

MENDIVE



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Original article

Educational guidance needs in families of people with disabilities: a challenge for nursing staff

Necesidades de orientación educativa en familias de personas con discapacidad: un reto para el personal de enfermería

Necessidades de orientação educacional em famílias de pessoas com deficiência: um desafio para a equipe de enfermagem

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ABSTRACT

The present study is developed motivated by the importance of recognizing the educational guidance needs of family members of people with disabilities who live in the community, and the role of nursing staff in this sensitive work. The objective is proposed: to characterize the behavior of the educational guidance needs of families of people with disabilities in the Acamixtla community, Municipality of Taxco de Alarcón, Guerrero, Mexico, using historical-logical and analysis-synthesis as theoretical methods, as well as the survey and the group interview as empirical level methods. We worked with a sample of 12 family members of people with disabilities from the community, selected from a non-probabilistic and intentional sampling. The results reflected that the need to receive some type of educational guidance is recognized, especially regarding knowledge about disability, health management and educational management; as well as the relevant role of nursing staff in meeting the educational guidance needs of families. It is concluded that it is necessary to design educational actions from the perspectives of primary health care, which strengthen this sector that is so sensitive and demanding of support.

Keywords: educational orientation; family; nursing staff.

RESUMEN

El presente estudio se desarrolla motivado por la importancia de reconocer las necesidades de orientación educativa de los familiares de personas con discapacidad que viven en la comunidad, y el papel del personal de enfermería en esta sensible labor. Se propone como objetivo: caracterizar el comportamiento de las necesidades de orientación educativa de las familias de personas con discapacidad en la comunidad Acamixtla, Municipio de Taxco de Alarcón, Guerrero, México, empleando como métodos teóricos el histórico-lógico y el de análisis-síntesis, así como la encuesta y la

entrevista grupal como métodos del nivel empírico. Se trabajó con una muestra de 12 familiares de personas con discapacidad de la comunidad, seleccionados desde un muestreo no probabilístico e intencional. Los resultados reflejaron que se reconoce la necesidad de recibir algún tipo de orientación educativa, sobre todo respecto a los conocimientos sobre la discapacidad, manejo de la salud y manejo educativo; así como el papel relevante del personal de enfermería en la satisfacción de las necesidades de orientación educativa de las familias. Se concluye que es necesario diseñar acciones educativas desde las perspectivas de la atención primaria de salud, que fortalezcan este sector tan sensible y demandante de apoyo.

Palabras clave: orientación educativa; familia; personal de enfermería.

RESUMO

O presente estudo é desenvolvido motivado pela importância de reconhecer as necessidades de orientação educativa dos familiares de pessoas com deficiência que vivem na comunidade e o papel da equipe de enfermagem nesse sensível trabalho. O objetivo é caracterizar o comportamento das necessidades de orientação educacional das famílias de pessoas com deficiência na comunidade de Acamixtla, município de Taxco de Alarcón, Guerrero, México, utilizando como métodos teóricos o histórico-lógico e a análise-síntese. e a entrevista em grupo como métodos de nível empírico. Trabalhamos com uma amostra de 12 familiares de pessoas com deficiência da comunidade, selecionados a partir de uma amostragem não probabilística e intencional. Os resultados refletiram que é reconhecida a necessidade de receber algum tipo de orientação educacional, principalmente no que diz respeito ao conhecimento sobre deficiência; gestão em saúde e gestão educacional; bem como o papel relevante da equipe de enfermagem no atendimento às necessidades de orientação educativa das famílias. Conclui-se que é necessário desenhar ações educativas na

perspectiva da atenção primária à saúde, que fortaleçam esse setor tão sensível e exigente de apoio.

Palavras-chave: orientação educativa; família; equipe de enfermagem.

INTRODUCTION

The family has been, for some time, the center of many investigations that have constituted an entire theoretical-methodological arsenal that has served as a source to solve the different scientific problems that arise from its attention; However, there are problems that affect the family and that require special attention, since these are paths that are very little traveled within the family world.

This research is the fruit of the motivation to understand the universe of the family in its most intricate and interesting spaces of development; In this case, the reality of families who have had before them the challenge of carrying out the training of boys and girls with Special Educational Needs (hereinafter SEN), particularly in the intellectual area.

On this occasion, the study is based on the need to delve into a problem that, although it does not appear very frequently in our environment, in our opinion it does deserve special attention and adequate guidance, since it generates a very interesting dynamic. and complex, nuanced by very diverse myths, prejudices, stereotypes and resistance, both from within the family and from the other components of the social scenarios in which they are inserted.

It is worth assuming that the concept of SEN adopted by Mexico would be applicable to students who:

compared to his group mates, he has difficulties learning the

contents established in the curriculum, which is why he requires greater and/or different resources to be incorporated into his educational process in order to achieve the educational goals and objectives (García *et al.*, 2000, p. 49)

The concept of SEN is also comprehensive, as it refers to children and young people whose needs require specific attention during part of their schooling or throughout this period. This special attention will derive from different degrees and personal capacities of a physical, mental, cognitive or sensory order. In a certain sense, as Ainscow, Slee and Best (2019) state, Salamanca proposed an inclusion approach, although he called it integrative education or educational integration.

Among the multiple health programs that exist worldwide and particularly in Mexico, to improve the quality of life of the population, is that of care for people with SEN, to achieve, to the extent of their possibilities, their reintegration into society, especially to their families and the community.

So much so that, in 2013, the economic crisis caused the reorganization and reduction of government institutions, including the Ministry of Public Education (SEP), which caused the merger of the National Program for Strengthening Special Education and Educational Integration (PNFEEIE) with six other programs that served children from agricultural migrant families, in vulnerable situations, indigenous people, people with disabilities and even a program aimed at tele-high-schools, to create the Program for Educational Inclusion and Equity (PIEE) (DOF, 2013).

Likewise, the reform of the General Education Law (LGE) reaffirms the educational criteria stipulated in the Constitution and determines that inclusive education should address the needs, abilities, circumstances, styles and learning pace of all students, as well as eliminate any form of exclusion, discrimination and any

condition that constitutes a barrier to learning and participation (DOF, 2019b).

On the other hand, Article 15 of the General Law for the Inclusion of People with Disabilities declares that special education will have as its objective, in addition to what is established in the General Law of Education, the formation of independent living and the attention of needs. special educational needs that include, among others, severe learning, behavioral, emotional difficulties, multiple or severe disabilities and outstanding aptitudes, which allow people to have equitable academic performance, thus avoiding neglect, dropout, lag or discrimination (Niembro *et al.*, 2021).

In the field of public health, it is striking that the World Health Organization (WHO) in its Ninth General Program, Goal 7, highlights the idea that it is necessary to reduce disabilities, especially those that are avoidable, through measures appropriate preventive and rehabilitative measures and "Disabilities derived from sensory, locomotor and mental deficiencies will be significantly reduced among insufficiently served population groups" (WHO, 2018).

In this way, it is worthwhile from various roles, such as health professionals, particularly nursing, to actively address the prevention of these disabilities and, if they appear, to have the necessary tools for early intervention. In this way, achieve the educational, social and health improvement and transformation that is needed in each context.

Now, the objective of special education is to seek the formation of independent living for the person with disabilities, as well as attention to special educational needs from childhood.

An essential, basic and backbone space for this formation of independent life and, therefore, of the personality of the individual, is his family; Successive crises occur in it that test its adaptability and balance, as well as its more or less healthy functioning.

One of the most impactful life events that a family can go through is related to the presence of a child with special characteristics in its development, which do not satisfy the expectations or the ideal model that the couple had formed.

From this moment, the family begins to go through a period of adaptation and internalization that has been called by some authors, among them Castillo, B. (2021) and Quintero *et al.* (2020) as a stage of "elaboration of grief".

In this situation, family balance and its functioning are put to the test.

This event is followed by a stage characterized by fear, grief, and guilt known as depression, whose internal suffering will trigger various forms of manifestation.

When the doctor or psychologist tells the family about the problem, it is usually experienced as a strong moment, difficult to cope with and also to overcome and forget; It is a truly painful situation that is characterized by a group of emotional responses that tend to destabilize the couple and the family context (Cahuana *et al.*, 2022).

From the perspective of Vygotsky's (1981) historical-cultural approach, the essence of the interpretation of the socialization process of the disabled child in the intellectual area is that social prejudices break into this process and depress stimulation. Prejudiced parents become inhibited and then keep the child clinging to a kind of biological symbiosis, depriving them of other socializing contacts. This manifests itself, for example, when they leave him in his crib without the necessary stimulation, when they barely talk to him, smile or coo, when they do not stimulate him with physical manipulations and, later, when they do not play with the little one and also limit contact with possible playmates.

From the social-family point of view, according to data from the World Bank (WB) in its report titled "Inclusion of people with disabilities in Latin America and the Caribbean", it is stated that eighty percent of the population with disabilities in the world lives in countries with poverty; so the presence of a child with a disability demands extra expenses from the family budget, which is reduced according to the degree of impairment.

Parents often resort to overprotection to ease the burden on their children, rather than provoking and promoting independent action; primary factor for the acquisition of personal responsibility and social coexistence skills (Villavicencio, V *et al.*, 2018, p. 3).

Some positions maintain that a precarious or scarce situation in the family can increase family tension and stress. It is based on the idea that any disability that limits a family member can affect the family contexts and environment in some way. This means that emotional, social and economic instability is combined with a lack of knowledge about the problem, which worsens the situation and functioning of the family. This is especially true when the family lacks a guidance or education system that provides them with the necessary tools (Ragone M. 2023).

From the nursing role

The nurse who works in clinical or health education services in the community, at different levels of health care, has the main responsibility of providing nursing care. However, these are closely linked to health education, which favors the development of self-care capabilities, both in patients and families, to increase self-efficacy in their care (García *et al.*, 2019).

It has been seen that nursing professionals are one of the largest groups of health care providers, who are in the front line in terms of care and spend a large part of the time with the people who use their services, but they also systematically cover their families. This gives an

excellent opportunity to open opportune spaces for education.

Health education for patients is part of the nursing role and constitutes a central element of nursing care; It must be viewed from various perspectives, with the training of the nursing resource being one of the fundamental pillars so that education, as part of the professional role, is seen at the same time as part of the nursing care process; that is, integrated into the assessment, nursing diagnosis, planning, implementation and evaluation of care. Generally, the educational process is seen in parallel to the nursing work itself, instead of seeing it implicit within comprehensive, holistic and quality care. The latter generates a detriment to the educational action, since two separate processes are seen and each one has its stages: nursing process and educational process (Paz *et al.*, 2019).

This study attempts to venture into this universe, in which families can certainly benefit from the educational intervention of nursing staff, not only in an institutionalized environment, but above all in communities, where families of people with disabilities, in this case in the intellectual area, they insert themselves and lead their daily lives with many uncertainties, doubts and learning needs in order to have a more positive and stimulating impact on their children with disabilities.

From what has been analyzed above, it can be assured that the attention to families who have children with special educational needs, by health personnel, especially nursing, requires a thorough study of their characteristics, as this is a path that has not yet been completed. been sufficiently studied, which calls for more and more approaches and proposals for intervention.

From these approaches, a research question is derived: how do the educational guidance needs of families of people with disabilities behave in the Acamixtla community, municipality of Taxco de Alarcón, Guerrero, Mexico.

For this, it is necessary to establish a general objective: to characterize the behavior of the educational guidance needs of families of people with disabilities in the Acamixtla community, Municipality of Taxco de Alarcón, Guerrero, Mexico.

MATERIALS AND METHODS

A study developed from a mixed quantitative-qualitative paradigm is presented, in which the resources of both methodological approaches were used, both in the methods used and in their processing for the collection of the necessary information.

The type of study was descriptive and cross-sectional, since it goes deeper into the problem to identify its main characteristics; while a cut in time is made that offers an overview of the state of the problem at a given moment, for its possible subsequent transformation.

The theoretical methods used were: the dialectical method, as a basis and platform for the incursion into theoretical methods such as historical-logical, which allowed us to arrive at a systematization of the object of study from its manifestations throughout history, understanding its logic and contradictions; also the analysis-synthesis method, which was useful in terms of identifying the most substantial elements of the studied process, in this case the needs for educational guidance in the group studied, to transcend from there to the necessary syntheses or systematizations around to the same, from the theoretical point of view.

In the empirical field, the survey method was used, which revealed the main characteristics of the object of study, in terms of the main dimensions declared for it. In addition, the group interview was used, which offered a very enriching perspective of analysis from the group and interactive angle of the participants.

The analyzes were carried out using the SPSS statistical package in version 22 to process the survey data; and in the case of the interview, a coding and categorization process was carried out based on the dimensions that guided the understanding of the analyzed construct.

Study Category: educational guidance needs.

Analysis dimensions:

- Recognition of educational guidance needs for families of people with disabilities.
- Identification of educational guidance needs for families of people with disabilities.
- Proposals for improvement to respond to the needs of educational guidance for families of people with disabilities.
- Role of nursing staff in educational guidance, from the perspective of families of people with disabilities.

The information collected was methodologically triangulated, in order to present results in a comprehensive manner.

We worked with a sample of 12 family members of people with disabilities from the community, who were selected from a non-probabilistic sampling and an intentional selection, taking into account above all the criterion that they were currently living with a person with a disability. with due consent to participate in the research, excluding those who did not consent to participate and those who were with their family member in a delicate health condition at the time of the study.

After applying the information collection instruments, we move on to the analysis of the results obtained in the process.

RESULTS

The results are offered by triangulating the findings of the survey and the group interview and taking into account the four dimensions of the study of the *educational guidance needs category* (Fig. 1).

Recognition of educational guidance needs for families of people with disabilities

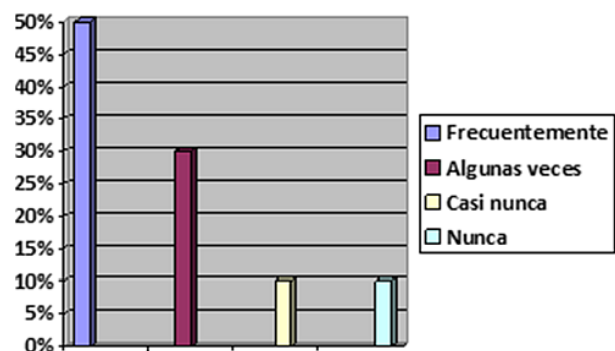


Fig. 1- Frequency with which participants recognize that they need educational guidance

Both in the survey and in the group interview, the participants stated more frequently that they recognize the need to receive some type of educational guidance, due to their situation of living with the reality of a person with a disability, especially in the case of family members of people of child age, which was evident especially in the group interview.

However, it was striking that a smaller group has almost never recognized this need, and even in their testimonies they claim not to have even realized that this could support or guide them in certain moments and critical situations they have gone through, one of the participants thus He stated: "We haven't even thought about it, the truth is that we have lived and lived without thinking that someone else can come and give us a hand."

Identification of educational guidance needs for families of people with disabilities (Fig. 2).

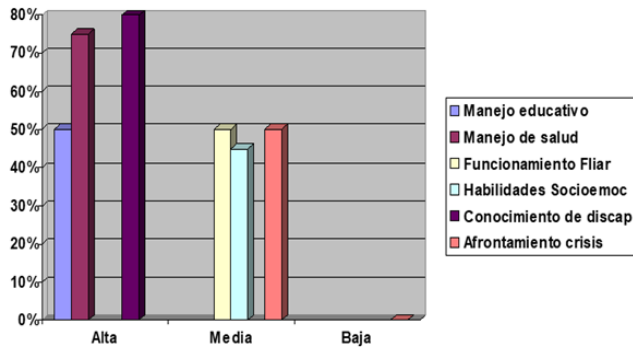


Fig. 2- Educational guidance needs identified by participants

As can be seen, in this case the main orientation needs of the participants are focused on knowledge of the disabilities suffered by their family members, which is usually a cause of doubts, uncertainties and sometimes bad practices in the family scenario.

On the other hand, it highlights the need for guidance regarding health management, since these are problems that in many cases coexist with alterations of various kinds or with symptoms and other pathologies that family members need to know about and, above all, they need to learn to manage properly.

Furthermore, among the most notable was the need for guidance for better educational management of their family member with a disability; this last element being of great value, due to the importance of the educational role of the family, especially when they attend a situation as sensitive as living with a disabled person.

Proposals for improvement to respond to the needs of educational guidance for families of people with disabilities

The proposals from family members to be beneficiaries of educational guidance were aimed above all at actions in the health sector, highlighting the following:

- Community workshops led by nursing staff, with the participation of families who need this type of help or guidance.
- Actions on virtual platforms (designed by the health sector in the territory), which allow the interaction of both the family and people with disabilities with innovative and motivating environments for guidance and learning.
- Meetings and talks with people who have had positive experiences and who can serve as paradigms and guides to those who find themselves in similar situations.
- Generation of leisure and coexistence spaces in which people in the community with disabilities feel comfortable participating and feel included.
- Inclusive activities of a sporting and cultural nature, in which people with disabilities and their families also participate.
- Systematic monitoring and attention by health workers to families of people with disabilities in the community, allowing permanent guidance and better practices and management at home.

Role of nursing staff in educational guidance, from the perspective of families of people with disabilities

In the graph shown below you can see that, even though not all families agree that the nursing staff plays an important role in this guidance work, there is a marked predominance of favorable criteria for this (Fig. 3).

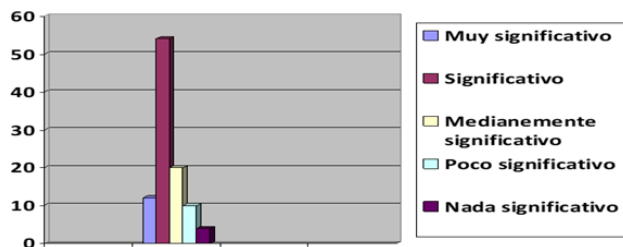


Fig. 3- Relevance of the role of nursing staff in educational guidance

DISCUSSION

By way of discussion it is important to start from the fact that it was appreciated the recognition by the participants of their need to be oriented from the educational point of view, especially in relation to the coexistence between parents and children of infant age, which is closely related to the criteria of Álvarez *et al.* (2019), considering that for parents "the expectations placed on children with disabilities who require greater support needs are less demanding than those expected in adults with mild and moderate disabilities" (p. 67).

In this sense, it is worth commenting that, for researchers on the subject, some parental attitudes, including overprotection, make it difficult for sons and daughters to make meaningful decisions and develop problem-solving skills (Morochó *et al.*, 2023). Authors such as Salazar (2022) suggest continuing to delve deeper into the study of these relationships.

According to other authors (Castro, Isla and Castillo, 2015), the identification or selection of guiding content deserves to consider the stage of development of the children, since this is directly linked to the aspects of greatest interest and that constitute needs. more heartfelt for families.

These previous findings are consistent with the results obtained in this research, since three fundamental areas of need for guidance were detected: knowledge of disabilities; health management; and educational management of their family member with a disability. All of this was linked to states of uncertainty, doubts and overprotective management evidenced by the participants.

The families studied were willing to offer in a resolute and active way very valuable suggestions for future educational guidance interventions, making it clear to the study that their views and contributions are the most realistic and effective way to reach a good psychoeducational transformation process, personalizing actions according to the specific life situation of those involved.

Indeed, the family can contribute ideas and actions that serve as guidelines for the actions of health professionals involved in ensuring effective and developmental inclusion for all. In fact, Viveros *et al.* (2022) highlight the need to shorten the gap between the family and the entire therapeutic process of rehabilitation, compensation, integration and inclusion; as well as the value of more assertive, direct and guiding communication with the entire team of health professionals, in this case the nursing staff.

On the other hand, it was evidenced in the study, in agreement with García and Gallegos (2019), the high percent of people who consider highly significant the relevance of the role of nursing staff in the development of educational guidance actions for this particular population.

It coincides with the criteria of Verdugo *et al.* (2022), by stating that currently the role of nursing covers a wide field of action in the field of health, since it participates in all levels of care, providing direct and indirect care to people throughout of his life, from the moment of conception until death.

Nursing plays a fundamental role in the accompaniment and comprehensive care of

people at all stages of their life path, so for families of people with disabilities it could become a true training, guiding pedestal and an important motivational spring for support and containment for these families, who often find themselves in vulnerable situations.

It can be argued that the issue of the needs for educational guidance by nursing staff to the families of people with disabilities constitutes a space that can still be, both theoretically and methodologically, more in-depth, considering that it is a dialectical process that transforms and enriches as humanity also evolves. The above is seen in the emergence of new needs, which are revealed in the criteria of the participants and which also denote new demands on health services.

On the other hand, it is worth highlighting, in conclusion, that the fact that the family members of people with disabilities studied recognize the need to receive some type of educational guidance is attractive and they focus this need fundamentally on the areas: knowledge about disability; health management and educational management, without underestimating that these needs are followed by other equally important ones such as family functioning; social-emotional skills; coping with crises, which builds the foundations for a structured and intentional guiding process. On the other hand, the level of maturation of these needs is evident in the development of families.

It is also concluded that the role of nursing staff in satisfying the educational guidance needs of families was considered significant by the vast majority of participants, which places these professionals in a valuable place for the community and could be expressing recognition for the work they do and that they could continue to do.

The results of this study put on the analysis table the relevance of designing educational actions from the perspectives of primary health care, which strengthen this sector that is so sensitive

and demanding of support to reach higher levels of well-being and health.

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