Research Article

Perception of the quality of family life of a group of disabled persons caregivers of the department of risaralda Colombia

Abstract

The analysis of the family as one of the most researched constructs in the social science Field of recent times, has led to identify variables that allow to establish how are their dynamics of relationship and how they influence the perception of quality of life, in addition to a differential analysis of family types, it has been found that families in which there is a person with a disability, the perception of life is significantly altered. In the present study, a group of caregivers of people with disabilities were asked about what their perception about the quality of family life was, finding by means of the proposed instrument, a map that establishes the most critical elements that make up a Situational analysis of the deterioration of the perception of life, being the variable of the state care the most important and in which more one fails in the attention to the disabled families.

Keywords: family, people in a situation of disability, status, quality of life, perception

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Abbreviations: WHO, world health organization; ECLAC, economic committee for latin america and the caribbean; DANE, national administrative department of statistics; RLCPD, registry for the location and characterization of people with disabilities; AAIDD, american association of intellectual disabilities and development; FQOLS, family quality of life survey; APA, american association of psychology.

Introduction

Family and disability are today two concepts that are not far from the academic field, rather, have been present as two constructs of significant scopes, not only in its theoretical function, but also in its functional activity, in its pragmatic activity, which means, in the first place, that there is a bi-directional relationship, which orders the construction of variables around them. The relation of concepts proposed here, will be approached from the focus of the psychological discipline, attending to the substantive variable of quality of life (hereinafter C.V.); On this concept an infinite number of positions and conceptions should be said, but the objective and what will be required of this exercise, will be to understand the relationship between Family-Disability-C. V.

According to the World Health Organization (WHO),[1] it is estimated that to date, a total of 15% of earth's population has some type of disability; with regard to Latin American's statistics, the Economic Committee for Latin America and the Caribbean (ECLAC)[2] consider that the quantity for Latin America is 50 million people. At the national level, according to the Census of the National Administrative Department of Statistics (DANE), it was found that for 2005 in Colombia, 2.624.898 people live in a disability situation, it should be noted that this is the last valid national data, because Colombia is preparing for its population census in 2018; however, this quantity is equivalent to 6.3% of the total population, also clarifying that, for May 2013, the registry for the location and characterization of people with disabilities (RLCPD), reflects that 981,181 people live with a disability diagnosis, which to date corresponds to 37.4%. It is evident that motor disability is significantly greater than visual disability, intellectual and auditory disability, finding that the lowest data corresponds to language disability.

Quality of life

Many authors have defined the CV familiar orientation to the response of individual needs, in this, there are tacitly two factors: subjective and objectives that participate with each other. These factors include physical aspects, such as materials and others such as psychological, emotional, social support, among others. According to the World Health Organization[1] the C.V. varies according to the perception that the person has about their place of existence, of their context, of their beliefs and of their values, in addition, of the objectives, the norms, the meaning of their existence and the expectations you go that the person has about his life. However, today the term of C.V., has been used in various fields: health, economics, politics and education and mental health. Health in general is a concept extracted from the global conditions of subjective stability, its deterioration implies that some of those scenarios that the subject lives are misaligned by various causes, in the case of mental health, the issue is much more Complex, because it focuses on evidencing these conditions in psychological terms, however, there the perception plays a decisive role, thus the mental health is deteriorated and diagnosed by the level of perception on it. Executioner and Martin quoted by Muñoz, Poblete & Jiménez,[3] commented that, the term C.V. is linked to increase and optimize the affective, emotional, physical, psychological and not only this, but also, the conditions in which people living coexist With intellectual disability, taking into account the needs that are presented in each person. In the same subject, Neef, Elizalde & Hopenhayn[4] Broaden the description of the relationship and/or link between need and satisfaction when it says:

a. The relationships that are established and that can be established, between necessities and their satisfactory make possible Build a genuinely humanist philosophy and Development Policy ".

However, relating la C.V. to the family, it can be mentioned that its C.V., changes depending on the perception and lifestyle that each person has. In addition, it refers to individual well-being, which relates to the satisfaction of fundamental needs that are subject to culture, values, context and personal factors that are totally subjective and objective.

Family

The concept of family appears in the eighteenth century. The American Association of Psychology (APA)[5] defines it as: "Kinship unit consisting of a group of individuals united by bonds of blood, marriage, adoptive or other intimate ties". Although there is no agreement on its definition, it can be observed according to the different approaches of the social disciplines, each one expresses according to its relevance the variables that compose it, but in general, in unison, the family is fundamental part of the subject and in turn of The Society. The family can be seen as a system that is open and active within society and in turn within the social groups, since it is a relationship that not only exists among the members of the same nucleus, but also between people who differ in how To sex, age, gender, physical and mental aspect, which leads to the determination that the independent family of the place, space and time in which it is located, is part of a group that provides care, protection, company, security and socialization.

As an open system, the family is permeated by its environment, but there is also a bi-directional relationship, so the family also builds its environment, even determines it. In this dialectical relationship, the family in its dynamics and structuring interferes with the subject's mental health levels. In this sense, the determination of the role implies the burden of health with which the subject can cope, the case of the woman for example, the risk of vulnerability multiplies when the family system has no dynamics of functionality, so testify Gonzales, Rivas, et al.;[6] They inquired about the level of family functionality in women victims of domestic violence, finding that, the family plays an important role in establishing risk at the subjective level in the perception of La C.V. On the other hand, the family, as had already been stated, is subject to its context, thus, contexts with few health indicators can influence the deterioration of the family and subsequently become apparent in the individual mental health.[7]

Disability

The American Association of Intellectual Disabilities and Development (AAIDD)[8] redefines the concept by that of the limiting aspect, that is to say, affecting the normal development of the vital functions. However, such a partnership makes great emphasis on how society can stigmatize a person diagnosed with intellectual disability at any level. This "label", can generate psychosocial limits because the term of disability restricts a human being preventing the development of its potential in other areas of operation.

Like other concepts in this theoretical panorama, the mental retardation has undergone a change in the tenor of the changes of humanistic paradigms, which have greatly influenced the ontological conception of the subject, so things, what is now known as mental retardation and not It has its connotation of labelling and of incurable "sickness", giving way to a much more human position, of attention and social inclusion. This approach was taken up by the American Association of Mental Impairment (AAIDD) which states that:

a. Hirono´s mental retardation was defined as a general intellectual functioning below the average with origin in the developmental period and associated with maturing deficiencies, learning and social adaptation, including the element of age as a criterion Definitive. ``very.[8]

The current definition of disability takes into account various premises to establish an appropriate diagnosis, these premises were created by the American Association on Mental deficiency, which according to executioner, Verdugo, Córdoba and Gómez:

a. Hirono´s is characterized by significant limitations in both intellectual functioning and adaptive behavior as demonstrated in adaptive conceptual, social and practical skills. This disability originates before the age of 18 years ``very.[9]

Methodology

Method

This research is part of the quantitative method, with a transversal temporality and a descriptive objective to analyze the behaviour of variables.

Shows

A population was selected that is formed by 90 families with members in a situation of disability of the foundation CINDES of the city of Pereira, Risaralda. The selection of participants will be through a sampling of non-probabilistic type intentional. The sample will be 22% which indicates that it will be made up of 20 families with members in a situation of disability in the city of Pereira, Risaralda. As a study requirement, people in a situation of disability were considered to live with their caregivers, guardians and/or family members and be diagnosed with intellectual disabilities.

Instrument

The Family Quality of Life Survey (FQOLS) was used in this research, it was developed by the Beach Center on Disability in 2003 of the University of Kansas, USA, and it was adapted to the Colombian population by Verdugo, M; Cordoba, L; & Gomez, B in 2005 and 2006. The scale has 41 items that are associated in five dimensions: family interaction, role of parents, emotional, physical and material wellness, and related supports with the person in a disability situation. This scale is structured in three sessions, sociodemographic information, support information and information on family life's quality. With regard to the scale's psychometric properties, those who validated it in Colombia have found the following: "Cronbach's alpha of 0.90 for the family interaction's domain, 0.82 for general resources, 0.87 for health and safety, and 0.86 for parental role".[10]

Results

The first part of this exhibition of the results of this research will be the data describing the sample analyzed; Thus of the 20 people who were applied the instrument and the characterization card, 80% were women caregivers of people who coexist with the diagnosis of disability, mostly with 65% are parents or mothers. Of the general sample, 40% manifest to be married and a separate one (20%) and in another type of relationship (20%). Half of the population does not refer to their employment situation, 20% are inactive, in this sense, 80% refer to being unemployed and 40% have baccalaureate studies, followed by higher studies (35%) and primary education (25%). Almost half of the population with a 45% refers to income between two and three minimum wages, followed by a minimum wage with 30%, also 20% of the population that persists with less than a minimum wage, the respondents, who in their entirety are, caregivers of people with disabilities, refer to living with their family members daily.

According to the results, 50% of the respondents' relatives indicate that the level of disability is moderate, only 15% manifests behavioural problems, and 80% have another type of disability outside the one previously diagnosed by the Specialists. Intellectual disability is present at 30% in the sample followed by Autism spectrum disorder, attention deficit and hyperactivity disorder, and Down syndrome with 15% respectively. All persons in a disability situation are single and 90% have primary studies, only 10% do not have any type of study. Another fact to consider is that the average age of caregivers is 59 years and that of people in a situation of disability is 18 years, also, mostly 90% say that they only have a relative with disabilities. Most respondents live with the mother, being the main caregiver. It also means that persons in a situation of disability have access to services such as education and health, with 39% and 37% respectively, followed by other services they can obtain.

Table 1 & 2 have expressed the statistics of the levels of importance and satisfaction that the participants refer to in Table 3. We observe ranges of normalcy in importance, however, in the interaction there is a higher score (40 points), although not enough to be meaningful, it is important to emphasize that participants give importance to the level of interaction with other Family, with other people and in general, the interaction that the person in a situation of disability can have. In terms of satisfaction, there are also ranges of statistical normalcy, but the item asking about resources is very low in relation to others, which means that respondents are not entirely satisfied with the resources to which their Families with disabilities can access.

Table 1 Importance of quality-of-life scale factors

	Level of importance of interaction	Role level of importance	Level of importance of safety and health	Level of importance of resources	Level of support importance
Half	39,75	36,15	36,15	34,65	35,75
Medium	39,50	37,00	37,00	33,00	35,50
Fashion	45	40	40	32	40
Desv. Typ.	4,700	3,977	3,801	3,829	3,864
Minimum	29	29	31	29	31
Maximum	45	40	40	40	40

Table 2 Level of satisfaction of quality of life scales

	Satisfaction level, satisfaction	Level of satisfaction of the role	Level of satisfaction of health and safety	Level of resource satisfaction	Level of support satisfaction
Half	35,40	33,40	31,50	28,10	28,40
Medium	37,00	33,50	32,00	28,50	29,00
Fashion	45	40	40	40	24
Desv. Typ.	10,570	7,612	8,179	8,296	6,977
Minimum	9	8	8	8	8
Maximum	45	40	40	40	40

Table 3 Critical quadrants of the family life scale map

Quadrant 1		
Item	**N**	**%**
My family enjoys the time spent together.	3	15,8%
My family has support to get the benefits of the Government that the member needs.	4	21,1%
Quadrant 2		
Item	**N**	**%**
My family is able to manage the ups and downs of life.	2	3,8%
My family has hope in the future.	2	3,8%
The members of my family will support each other to achieve the goals.	2	3,8%
My family members openly talk to each other.	2	3,8%
My family solves the problems together.	2	3,8%
The members of my family will show that we love each other and care for each other.	2	3,8%
The members of my family have good relations with the extended family (grandparents, sister-in-law, etc)	2	3,8%

Table Continued..

The members of my family are proud of each other.	2	3,8%
Quadrant 3		
Item	**N**	**%**
My family members have the resources to move to the places where they need to be.	3	14,3%
Quadrant 4		
Item	**N**	**%**
My family has support to get good health care for our family member with disabilities.	3	11,5%

Finally, the applied instrument allows a final valuation according to a profile that establishes 4 quadrants where the items that are critical are identified, in which one should pay attention for subsequent individual attention, it has been called "map of the scale of life Familiar "; Quadrant 1 is where there is a greater conflict and thus until reaching the 4 quadrants. The items that scored the highest in each of the quadrants are then expressed. As you can see, the item that most do and will be the most attention given that it is in the first quadrant, is the question about the benefits of the Government on people in a situation of disability, for 21% of the population is a topic of interest the No T Support from State enterprises, in the same way it is, the need and the importance that people give to family members with disabilities and in general, that the family enjoys the time spent together. Not least, it is the relevance of respondents that people have resources for mobilization to the places that are needed with 14%, also, there is a concern in front of the support to get good health care with 11.5%.

Discussion

The substantive indicator of the quality of life within the family system, understood as a structure amalgamated by a type of biological relation and also of symbolic reference, is the positive perception of the conditions of coverage of necessities of Biological type and also of psychological type, in these latter include the social, emotional, cultural and normative needs that are involved and determined largely by the psychological note characteristic of the human subjects, in this sense, the Perception of satisfaction and importance of such needs is asked by the application of a map of quality of family life, as indicated by the "family quality of life scale"; The interest of the research focused on understanding how caregivers of "disabled" people manifest that perception that sustains the quality of life of those who present some kind of biological and psychological deficit, but the Research present only asked caregivers, who are "daily" with the persons subject to therapeutic intervention plans. From the above it follows two conclusions that, in addition to being delimited in the sample of the research, they also orient and frame the results: on the one hand, it is to the carers who were asked to respond, on the other, they are in a center of reception and support P Ara people who are previously diagnosed with some type of disability. Thus it is established that, in addition to the number of quantitative possibilities, there is an interesting symbolic reference at the qualitative level, which could also be the field for further inquiries on the subject: How does the forms of social perception operate, Established through social representations, about the quality of life in its dimensions of importance and satisfaction in people with disabilities?, here it was treated in a shallow way, also delimited by a number, however, it opens a path of Interpretation, people, as shown at the general level, give greater weight to the importance than to the satisfaction of the necessities, which would result in a social level complaint about the social and governmental responsibility towards the people who present Disability, and scores indicate that at the family level there is also a specific demand: both family and social support networks are really important in the positive perception of quality of life.

The caregiver plays a significant role, in the sample, a behaviour is observed about the population: they are people who without employment obtain in their home more than two minimum wages, which could indicate that they have dedicated in their life only to the care of the person with disc Apacity, they are aware of their basic necessities and they are their daily support, so that the quality of life falls especially on them; Rea, Acle, Ampudia & García,[11] coincide in their research that there is a negative position in front of the care of children with disabilities given the ignorance of the disease and its dimensions, arises from there a panorama of despair and depression in front of How to address the care of these people, however, and as indicated in this research, the basic needs of both caregivers and persons in condition of disability, are covered and satisfied as long as you have access to the foundation responsible for The therapies and other elements of the care, the knowledge of the disability strengthens interaction and family functioning, so ensure Rea et al.,[10] which coindice with the level of importance that was given to the need for interaction of the participants in the face of the satisfaction of resources.

In this same sense, the caretakers, Córdoba, Gómez & Verdugo,[9] applying the same instrument as the present research project, declared that there was a dissatisfaction in front of the support and in general, of the indicators of support to people with Disability, although it was an item that was within the quadrants, is not presented as the most relevant, however, the family interaction and state resources are very relevant to the level of dissatisfaction and importance. Here is the most significant conclusion of the study: the family nucleus, and in itself the family play a decisive role in the perception of quality of life in people diagnosed with disability and even more, when as in the present project it was found that the Population not only had a single diagnosis, but several. From a vision of ecological systems, the macro system and the Mesosistema interfere in the functioning of the micro system and in the particular person, the family and the government are two providers of quality of life in the person with disability and in the person Caretaker, if the latter are well, can be represented in the perception of quality of life, concluding that the state and after him, the family, play a significant and decisive role in expressing the perception of quality of life in a person in Situation of disability.

The Support network[12–17] is the primary breadwinner that generates ideal conditions, of general health and specifically of mental health in people with disabilities, this network is composed of: family and in it carers and state and in it public policies of satisfaction of Basic necessities and of educational and labour inclusion. Thus, the caretaker who is the subject of public policy is better able to make such care, also, if public policies are oriented towards the inclusion of people with a diagnosis of disability, the level of quality of life at the family level It is rising, for the present case, the people object of the foundation have a low level of study and no working condition, but if they have family nuclei that provide the first level of satisfaction of necessities. The fact that the family is well and suggests that the person with a disability is well, is a conclusion that is taken out of the test results, so in Quadrant 2, people consider that work on the family is a priority, the establishment of quality relationships and high communication rates, make up a solid support network with a view to achieving positive goals for people with disabilities, there plays a decisive role in the context, as evidenced in Gonzales & Reyes.[7]

What to do in the face of the future after the results are known? This issue is the second point in the agenda of the discussion of the results, it could be presented in two parts, the first is that, from the knowledge of the maps of quality of family life of the population investigated, could generate better plans of action to level L Psychological on them, thus the preceding investigations have also interested in that, once the results are known,[18,19] work plans are implemented on and with the families of which one or more of its members present some disability, for the present case, it would be interesting to strengthen relations at the family level, in addition to strengthening with those who correspond, the state resources, with them could work special and specifically on caregivers, as they are those who are day to day care for people with disabilities, it has been shown that if they present irregularities in their health and mental health, this is reflected on the person with disabilities.

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Conflict of interest

The author declares no conflict of interest.

References

1. Discapacidad y Salud. Organización Mundial de la Salud, Geneva, Switzerland; 2017.
2. Informe Regional Sobre La Medición De La Discapacida. Comisión Económica para América Latina y el Caribe. *Español*. 2014:p. 1–48.
3. Muñoz Y, Poblete Y, Jiménez A. Calidad de vida familiar y bienestar subjetivo en jóvenes con discapacidad intelectual de un establecimiento con educación especial y laboral de la ciudad de Talca. *Interdisc*. 2012;29(2):207–221.
4. Neef M, Elizalde A, Hopenhayn M. Desarrollo a escala humana. Barcelona, España; 1993. p. 1–96.
5. American Psychologycal Association, Diccionario Conciso de Psicología. Manual Moderno, México; 2009.
6. Gonzales J, Rivas F, Marín X, et al. Niveles de disfunción familiar, en veinte mujeres víctimas de violencia intrafamiliar en el municipio de Armenia. *El Ágora USB*. 2013;13(2):399–410.
7. Gonzales J, Reyes J. Tipificación del tipo de disfunción familiar de un barrio vulnerable de la ciudad de Ibagué-Tolima. *Poie*. 2014;27:1–11.
8. American Association on Intellectual and Developmental Disabilities. Discapacidad intelectual: definición, clasificación y sistemas de apoyo. Alianza editorial, Madrid, España; 2011. 352 p.
9. Córdoba L, Gómez J, Verdugo MA. Calidad de vida familiar en personas con discapacidad: un análisis comparativo. *Unive Psycho*. 2008;7(2):369–383.
10. Córdoba L, Verdugo M, Gómez J. Escala de Calidad de Vida Familiar: Manual de aplicación. Salamanca, España; 2011. 49 p.
11. Rea A, Acle G, Ampudia A, et al. Caracterización de los conocimientos de las madres sobre la discapacidad de sus hijos y su vínculo con la dinámica familiar. *Act Colom Psico*. 2014;17(1):91–103.
12. Córdoba L, Mora A, Bedoya A. Familias de Adultos con Discapacidad Intelectual en Cali, Colombia, desde el Modelo de Calidad de Vida. *Psykhe*. 2007;16(2):29–42.
13. Córdoba L, Henao C, Verdugo MA. Calidad de vida de adultos colombianos con discapacidad intelectual. *Hacia promoc salud*. 2016;21(1):91–105.
14. Merino S. Calidad de vida de los cuidadores familiares que cuidan niños en situación de enfermedad crónica. *Avan enferm*. 2004;27(1):39–46.
15. Gómez V, Córdoba L. Calidad de vida en familias de jóvenes con discapacidad intelectual. *Rev Fac Med*. 2013;61(2):80–90.
16. Giraldo C, Franco G. Calidad de vida de los cuidadores familiares. *Aquic*. 2006;6(6):38–53.
17. Salcedo R, Liébana JA, Pareja JL, et al. Las consecuencias de la discapacidad en familias de la ciudad de Ceuta. *Rev Esp Orie y Psicopedag*. 2012;23(2):139–153.
18. Mirón Canelo JA, Alonso Sardón M, Serrano López de las Hazas A, et al. Calidad de vida relacionada con la salud en personas con discapacidad intelectual en España. *Rev Panam Salud Publica*. 2008;24(5):336–344.
19. Peralta F, Arellano A. Familia y discapacidad. Una perspectiva teórico - aplicada del Enfoque Centrado en la familia para promover la autodeterminación. *Electronic Jour Rese Educat Psycho*. 2010;8(22):1339–1362.

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