

DISABILITY AND FAMILY IN MULTICULTURAL CONTEXTS. A STUDY ABOUT THE REALITY IN THE AUTONOMOUS CITY OF CEUTA

DISCAPACIDAD Y FAMILIA EN CONTEXTOS MULTICULTURALES. UN ESTUDIO SOBRE LA REALIDAD EN LA CIUDAD AUTÓNOMA DE CEUTA AS NECESSIDADES EDUCATIVAS ESPECIAIS E A FAMÍLIA EM CONTEXTOS MULTICULTURAIIS. UM ESTUDO SOBRE A REALIDADE NA CIDADE AUTÓNOMA DE CEUTA

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ABSTRACT: With the objective of improving the well-being and quality of life of people with disabilities and their families, a study was carried out in the city of Ceuta to analyze and describe the needs of this group. For that purpose, 202 families (Christian and Muslim) were interviewed; all of them members of the different NGOs that care of provide services to the disabled collective of the city.

This exploratory and descriptive study adopts a methodological approach of a quantitative nature, developed through the application of a questionnaire on attitudes of families towards disability, based on the Salamanca Family Quality of Life Scale. The variables under study were Disability Perception, Support Network, Demand for Resources and Respite and Leisure.

The main results of the study made it possible to detect different deficiencies in terms of accessibility, locomotion, technical resources, economic resources, leisure activities, social integration, training and work orientation, which were lower than expected.

At the same time, it was possible to verify that, depending on the type of NGO that provided services, the opinions varied in all the dependent variables. On the other hand, the variables: sex of the child with a disability and the carer's employment situation do not show differences in the opinions on the variables considered.

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<p>PALABRAS CLAVE: discapacidad familia percepción red de apoyo recursos programa respiro</p>	<p>RESUMEN: Con la finalidad de mejorar el bienestar y calidad de vida de las personas con discapacidad y sus familias se llevó a cabo un estudio en la ciudad de Ceuta destinado a analizar y describir las necesidades de este colectivo. Partimos de la consideración de que las familias alcanzan el nivel de calidad adecuado cuando todas sus necesidades y demandas están cubiertas, sus miembros disfrutaban conjuntamente en familia, incluso persiguen y logran propósitos que son importantes para ellos.</p> <p>La investigación contó con los testimonios de 202 familias (57,4% cristianas y 42,6% musulmanas) pertenecientes a las diferentes asociaciones de discapacidad que prestan sus servicios en la ciudad. Este estudio de tipo exploratorio y descriptivo adopta un enfoque metodológico de carácter cuantitativo, desarrollado mediante la aplicación de un cuestionario destinado a medir las actitudes de las familias hacia la discapacidad, basado en la Escala de Calidad de Vida Familiar Salamanca. Las variables objeto de estudio fueron la Percepción de la Discapacidad, Red de Apoyo, Demanda de recursos y Respiro y Ocio.</p> <p>Los principales resultados del estudio permitieron detectar distintas carencias en lo relativo a necesidades de accesibilidad, locomoción, recursos técnicos, recursos económicos, actividades de ocio, integración social, formación y orientación laboral, situándose en valores inferiores a los deseables.</p> <p>También se pudo comprobar que las opiniones resultaban muy diferentes en función de la asociación de pertenencia y que el sexo del hijo con discapacidad y la situación laboral del cuidador no influyen en las variables consideradas.</p>
<p>PALAVRAS-CHAVE: NEE familia percepção rede de apoio recursos programa de descanso</p>	<p>RESUMO: Com o objetivo de melhorar o bem-estar e a qualidade de vida das pessoas com Necessidades Educativas Especiais (NEE) e as suas famílias, foi realizado um estudo na cidade de Ceuta, visando analisar e descrever as necessidades desse grupo. Consideramos que as famílias atingem o nível de qualidade certo quando todas as suas necessidades e solicitações são cobertas, e os seus membros usufruem dessa qualidade em família, conseguindo mesmo alcançar os propósitos que são importantes para eles.</p> <p>A investigação contou com os depoimentos de 202 famílias (57,4% cristãs e 42,6% muçulmanas) pertencentes a diferentes associações que prestam os seus serviços na cidade. Este estudo exploratório e descritivo adota uma abordagem metodológica de natureza quantitativa, desenvolvida por meio da aplicação de um questionário destinado a medir as atitudes das famílias em relação às necessidades, com base na escala Escala de Calidad de Vida Familiar Salamanca. As variáveis estudadas foram a percepção de NEE, a rede de apoio, a procura por recursos, descanso e lazer.</p> <p>Os principais resultados do estudo permitiram detetar diferentes carências em relação às necessidades de acessibilidade, locomoção, recursos técnicos, recursos económicos, actividades de lazer, integração social, capacitação e orientação laboral, situando-se estes em valores inferiores ao desejável.</p> <p>Verificou-se também que as opiniões foram muito diferentes, dependendo da associação a que pertenciam e que o género da criança com NEE e a situação de trabalho cuidador não influenciam as variáveis consideradas.</p>

1. Introduction

With the aim of improving life quality of persons with disability and their relatives in Ceuta, a review was done of the different components that define this quality of life, in view of past research and studies.

We can say that there is quality of life to the degree in which those affected (relatives and offspring with disability) satisfactorily perceive the different aspects that define their situation. This perception depends in turn on the basic needs

of the persons with disability and their surroundings (Verdugo, 2000). On an empirical level, the indicators of quality of life translate in the perception about the situation surrounding the disability, personal resources and collective resources available, of the social support the person with disability and his or her surroundings count on as well as time off in care and leisure they can enjoy.

Family life quality defined by Hoffman, Marquis, Poston, Summers and Turnbull, (2006), mentioned in Verdugo and Rodríguez (2011, pp. 30-31) in the five dimensions as stated in Table 1.

Tabla 1: Dimensiones que definen la calidad de vida familiar

Dimensions	Items
FAMILY INTERACTION	Enjoy time together Open expression of each other Solve problems together Support each other to achieve goals Show love and concern for each other Face difficulties of life.
ROLES OF FATHERS AND MOTHERS	The family members: Help the person with disability to: Be independent Carry out tasks and activities Get along well with others Make suitable decisions Know other people that form part of the life of the disabled member, such as friends, teachers, etc. Have time to be occupied in the needs of the person with a disability.
EMOTIONAL WELLBEING	The family: Has necessary support to alleviate stress. Has friends and other persons that offer support. Has some time for themselves. Has external help for dealing with special needs of all the members of the family.
PHYSICAL AND MATERIAL WELLBEING	The family: Has means of transport. Receives medical assistance as needed. Can assume the expenses. Feels safe at home, at work and in the neighborhood. Feels informed.
SUPPORT RELATED TO PERSONS WITH DISABILITY	The person with disability has support to: Progress at center or work Progress at home Make friends The family has good relations with service providers that work with the disabled person.

Source: Verdugo and Rodríguez (2011) Intervention guide and backing support for families of persons with disability (p. 31).

With the passing of the years (Martínez, Casas, Fernández and Montero, 2012) views about disability have been associated to the social media in which they are produced. The importance of support in order to reach satisfactory results, a methodological focus centered on the person and favoring their personal control, make the family the corner stone in the response to disability situations.

During the Eighties and Nineties, society began to show concern for the families and their needs, with a more in depth focus on the analysis of roles that family members should play in a family with offspring with disability, with studies done on concepts such as: stress and family anxiety.

In order to approach the problems of families with offspring with disability, it is necessary to pause and consider a concept that describes disability as "diversity". According to Urbano and Yuni (2008, p. 74): "the specialness of diversity is found in the complex multiplicity of diversity, a condition in which recognizing what is identical and so that an exchange of what is similar/different takes place". No disability is the same

as another, and just as there are no two children that are the same, each child and each family is different. There is a great variety of elements that define the condition of disability, Carrete (2012) describes the following ones: the type of déficit, the age acquired, the moment it is diagnosed, the personal history, its capacities, characteristics, financial and social situation, the place in the family, the support network available, etc.

Speaking today about quality of life in families with offspring with disability means analyzing what situation are we in now? Which are the main needs and concerns of families with offspring with disability in Ceuta? For the time being, the family continues being the entity in charge of the care of the relative with a disability, without in many cases, this effort being acknowledged. If we refer to quality of family life for Turnbull, Summers and Poston (2000), mentioned in Verdugo (2000) the families reach a quality of life when all their needs and demands are covered, their members enjoy living in the family and even pursue and achieve purposes that are important for them.

We must take into account that the families go through a series of trials (from the impact of the disability at the time of diagnosis and also throughout the family vital cycle) with the aim (Núñez, 2007) of understanding the needs, dilemmas, tensions, inconveniences and problematic aspects. Besides, the protection factors for adequate social and family integration and indicators of risk of conflict should be analyzed in families with offspring with disability.

In current society, since Lambert (1982), Gante (1989) and Cunningham (1992), mentioned in Ortega, Salguero and Garrido (2007, p. 118) pointed out that the arrival of a child in the family is an unforgettable experience, we should acknowledge that the meaning of the birth can be different in each couple. Each family has its own scale of values, its history, beliefs, customs and traditions, and the result of these make the family become a micro-cosmos.

At the very moment the parents receive the news that they are expecting a child, some expectations about the baby are created, but the fears for its health or if the child will have any deformity is always in the minds of the parents, although, due to the anxiety and fear these provide, tend to be discarded and not much importance is granted to them.

However, all the expectations and illusions are drastically broken if the child is born with any disability and/or developmental problema. According to Bechara (2013, p. 16): "the birth of a baby with disability exteriorizes the lights and shadows of each of the parents, expresses and puts to trial the strengths and weaknesses of the modes of functioning in the setting of their vital experiences" and a day starts (McGill, 1995) full of hard sentiments and emotions, complicated options, peregrinations to different specialists and a need for information and services. For Sánchez (2014) the family enters a stage of disorganization and despair in which its structure could be affected and the roles played could be re-structured because of the situation. A child with a disability places the family before one of the most important challenges of its life.

We have to consider that all families, aside from their nature, must carry out similar functions. However, these are harder to fulfill when it comes to attending and providing answers for the child with disability, as resources, aid and support are more necessary and at times permanent and indispensable, and the families are not prepared to provide the answers to these needs. As Sánchez (2006) suggests, the configuration, origin, function and structure are characteristic factors which also should be considered in a family with a member

that has disability, with three levels (social and financial, family structure and gender of the person with the disability). Thus, the financial level of the family will have an influence, on the rehabilitation opportunities among others, medical care and access to new technologies. The family structure has an influence too, as the disability is a stressor for the family and in many cases, the presence of a child with disability is a precipitating factor in breakup of the marriage and an important source of conflict in the family ties. Lastly, this author distinguishes by gender the attention and support the parents offer.

Regarding the most common family alterations that the disability can provoke, these can be divided into three groups: structural alterations, emotional impact and procedure alterations. Regarding structural alterations, the family is affected by the presence of a member with disability and roles and functions within the family start to change. The role of caregiver normally follows cultural patterns and in most cases is the woman who is in charge of the care and attention, with a strong bond being produced between the caregiver and the offspring with disability.

As far as the emotional impact, the disability introduces a painful experience in the family, in which feelings and emotions play a dominant role. According to Herrero, mentioned by Fernández and García (2006), the family faces a mourning because of the loss of identity as a healthy family or healthy person and there are two reactions that can arise: adapting or denial. A initial period that Sánchez (2014) identifies as emotional shock of non-acceptance, of mourning. In it the family enters into a stage of disorganization, despair characterized by suffering from stress, discomfort and in which different conflict situations are produced between the different family ties (matrimonial, parental and fraternal). And a second period or stage of acceptance, of role reorganization within the family functioning with the purpose of improving the quality of life of the family unit.

Lastly, procedural alterations are interferences that arise between tasks oriented towards the interior of the family and external needs.

These alterations have been determined in our simple through the following variables: perception of the disability (emotional impact), support network (structural alterations), time off and leisure (structural alterations) and demand of resources (procedural alterations).

As far as the needs demanded by the families, it is interesting to have as reference the research carried out by the Sociological Research Team (EDIS, 1999) headed by Gómez González and financed by IMSERSO, about the needs, demands

and situations of families with minors that have a disability.

Another important document is the world disability report (2011) which provides detailed information and proposes measures to improve quality of life of people with disability, besides favoring the application of the Convention of the Rights of Persons with Disability passed by the United Nations (2006). Further on, in the Integral Plan for Backing the Spanish Family (PIAF, 2015-2017), a strategic line is presented for backing for families with special educational needs that considers specific goals and measures related to the disability that attempts to provide solutions to the problems that the families present and continue advancing in the purpose of improving quality of life of the persons with disability and their relatives.

The Action Plan of the Spanish Strategy about Disability 2014-2020 was one of the acts passed by the Government on the 12th of September of 2014. The action plans are set out in: "In the International Convention about the rights of persons with disability (UN, 2006), in the instructions of the European Strategy about Disability 2010-2020, in the European Strategy 2020 and in the Spanish Strategy about Disability". The plan is organized around five axis that are priorities: equality for all persons, employment, education, accessibility and dynamic economy measures. These axis mentioned are developed by means of operational goals and actuations.

2. Justification and goals

The research undertaken attempted to answer our research problem which was formulated in the following terms: *Which are the current needs and demands of families with offspring with disability in the Autonomous City of Ceuta?*

This wide question was specified in the following questions:

- How does the disability condition the daily functioning of the family? How are the roles played from the point of view of care given?
- What perception do the family members have of the disability of their children? Does this perception differ depending on culture and/or religion?
- What is their degree of satisfaction with the services received from the different institutions? Do these offer a good quality of life to the users?
- Do social-demographic variables have an influence on the variables studied?
- How does the type and degree of disability have a repercussion in technical and human needs of the different associations?

In order to answer the questions above, in this research the following general goals were stated:

- 1st. Analyze and describe the needs of persons with disability and their relatives in a multi-cultural context.
- 2nd. Evaluate the levels of perception of the disability, support network, demand of resources and time off in the families with a member with disability.

As of these, the following specific goals were formulated:

- 1st. Identify accessibility needs, locomotion, technical resources, financial resources, leisure activities, social integration, training and work orientation.
- 2nd. Evaluate the parameters that define quality of life of families with offspring with disability.
 - 1st. Contrast the differences between cultures and religions of those polled when it comes to evaluation of the disability.
 - 2nd. Determine the influence of the variable "gender of the offspring with disability" in the opinion of the caregivers when it comes to perceiving the disability, demanding support, resources and time off.
 - 3rd. Analyze the relation of the variable "associations" with the perception of the disability, support network, demand of resources and time off in families with offspring with disability.
 - 4th. Find out if there are relations between the variables mentioned in the questionnaire and the degree of disability.
 - 5th. Evaluate the relation between the age of the caregiver and perception of the disability, support network, demand of resources and time off.
 - 6th. Study the variable "employment situation of the caregiver" with regards to the dependency variables.
 - 7th. Study the variable "educational level of the caregiver" with regards to the variables mentioned before.

3. Methodology

3.1. Participants

The sample (n=202), is formed by families with offspring with disability that were being attended in the different associations and who voluntarily accepted forming part of the study.

Potentially, those polled could belong to any of the four main religions of the city, however, we only found users belong to Christian and Muslim

beliefs, in spite of the number of associations of disability visited and the large number of persons polled.

The size of the sample has been determined by the availability of the families to participate in

the study and by their presence in the centers at the different times of measurement. Distribution of the sample is shown in Table 2.

Table 2. Distribution of the sample

Disability associations	Participating families	Total families	%
Asociación Salud Mental Ceuta (ACEFEF)	12	44	27.27
Asociación Ceutí de Familias de Personas Sordas (ACEPAS)	24	50	48.00
Asociación Española de Familias de Personas Sordociegas con Discapacidad Sensorial y/o Graves carencias de Comunicación de Ceuta (APASCIDE)	12	37	32.43
Asociación Asperger Ceuta	9	13	69.23
Asociación Autismo Ceuta	33	56	58.93
Federación de Asociaciones de Personas con Discapacidad Física y Orgánica de la Ciudad Autónoma de Ceuta (COCEMFE)	13	337	3.85
Organización Nacional de Ciegos Españoles (ONCE Ceuta)	10	156	6.41
Plena Inclusión Ceuta	36	113	31.86
Asociación Programa de Ocio Inclusivo (PROI)	9	10	90
Asociación Síndrome de Down Ceuta	40	46	86.95
TOTAL	202	858	23.54
Source: Own elaboration			

3.2. Collection of information instruments

The instrument for collecting data we have chosen, within the methodological focus selected, has been the poll. We consider that for the purposes of our research this technique is the most adequate due to “its enormous potential for accessing the mental part of the persons, and also their vital part through which we discover their daily living and the relations they maintain [...]. In this sense, the interviews were pertinent as they contribute in situating the quantification in a wider social and cultural context” (López and Deslauriers, 2011, p. 1).

A questionnaire was created of the attitudes of families towards disability in Ceuta, based on the Scale of Quality of Family Life of Salamanca (Córdoba, Verdugo and Gómez, 2011). This is an adaptation of the Family Quality of Life Survey, carried out by the Beach Center on Disabilities

in 2003. We also included some matters of interest in the Zarit Scale, Reeve and Bach-Peterson (1980), which evaluates the overload of the caregiver in dependents. Lastly, data was consulted from the study carried out by Amador and Gudiño (2004), in which the importance of the family attitude towards disability is underlined (Universidad Autónoma Metropolitana Iztapalapa).

With the contributions listed above, our questionnaire was made with a total of 50 items measured in the Likert type scale. The alternatives to items 1 to 41 collected the degree of agreement-disagreement about the following criteria: Perception of Disability in the family, Support Network for the families, Resources, Time Off and Leisure. Of items 42 to 49 four different alternatives were created for each one of the items, with a fourth option “Others (state which)” as an item with an open question. Lastly, in item 50, the families can also tell the achievements reached and

aspects that make them feel most proud of their offspring with disability, besides providing claims.

As far as the system of registration used, answer pages were used that included the four blocks, semi-open questions, besides the only open item measured in the questionnaire.

3.3. Variables

In poll and observational studies, independent variables are usually considered as classifying variables and are defined as the set of personal characteristics and social demographic characteristics of the persons polled. As opposed to the above, we considered as depending variables those whose behavior can be explained or prognosed by one or more independent variables.

Variables considered in this research are:

- Independent variables
 - Gender of the offspring with disability (male/female)
 - Gender of caregiver (male/female)
 - Age of offspring with disability (1-60 years)
 - Age of caregiver (17-85 years)
 - Association belonging to (ONCE Ceuta, COCEMFE, ACEFEP, ACEPAS, APASCIDE, Síndrome de Down Ceuta, Asperger Ceuta, Plena Inclusión, Autismo Ceuta y PROI).
 - Culture and religión (Christian/muslim).
 - Degree of disability (25-53, 54-68, 69-78, 79-100)
 - Diagnosis (visual disability, hearing disability, intelectual disability, motor disability, síndromes, rare disorders, development disorders and mental disorders).
 - Other associated pathologies (perceptual disorders, intelectual disability, psycho-motricity, rare disorders, neurological disorders, congenital síndromes, development disorders, psychological disorders, physical disorders and behavior disorders).
 - Employment situation of the caregiver (full time worker, part time worker, unemployed, housewife, retirees, public pensioner).
 - Educational level of the caregiver (no studies, grade school, high school, college)
 - Other members with disability in the family (type of relationship) (Yes/no), (brother/sister, mother and father).
 - Number of siblings (0,1,2,3,4..)
- Depending variables:
 - Perception of the Disability: self-perception of the situation the family is in, measured by the degree of anguish experienced by the existence of a relative with disability cared by the family. Median value obtained in the answers to block I of the questionnaire

(items 1, 2, 3, 4, 5, 6 and 8). With these items it was possible to measure variables such as: fear, guilt, lack of understanding, personal abandonment and dependency.

- Support Network: referred to the set of relatives, neighbors or friends counted on for care of the offspring with disability. It corresponds to the average of the answers of block II of the questionnaire, which is formed by the following items 10, 11, 12, 13 and 15. These items were stated in a nominal qualitative scale with four categories which manifested the following variables: family cohesion, assumption of the disability, relations with the closer environment and social rejection.
- Demand of resources: considers the degree of sufficiency of existing resources in the city for attention of offspring with disability. Average value obtained in the answers to all items in block III of the questionnaire: 19, 20, 21, 22, 23, 25, 26, 28, 29, 30 and 33. These items measured issues related to bureaucratic procedures, information received, social and economic status, technical means and opinions about the services.
- Time off and Leisure: considers the availability of enough time for the caregiver to feel "liberated" from direct attention towards the offspring with disability. This variable was determined through the measurement of the following items 34, 35, 36, 37, 38, 39 and 41. The items measured subjects such as external support, work opportunities, adapted leisure, social relations and associations.

3.4. Procedure

Of the total population defined in Table 2 (858 families) we were only able to work with those who assisted to the associations and wanted to form part of the study (23,54% of the total).

Application of the questionnaires was done during the months of February to June of 2017, in the different disability associations in Ceuta in the afternoons or by telephone in the mornings or afternoons.

Those polled were informed of the goals we were seeking with the research and the different dimensions we wanted to collect information about.

The items were formulated orally by the pollster who was in charge of collecting the answers (some of the parents which were Muslim did not speak Spanish fluidly) underlining the anonymity of the answers, the importance of their collaboration and the need of sincerity and confidentiality of the answers to that the work would be valid.

4. Results

Firstly we present the distributions of frequencies of the main variables of the study considered as indicators of quality of life.

Next, we present the main results of the analysis done of those variables that define quality of life in the subjects of the sample. It has been verified that the variables stated in a theoretical framework (perception of disability, support network, demand of resources and time off and leisure) and even some social demographic variables are capable of explaining in a significant way the dependent variables analyzed.

4.1. Perception of the disability

The existence of a relative with a disability usually causes an alteration in family habits that generates anguish in the caregivers because of the self-imposed obligations they assume and limitations in time and resources this implies.

In this study, families polled stated that the disability of the relative generates a degree of anguish that can be considered moderate (47,5%) or low (33,7%).

4.2. Support Network

Relatives, friends or neighbors to seek support from for caring for the offspring with disability enable the caregiver to feel accompanied in tasks to be assumed and become free from part of their obligations.

When asking the caregivers about these aspects related to support they count on for caring for the offspring with disability, it was verified that these were very few as most (71%) stated being "very dissatisfied".

4.3. Demand of Resources

When resources, both public and private that the community offers this collective, are insufficient, different types of demands arise from the caregivers. In the case of the city of Ceuta, results collected state that 3,5% of the subjects polled do not receive any type of aid from the IMSERSO. Of the rest, the greater percentages correspond to those considered sufficient (47,5%) or insufficient (40,1%).

4.4. Time off and leisure

Time off available that caregivers can use to cover their times of leisure and rest are usually inversely

proportionate to available community resources and support received from friends and relatives.

Data collected enables verifying that over half the collective polled (59,4%) enjoys enough time to cover these personal needs. As opposed to this, 32,7% considers it to be insufficient.

According to the data analyzed, considered as indicators of quality of life, we can state that the families of Ceuta with offspring with disability in their care feel moderate anguish because of this situation, they have little support from relatives and friends, although the sufficiency of resources offered by the Administration enables them to enjoy enough family time off.

Once this general data is presented, we move on to offer, in the following sections, results obtained from the inferential analysis through which it was determined which are the circumstances that, to a greater degree, had an influence in the opinion of the caregivers. For this statistic tests were applied destined to check if there were significant differences between groups formed as of the classification variables.

In our case, the following were applied: t by Student or U by Mann-Whitney for comparisons of the two independent groups and ANOVA of one factor when it was three or more groups.

4.5. Gender of the offspring with disability and opinion of the caregivers

After checking fulfillment of normality and variant equality requirements, a decision was taken to apply the t Student tests in the case of variables "perception of disability" and "demand of resources" and the U by Mann-Whitney for "support group" and "time off". Results obtained from application of the preceding tests, collected in Table 3, make clear that gender does not have an influence in the opinion of the caregivers ($p > 0,05$).

Table 3. Contrasts for equality of averages between the sexes

Variables	Average differences	Applied test	Significance
Disability perception	0,0841	t	0,328
Resource demand	-0,0417	t	0,346
Support network	0,0870	U	0,176
Time off and leisure	-0,0079	U	0,904

Source: Own elaboration

4.6. Type of Association and opinion of the caregivers

Services offered by the different associations for disability existing in the city make the families perceive their situation diversely. With the aim of determining if these differences were significant, an analysis of variability was done (one factor ANOVA) that enables contrasting the equality of averages of three or more independent populations and with normal distribution, results of which are in Table 4.

Variables	F	Sig.
Disability perception	3,231	0,001
Support network	2,810	0,004
Resource demand	2,637	0,007
Time off and leisure	4,595	0,000

Source: Own elaboration

Results of the F test make it clear that there are significant differences ($p < 0,05$) between the different associations for each one of the dependent variables. Contrasts made a posteriori enable us to conclude that:

- There is a greater perception of disability in relatives of the Asociación Autismo association, followed by the Down Syndrome of Ceuta association and lastly ACEPAS.
- Families of the PROI Association feel more satisfied with the support network than those belonging to the Asociación Autismo followed by COCEMFE.
- The association that has greater demand of resources is the Down Syndrome followed by Asociación Autismo Ceuta and ACEPAS.
- The PROI association stands out from the associations as being the one in which the relatives enjoy greater time off time and leisure.

4.7. Culture and religion

Results obtained in the study indicate that assumption of the disability is conditioned by culture, religion or family belief system of the person with the disability. In this way, in the case of the Muslim collective in open answers, they give more expression to the problem from a religious and existential point of view; as opposed to the Christian

community which does not attribute the same variables to the disability of the relative.

After verifying fulfillment of the requirement of normality and uniformity of the variants, application was done of the tests for independent groups: t in the case of "demand of resources" and U by Mann-Whitney in the other variables). Results are shown in Table 5.

Variables	Average differences	Applied test	Significance
Disability perception	0,061	U	0,407
Resource demand	0,0791	t	0,073
Support network	0,1332	U	0,021
Time off and leisure	-0,0368	U	0,592

Source: Own elaboration

As of the results obtained in both tests, we can say that the Religion has an influence in the opinion of the caregivers only in the Support Network ($p = 0,021$) and the Muslim collective is the one with less aid from relatives and friends.

4.8. Degree of disability

As a greater degree of disability demands more dedication on behalf of the caregivers, it seems evident that their opinions may be affected by this circumstance.

In order to contrast the differences of this variable four categories were established that correspond to the following degrees: low (25-33), moderate (54-68), high (69-78) and severe (79-100) and most suitable test selected was the ANOVA uni-factorial.

Results of test F make it clear that there are significant differences ($p < 0,05$) between the groups defined according to the degree of disability solely in the variable of time off and leisure. After applying contrasts a posteriori, it was determined that there are significant differences only between the relatives of subjects that present a degree of severe disability, with respect to those in the group of low disability ($p = 0,015$) and moderate ($p = 0,007$).

4.8. Age of the caregiver

Taking into account that the spread of the data was very high, it was grouped according to age intervals stated in Table 6.

Years	N	%
17-27	12	5,9
28-38	48	23,8
39-49	64	31,7
50-60	55	27,2
61-71	16	7,9
72-85	7	3,5
Total	202	100,0

Source: Own elaboration

As of the groups mentioned above and with prior check of pertinent requirements (normality and uniformity of the variance), ANOVA one factor was again selected as most suitable test whose results enable stating that the age of the caregiver is directly related to the perception of the disability ($p=0,004$) and their opinion of the support network ($p=0,02$).

4.10. Employment situation of the caregiver

Although it is evident that employment obligations of the caregiver are an obstacle for care of the offspring with disability and should have an influence on the answers in the questionnaire, it was verified that they do not differ significantly.

Results of the F test make it clear that the greatest differences between the different employment situations of the caregivers are seen in the variable of time off and leisure, although these are not significant ($p>0,05$) and, given that in the rest of the variables the same happens, it must be admitted that, in spite of what could be expected, the caregivers have similar opinions independently from their employment situation.

4.11. Educational level of the caregiver

After using the educational level as a variable for categorization in establishing the groups, the ANOVA one factor was done whose results enable stating that the perception of disability is the only variable that does not seem affected by the educational level of the caregiver ($p>0,05$), and the demand for resources is the one that presents greatest differences between the levels of education of the caregivers ($p=0,003$).

4.12. Open question

Results from item 50 (I would like you to tell me the achievements and what you are proud of) were categorized in seven answer options: sociability, affectivity, independence/autonomy, motivation, personality, lack of complexes, academic productivity, responsibility and nothing.

The greatest percentage corresponds to the families that answered the "motivation" option (24,3%), followed by 22,3% of the relatives that highlighted affectivity of their offspring, 19,3% state independence/autonomy, 13,9% underlined personality, 8,9% expressed sociability of their offspring and quite a distance away we observe the rest of the answer options. Results can be seen in Table 7.

Area	n	%	Opinions of the parents
Sociability	18	8,9	- "Communicates well and relates to the children at school". - "Communicates with an alternative system, is very active and sociable". - "Has managed to relate to other people, has empathy and relates to children of the same age in spite of difficulties".

Affection	45	22.3	<p>-“Is very happy, loving and transmits joy”.</p> <p>-“Has a great heart and cares about me”.</p> <p>-“I am proud to have him, he is the greatest gift life has given me, the extra loving and close bond I have with him I don’t have with my other child”.</p> <p>-“Affection and love provided to the family”.</p> <p>-“Is extremely loving with the family, I don’t believe the love can be equalled to that transmitted by him. I advise no parent to despair”.</p> <p>-“I feel proud, I am happy when he embraces me and kisses me”.</p> <p>-“She is a girl that provides me with love and joy more than her other siblings. Is a gift from God, helps me a lot with the bay without jealousy and giving love”.</p> <p>-“Proud of the love he provides me with, is very loving, loves me a lot and the bond is mutual”.</p> <p>-“Always happy and joyful”.</p> <p>-“Now is always kissing me and is much more loving”.</p> <p>-“Is very sweet, loving, has lots of empathy, although I am sorry for having over protected her”.</p> <p>-“Demands love and affection all the time”.</p> <p>-“I feel proud that he kisses me and has physical contact with me (before he rejected me). Now he shows love.</p>
Independence/Autonomy	39	19.3	<p>-“Me siento orgullosa de todo: de su independencia económica, del respeto de la gente y el status social”.</p> <p>-“I am proud that she goes out alone with her friends, and for her to sleep alone with the lights off”.</p> <p>-“Thank God, they dress on their own, eat on their own and are independent”.</p> <p>-“She reads well, goes down the steps and goes to the bathroom alone”.</p> <p>-“Has sphincter control and rides a bicycle”.</p> <p>-“Takes medication and assumes the disability”.</p> <p>-“Is independent”.</p> <p>-“Has learned to read and write”.</p> <p>-“Gets up alone, goes to the bathroom and has sphincter control”.</p> <p>-“Is more and more autonomous, learned to read at the age of six”.</p>
Motivation	49	24.3	<p>-“Is understanding and a fighter, I am amazed at her motivation”.</p> <p>-“Of all the efforts”.</p> <p>-“Of the bravery for facing life”. -“Has great willpower from having confronted all that happened to him, knows what he wants and would need to find a job”.</p> <p>-“Of all he has achieved with effort, is a fighting person”.</p> <p>-“Of his battle, motivation in spite of the disability continues studying”.</p> <p>-“Speaks perfectly and wants to surpass himself every day”.</p> <p>-“Day by day he progresses, he does not feel different, is totally integrated”.</p> <p>-“Of his motivation and adaptation”.</p> <p>-“Of her willpower and vitality even though she is so small”.</p> <p>-“With great difficulty studies and thanks to the association that provides him with an interpreter, can do courses and continue training”.</p> <p>-“Every day surpasses himself in his studies”.</p> <p>-“Manages to reach things little by little”.</p> <p>-“Of his progress (lots of things he has overcome from the syndrome), interest, dedication to learning and fight to not make mistakes”.</p> <p>-“When he corrects himself and makes an effort to approach others”.</p> <p>-“100% proud of his spirit of overcoming things and finding his place in society”.</p> <p>-“That he managed to learn to walk, eat and communicate”.</p>
Personality	28	13.9	<p>-“Everyone speaks very well about him, he is polite and solidary”.</p> <p>-“The honesty of my son”.</p> <p>-“Is introverted and relates little with others”.</p> <p>-“Is very conformist and accepts everything, reasons a lot”.</p> <p>-“Of everything, is an excellent person”.</p> <p>-“Of being my daughter, for me she is very special”.</p> <p>-“Has a special gift, we have lots of connection”.</p> <p>-“Of his way of being, simplicity, humility, timidity, has no evil in him, has lots of friends, besides being serious and responsible in his job”.</p>
Lack of complexes	4	2.0	<p>-“Has no complexes”.</p> <p>-“Has great assumption of the disability, has no problems in adapting or integration, got married, had a child, goes to the driving school and kindergarten tutorials of her child”.</p> <p>-“I am proud of my son because he is a boy that integrates and adapts just like any other without any type of complex and makes an effort to learn every day more”.</p> <p>-“Has no complexes (wears large earphones)”.</p>

Academic yielding	5	2.5	-“Learned to read very quickly thanks to video games”. -“Is getting great grades at school and does homework on his own”.
Responsability	5	2.5	-“I feel proud of him, he has always been very studious and helped others with their studies”. -“Helps with chores at home, makes an effort at school and feels grown up”. -“I am proud of all I have achieved with her, today she is working and in the afternoons studies”.
Nothing	9	4.5	-“Has achieved very little”. -“The truth is that I am not happy, his character changed a lot and living with him is not easy”. -“I see him very depressed and his mood changes a lot”.
Total	202	100.0	
Source: Own elaboration			

5. Discussion of the results

The results obtained in this research reveal that one of the most important factors that define quality of life is the amount of resources available both personal and social (Ramos, 2011), that in the study prove to be insufficient for the majority of those polled, although a good amount of them consider them sufficient; thus we could place this indicator on a level of medium-low satisfaction.

Another one of the definition aspects of quality of life according to the autor mentioned above, the support network, resulted in being very insufficient in the case of people with disability and their relatives living in the city of Ceuta, where a vast majority considered this network as insufficient or very insufficient, which equally undermines the potential quality of life of those affected.

Also, time available for leisure activities and rest is another one of the great indicators of quality of life of the families analyzed (Celiméndiz, 2004). In this sense, although a majority considered this time period as sufficient, also noteworthy was the sector that did not have a minimum time off and leisure period or this was insufficient. Due to all of this, we can state that the satisfaction level was located on levels of medium-low, which is directly associated to the lack of support network.

Taking into account the three aspects listed above, the perception of disability is shaped. This in turn shapes the impact level that living with disability and care of offspring with disability has on the relatives (Sánchez, 2014), as this can affect very diverse aspects of daily living and family living (stress, anxiety, depression, tensions, marital problems, fraternal jealousy, paternal jealousy, among others). Thus, the result of our analysis seems to confirm that low levels in these variables,

generate a marked anguish perception of the relatives, who in most cases qualify it as moderate, which affects, with time, their emotional, employment, affective and social stability.

A noteworthy circumstance was that the quality of life of the caregiver relative is much worse in the case of women (above all, mothers), who assume the greatest load of the caregiving (Peñañiel, 2012). Although most of those polled were women, it has been possible to verify that, taking into account the data analysis, that both polled (father and mother) share the tasks, although it is evident that the greater weight is borne by the woman always and besides this, the women are more involved in seeking greater quality of life for their offspring. One of the most important factors that define quality of life is the amount of resources available both personal and social (Ramos, 2011), which in the study done prove to be insufficient for a majority of those polled, although a good amount of them consider the resources as sufficient; thus we could situate this indicator on a medium-low level of satisfaction as pointed out by (Rodríguez Verdugo and Sánchez, 2008).

Another fact to be pointed out and which could result to be somewhat counterproductive for the offspring with a disability is the frequent over protection by the mother especially, who because of fear or instinct tends during the first years in which the disability is detected, to undermine the autonomy and independence of the child. This in turn limits social interactions of the person with disability and others as well as other people who do not belong to the family circle (Herrero mentioned in Fernandez and García, 2006), which in turn can affect future development of the child as an individual. This happens sometimes because many mothers do not adequately face the fact or acquire an erroneous idea about the limitations of

each disability. This is confirmed in our research, and it has been observed that these over protective mothers are in turn are those most concerned about the future of the offspring with disability once they can no longer care for them or they die.

As far as the gender influence, various studies point out that the greatest load and dedication rests on the woman (Limiñana, Corbalán and Sánchez, 2011). Thus it has been verified on an empirical level in our study. However, it is curious to check how the perception of this circumstance is similar between men and women; as well as the demand of resources and time off and leisure is similar in a statistic way. However in the support network male caregivers score higher than women caregivers in their satisfaction level.

Depending on the type of disability (type of association), there is a greater or lower number of differences in the valuation of the four variables analyzed, the most significant being those related to disabilities due to development disorders, followed by brain paralysis and closing with Down Syndrome. In this sense, the empirical data provided by Carrete (2012) is proven correct which upholds that a great amount of experiential differences depending on the disability of the users and the different associations.

Although there is still little research done about cultural and religious differences, when it comes to facing the disability of the family member, there are studies that point to different ways of living and adapting to this circumstance (Castellanos and López, 2009). This fact can be verified in this study as significant differences have been found between the Christian and Muslim confessions when it comes to valuing their satisfaction with the support network they have.

With regards to the analysis of the influence of the degree of disability on the rest of the variables, important differences were found regarding time off and leisure. Thus, logically, the higher degrees of disability limited the family members to have available most of their time off and leisure, which can generate tensions and family problems as well as depressive states and less personal care (Suárez 2011, mentioned in Peñafiel 2012, p. 121).

Although there is recent research that equally sustain differences in experiencing of the disability depending on the financial and cultural level of the relatives, those with greater educational and cultural levels perceive disability worse, although they enjoy a greater support network, resources and leisure time (Sánchez, 2006). However, in our sample, these differences were significant in the support network, in such a way that the relatives with greater educational levels, were more satisfied than the rest. This did not happen when the

variable that had an influence was the financial level. This can be due to the fact that the relatives polled, who went to associations with simple access (whose quotas were not excessively expensive or even free of charge) presented social economic levels that were not very different between them.

Regarding the age of the caregiver, some authors uphold that the greater the age, the greater the worry, anxiety or anguish over their relative with disability (Fresnillo, 2011). However, this result can be interpreted wrongly if we attribute just the age of the caregiver as cause of the increase of worry. What usually happens (Gómez and Cardona, 2010), is that as the disabled person grows, both his or her needs as well as the social discrimination also increase and with this, the concern of the relatives. Therefore we would be speaking about an indirect influence or a mere co-variance. In fact, when isolating in our empirical study the influence due exclusively to the age of the caregiver, we do not detect important differences for this reason.

6. Conclusions

We can point out as main conclusions of this study it has been possible to identify the main needs of persons with disability and their relatives, levels of perception of the disability have been established, support network, demand of resources and time off in families with offspring with disability and a detection has been done of diverse lackings in needs for accessibility, locomotion, technical resources, financial resources, leisure activities, social integration, training and employment orientation, all located at values inferior to those desirable.

As far as difficulties or conditioners that may have limited development of the study, we must point out that, in spite of the majority collaboration of all the parties, we have found parents that tend to not fully assume the disability of their offspring, which can generate bias in answers that compromise the conclusions of this study.

Besides the above, we must also point out the low level of administrative involvement when it comes to enabling or financing this type of study, thus needs of the users are still hardly described and some have not been even identified.

Finally, another problem found is related to the linguistic aspect and the lack of interpreters when it comes to applying the instruments. We remind the reader that a percentage of those polled lacked sufficient dominance of the Spanish language.

To conclude, we wish to point out that an interesting way for future research could be centered on the evaluation and improvement of the psychological state of the relatives. We suspect that this state improves when the relatives enjoy greater

time off and leisure time. Thus research should be centered on the creation of administratively articulated measures, that bring recreational activities to these persons who in general may suffer from high levels of stress, anxiety and depression.

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