress was not statistically significant ($\beta = 0.064$, $p = .158$). The socioeconomic effect of fathers and their stress on the mothers' FQOL was not statistically significant ($\beta = -0.081$, $p = .033$). For Marsha, Brown, Mccann (2020) explain in their study that there are signs of guilt, feelings of pain and loss for the expected healthy baby that parents experience in the first stage, that is why it is important; coincides with Benito, et, al (2016) when he explains that with disability there are feelings such as loss, pain, doubt, threat, shock and impotence. The stage that the family goes through is shock or initial shock upon receiving the diagnosis; therefore it is important to consider what Phonix et al. (2019) that parents had expectations about the availability of the service and how it would be offered and whether the services included their knowledge, skills, relationships and communication with children and parents. In the study by Nabbout et al. (2020) 50% of parents answered that having a child with DS upsets their social life and their relationships with family and friends all the time or very often.

5 CONCLUSIONS

In relation to the first step of the method, the greatest amount of

information on the families that have a relative with a disability has been sought, queries made in databases to find the greatest number of information on the families that have a relative with a disability, and other sources, considering a time of the last five years, finding in the systematic review that 25% are descriptive Inferential research, followed by 17% which is an econometric method, 9% is Inductive, Descriptive Qualitative and 8% is respectively for Narrative, Qualitative, Case Studies, Theoretical and Descriptive Debate. In the second step, the theory or the construct that may be useful to carry out measurements in a standardized way on the functioning of families that have a relative with a disability was found, it has been possible to collect various data within the selected articles since it has been determined that stress in the mother and father controls the quality of life and 33.33% of the studies reviewed have coincided, the variable that is affecting the theory, despite perceived good health, families suffer from stress, economic support necessary is not related to the quality of life of the caregivers, but if the expectations of the parents towards the service provider

Finally, in the third step to know which variable is affecting the theory about the functioning of families that have a relative with a disability, the selected information emerges that 58.33% of the investigations as a sample have considered fathers and mothers, of which 50% of the study have studied the repercussions of various disabilities, followed by ID with 16.66%; the rest has 8.33% between ID, ASD, FQOL

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