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REVIEW

Characteristics of the family caregiver of a child with intellectual disability: Integrative review

Características del cuidador familiar del niño con discapacidad intelectual: Revisión integradora

Características do cuidador familiar de uma criança com deficiência intelectual: Revisão integrativa

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Abstract

Introduction: The family caregiver, an intrinsic unit in the context of children with intellectual disabilities, requires help to carry out various activities, because their subject of care cannot carry them out on their own, since they require more care and supervision. **Objective:** Describe the main characteristics of the family caregiver of a child with intellectual disability. **Methodology:** Integrative review in PUBMED, LILACS and Scielo databases, considering as inclusion criteria: seniority ≤ 10 years, in English, Spanish and Portuguese, that the study subject was the family caregiver (mothers or fathers) not the child with intellectual disability. The descriptors family caregiver, intellectual disability, child, informal caregiver and the Boolean operator AND were used. 494 articles were obtained, eliminating 474 that did not meet the inclusion criteria. 20 articles were analyzed and 13 were discriminated, therefore only 7 made up the sample. **Results:** The caregivers were between 35 and 40 years old; they were from the middle or lower social class, with secondary school finished. The caregivers were mainly housewives and experienced depression, anxiety and stress, some used the religious coping mechanism. **Conclusions:** Care overload and life quality in caregivers depended on the severity of the child's disability, and whether or not they were sent to special institutions. Nursing interventions should be aimed at identifying family functioning trying to improve the quality of life of the caregivers and develop family empowerment to reduce work overload and the psychological symptoms they show.

Key words: Nursing; Caregivers; Intellectual disability; Child (DeCS).

Resumen

Introducción: El cuidador familiar, unidad intrínseca del contexto de los niños con discapacidad intelectual, requieren ayuda para realizar diversas actividades, porque su sujeto de cuidado no puede efectuarlas por sí mismo, y éstos demandan más cuidados y supervisión. **Objetivo:** Describir las principales características del cuidador familiar del niño con discapacidad intelectual. **Metodología:** Revisión integradora en bases de datos PUBMED, LILACS y Scielo, considerando como criterios de inclusión: antigüedad ≤ 10 años, en idioma inglés, español y portugués, que el sujeto de estudio fuera el cuidador familiar (madres o padres) no el niño con discapacidad intelectual. Se utilizaron los descriptores family caregiver, intellectual disability, child, informal caregiver y el operador boleano AND. Se obtuvieron 494 artículos, eliminándose 474 que no cumplían los criterios de inclusión. Se analizaron 20 artículos y se discriminaron 13, por lo cual solo 7 conformaron la muestra. **Resultados:** Los cuidadores tenían entre 35 a 40 años, eran de clase social media o baja, con secundaria terminada, las cuidadoras eran principalmente amas de casa; los cuidadores experimentaron depresión, ansiedad y estrés, algunos utilizaron el estilo de afrontamiento religioso. **Conclusiones:** La sobrecarga de cuidado y calidad de vida en los cuidadores dependió de la gravedad de la discapacidad del niño, y si los enviaban o no a instituciones especiales. Las intervenciones de enfermería deben estar encaminadas a identificar el funcionamiento familiar para intentar mejorar la calidad de vida de los cuidadores y desarrollar el empoderamiento familiar que disminuya la sobrecarga de trabajo y síntomas psicológicos que padecen.

Palabras clave: Enfermería; Cuidadores; Discapacidad intelectual; Niño (DeCS).

Abstrato

Introdução: O cuidador familiar, unidade intrínseca no contexto da criança com deficiência intelectual, necessita de ajuda para a realização de diversas atividades, pois seu sujeito de cuidado não consegue realizá-las sozinho, pois necessita de mais cuidados e supervisão. **Objetivo:** Descrever as principais características do cuidador familiar de uma criança com deficiência intelectual. **Metodología:** Revisão integrativa nas bases de dados PUBMED, LILACS e Scielo, considerando como critérios de inclusão: antiguidade ≤ 10 anos, em inglês, espanhol e português, que o sujeito do estudo fosse o cuidador familiar (mães ou pais) e não a criança com deficiência intelectual. Foram utilizados os descritores cuidador familiar, deficiência intelectual, criança, cuidador informal e o operador booleano AND. Foram obtidos 494 artigos, eliminando-se 474 que não atendiam aos critérios de inclusão. Foram analisados 20 artigos e discriminados 13, portanto apenas 7 compuseram a amostra. **Resultados:** Os cuidadores tinham entre 35 e 40 anos; eram de classe social média ou baixa, com ensino médio completo. Os cuidadores eram principalmente donas de casa e vivenciavam depressão, ansiedade e estresse, alguns utilizaram o mecanismo de enfrentamento religioso. **Conclusões:** A sobrecarga de cuidados e a qualidade de vida dos cuidadores dependiam da gravidade da deficiência da criança e do encaminhamento ou não para instituições especiais. As intervenções de enfermagem devem ter como objetivo identificar o funcionamento familiar tentando melhorar a qualidade de vida dos cuidadores e desenvolver o empoderamento familiar para reduzir a sobrecarga de trabalho e os sintomas psicológicos que eles apresentam.

Palavras-chave: Enfermagem; Cuidadores(as); Deficiência intelectual; Filho(a) (DeCS).

Introduction

The World Health Organization (WHO) describes disability as a frequent concept that addresses deficiencies, activity restrictions and intervention limitations, reflecting the interaction between society and the characteristics of the human being who lives in such society. Impairments are problems that affects the body preventing task performance and participation in life situations (1). Worldwide, it is possible to detect the incidence of intellectual disability (ID), visualizing it mainly in the functionality of the individual, presenting an immediate prevalence of 1-4%. Latin America shows a regularity that is four times higher than the aforementioned prevalence, due to its relationship to situations such as malnutrition, complications during and after pregnancy, prematurity, lead poisoning, dysfunctions of the Central Nervous System (CNS), and low financial resources (2). According to data from the National Institute of Statistics and Geography (INEGI by its acronym in Spanish), approximately 8 million people were reported having a disability, that is, approximately 6.4% of Mexico’s population (3).

Disability affects personal development, which is an experience at personal, family and cultural level, affecting not only the person who suffers from it but also their entire environment and their caregivers (4). The Diagnostic and Statistical Manual of Mental Disorders (DSM-V) defines ID as a disorder that begins during the course of development and that involves limitations of intellectual work, as well as adaptive behavior in the conceptual, social and practical domains (5).

The family caregiver is an intrinsic unit in the context of children with ID (6). These children require help in carrying out the diversity of activities that due to their condition make it impossible for them to carry out, demanding supervision according to their degree of disability (7). According to the Royal Spanish Academy, the caregiver is "the person who cares, who is careful or very involved" (8), the family caregiver is "the person close to the child with disabilities who is responsible for providing support mainly to his/her physical and emotional activities in a permanent and compromised way" (9,10). Therefore, informal care is characterized by being an activity usually performed by women, unpaid, developed in the domestic sphere and based on kinship and affective relationships (11), in addition to not having training and having a high level of commitment toward their homework, regardless of limits and schedules (12).

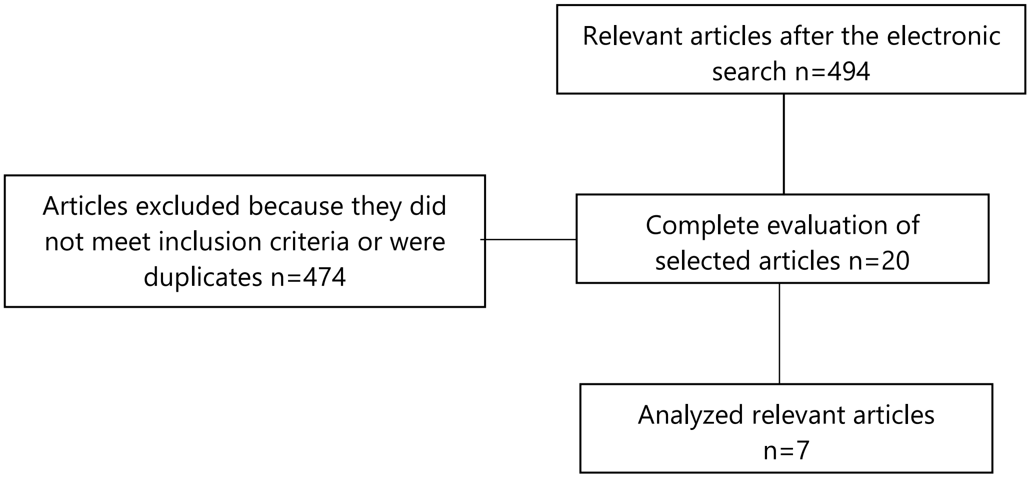
The caregiver requires family and social support, establishing limits on their task and delegating functions and care, allowing themselves to receive help to put aside their role as a critical person for the care recipient (12,13). In mid-2016 (14), in Mexico, according to the data provided by the National Survey of Occupation and Employment (ENOE), approximately 286 thousand people had the responsibility of caring for dependent individuals. Being the case, the well-being and health of caregivers is of vital importance for nursing personnel. Their actions can have cultural recognition and a strengthening regarding the support to caregivers from the field of public health (15-17). Based on the above, a comprehensive overview is provided for nursing to develop various interventions in the informal caregiver, contributing to the scientific output of care, the subject-matter of the nursing profession. In addition to have a significant impact on the health of the family or informal caregiver. The objective of this review was to describe the main characteristics of the family caregiver of a child with ID, in order to identify the main needs that caregivers express, to design nursing care interventions that can meet these needs, that is, to care for the caregiver.

Methodology

Integrative review was carried out, allowing the synthesis of knowledge on a specific topic, helping to reconceptualize a problem and a contribution to the advancement of the nursing discipline (18). Likewise, it facilitates the formulation of general conclusions and reflections on future research (19). In nursing, this type of evidence accelerates the transfer of generated scientific knowledge to nursing practice in different scenarios (20). The guiding research question was: What evidence does the literature have about the characteristics of the family caregiver of a child with ID? The bibliographic search was carried out from February to March 2021 in the following databases: National Library of Medicine (PUBMED), Latin American and Caribbean Literature in Health Sciences (LILACS) and Scientific Electronic Library Online (Scielo), using the descriptors family caregiver, intellectual disability, child, informal caregiver, and the Boolean operator AND.

The inclusion criteria established were articles in Spanish, English and Portuguese, published from 2011 to 2021, family or informal caregiver of a child with ID as subject of study; the exclusion criteria included professional caregivers or people who received financial remuneration for the care offered. For the synthesis of data, the objectives, methodology, results and main conclusions of each of the articles reviewed were considered; likewise, the characteristics of the family caregiver were taken into account. 494 articles were located with the search terms and filters used, of which 474 articles that did not meet the inclusion criteria and duplicates were excluded. After the analysis of titles and abstracts, 21 articles were selected that met the inclusion criteria, a critical reading and discrimination of articles was carried out, leaving a sample of 7 articles to analyze (Figure 1).

Figure 1. Search Protocol for Scientific Articles, 2021.



Source: Own development

To carry out the integrative review, the PRISMA quality criteria that apply to the aforementioned methodology were taken up. These PRISMA quality criteria clearly provides the objectives or questions addressed by the review, which specify the inclusion and exclusion criteria of said review, specify the methods used to assess any bias, specify the methods used to present and synthesize the results, provide the total number of studies and participants included, as well as their characteristics, providing a general interpretation of the results and their important implications (21).

Results

The studies were carried out in the last 10 years, in different countries such as Japan, Australia, Mongolia, India and China; it was observed that the English language was the predominant language and the methodological approach of all the studies were quantitative and descriptive. The samples studied in the reviewed articles were between 80 and 1659 family caregivers of children with ID. The most commonly observed topics were assessing the level of burden and the severity of depression of the mother and father, related to the care of children with ID who either attended a special school or not, factors associated with the empowerment of caregivers who were family members who raised children with ID, the psychological status and its relationship with the caregiver's coping styles, family operation and quality of life (QoL) of the caregivers as well as the family QoL of the caregivers of children with ID, and from these the various situations experienced by the caregiver can be identified, in addition to be an opportunity for the nursing approach to the family caregiver (Table 1).

Table 1. Description of articles reviewed, 2021: n=7

Title	Authors	Magazine/ Year	Study type	Methodology
Caregiver burden in children with intellectual disability: Does special school education help? (22)	Ramasubramanian, Chellamuthu, Selvikumar, Pandian, Gopi.	Ind Psychiatry J. 2019	Descriptive/ Correlational	The Zarit Burden Interview scale was used to assess the level of burden experienced by caregivers. The Major Depression Inventory scale was used to assess the severity of depression experienced by caregivers.
Family empowerment and associated factors in Japanese families raising a child with severe motor and intellectual disabilities (23)	Wakimizu, Fujioka, Nishigaki, Matsuzawa.	Int J NursSci. 2018	Descriptive	Cross-sectional anonymous questionnaire survey, 1659 primary caregivers raising a child with severe motor and ID in 89 special schools participated.
Psychological status and coping styles of caregivers of individuals with intellectual disability and psychiatric illness (25)	Panicker, Ramesh.	J Appl Res Intellect Disabil. 2019	Descriptive	The caregivers (N=80) of people with ID (n=40) and PI (n=40) were administered a sociodemographic questionnaire, a depression, anxiety and stress scale and a COPE inventory.

Mediating effects of family functioning on the relationship between care burden and family quality of life of caregivers of children with intellectual disabilities in Mongolia (26)	Kim, Kim, Park, Yoo, Gelegjamts.	J Appl Res Intellect Disabil. 2020	Correlational	Sample of 150 caregivers of children with ID from October 2017 to November 2017.
Health-related quality of life amongst primary caregivers of children with intellectual disability (27)	Arora, Goodall, Viney, Einfeld.	J Intellect Disabil Res. 2020	Descriptive	Caregivers of a child with ID between the ages of 2 and 12 completed an online survey to determine their QoL consistent with caregiver well-being using the EQ-5D-5L measure.
Family quality of life of Chinese families of children with intellectual disabilities (24)	Hu, Wang, Fei.	J Intelecto Discapacitado Res. 2012	Descriptive	Sample of 442 families, a confirmatory factor analysis was used to test the factorial structure of FQoL (family QoL).
The Early Positive Approaches to Support (E-PAtS) study: study protocol for a feasibility cluster randomised controlled trial of a group programme (E-PAtS) for family caregivers of young children with intellectual disability (28)	Coulman E, Hastings R, Gore N, Gillespie D, McNamara R, Petrou S, et al	Pilot Feasibility Stud. 2020	Randomized controlled trial	Participating families were assigned to intervention: control on a 1:1 basis, intervention families were offered the E-PAtS program immediately. Data were collected at the start of study, 3 months after randomization, and 12 months after randomization.

Source: Own development.

The sociodemographic characteristics identified with respect to the age of the caregivers ranged between 35 and 40 years (22, 23, 24). Fathers and mothers were the main caregivers (22), belonging to the middle class who finished secondary level (22, 23, 24). In the role of caregiver, despite being performed by both parents, it was evident the predominance of women (24) and 50% of them were housewives (19) who dedicated an average of 66 hours to the care of their children with disabilities (24).

It was found that mothers of children with ID suffered more burden and depression compared to fathers; likewise, school plays an important role in the severity of burden and depression, since it is higher among parents of children who do not go to school (22).

With respect to the empowerment of families who raised a child with ID, 1362 primary caregivers showed higher empowerment scores in relation to age, higher education, regional support, lower burden and greater use of institutions and home visiting services, higher income and better family ties. Likewise, health professionals had to address the family empowerment of younger and less educated primary caregivers (23).

Depression, anxiety, and stress of family caregivers were the main symptoms experienced by them regarding their psychological status and coping styles. Religion was the most used coping style. Thus, the mental health of caregivers is of crucial importance in the quality of care they provide to the child who receives care; moreover, the use of adequate coping styles can minimize the impact of the aforementioned symptoms (25).

It was found that family operation in relation to care burden and QoL of family caregivers should be taken into account since it partially mediates the care burden and QoL of the family member. In addition, family operation should be considered for the development of interventions that support the family QoL of caregivers (26).

Caregivers with lower income and lower social support had significantly lower QoL (27). Similarly, the family QoL of the child with a disability suggests a similar structure between Chinese and American families, and is affected by the different living conditions and severity of the child's disability (24).

The lack of programs and attention to family caregivers of young children with ID became apparent, which could start the provision of care by the family caregiver of the child diagnosed with ID (28).

Discussion

Based on the objective of describing the main characteristics of the family caregiver of a child with ID, the various situations that the caregiver experienced were identified, providing an opportunity to the nursing discipline for the care of the family caregiver. Although there are many known factors in the caregiver, the lack of identification of the conditions in the family caregiver of the child with ID is of great importance, since it represents a pillar in the main caregiver of the child with disability

It became evident that overload, depression (22) and low QoL (24,27,28) as some of the conditions that the family caregiver faces, similar results were found in the main caregivers of students with mild ID (29), as well as in part-time workers dedicated to the care of students with disabilities (30). The use of support systems to empower (23) family members and improve coping strategies (25) have had positive results for children diagnosed with ID, even so, reference is made to the lack of attention to the well-being of the family caregiver (28).

The secondary level completed (22-23) was the most recurrent educational level in caregivers, while in several studies (22, 23, 27) the average age ranged between 35 and 40 years, most were housewives (23), and religion was the most used coping style (25) , while depression emerged as the most common symptom in the family caregiver (22, 25), reaffirming what was found in parents of children with developmental and intellectual disabilities, such as autism and cerebral palsy (31). Likewise, it was identified that mothers of children with disabilities had more overload and depression compared to fathers (22), according to a study carried out on adolescents with disabilities, where the mother assumed greater responsibility (32). Family operation should be taken into account for the support in the QoL of caregivers (26). Factors such as social support (23, 27), family ties (23), and low income (27) affected the QoL and caregiver empowerment. Nursing can identify the needs of families and the main family caregiver of the child with ID to improve care and promote the health of their family and the well-being of each member (32). None of the studies included in this review were developed in Mexico, and the need for scientific research in low-income countries to develop support strategies for caregivers is evident (29-31). Currently in Mexico there is a high rate of ID (3), being very important to pay attention to the informal caregiver who is mainly responsible for the needs of the child, focusing the necessary resources on family caregivers to improve their health, so that they can see them reflected on the welfare of the care recipient.

Conclusions

The large percentage of studies are aimed at the child with ID, the nursing professional being an important actor in care of this illness; likewise, literature indicates the little existing evidence regarding a crucial element in the context of the child with ID: the family caregiver.

This review reflects how the family caregiver of the child with ID, father or mother, showed high levels of overload, depression, stress and low QoL, which can be addressed by the nursing personnel to reduce the negative impact on the child's family caregiver.

Conflicts of interests

The authors declare that there is no conflict of interest.

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